

**Exploring the experiences and use of text messages  
to enhance health behaviours and self-management  
in South Asian patients**

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**Dedication**

*In loving memory of my late father who has always taught me to follow my dreams, and pursue my true passions. Witnessing the completion of this thesis would have been a dream come true. The love and happiness you gave will never be forgotten.*

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## Abstract

This PhD thesis seeks to explore and understand the use and experiences of whether text-messaging in the South-Asian (SA) community enhances positive health behaviours, and self-management through the Florence (FLO) text messaging system. It also examines socio-cultural factors contributing to self-management, patient activation and engagement with text messaging. There is limited literature available on the use of text messaging systems in ethnic groups to support self-management to change health behaviour. In order to optimise self-management in SA ethnic minorities, understanding health behaviours, and behavioural change interventions (for example, mobile health) is becoming increasingly important. Therefore, Health behaviour and *behaviour change* are explored along with the contextual factors influencing the acceptance and uptake of text messaging.

A mixed methodology consisting of two phases took place within Diabetes and Endocrine clinics held in the Midlands, UK. Phase one included the quantitative element in which the Patient Activation Measure (PAM) was completed to understand participants' level of skills, knowledge and confidence to self-manage their long-term condition; whilst, phase two utilised qualitative interviews to explore and understand SA participant (n=40) experiences of using a text messaging system and their self-management behaviours. Data was obtained from both users (n=20) and non-users (n=20) of the FLO system.

The PAM was executed for the first time across a SA sample, and vital to provide insight to where SAs are up to with their self-management, and what healthcare providers can do to optimise their self-management. In general, users had higher patient activation levels and better self-management behaviours. Particular themes contributing to SA participant engagement with text messages and self-management included demographics (age, gender roles, ethnicity, religion, education levels and socio-economic/employment status) family support, health beliefs and cultural norms, adoption of traditional remedies over western or prescribed medications, religious and fatalistic beliefs, and language barriers. The findings also generated new knowledge by providing an underpinning on theoretical constructs that played a significant role to better understand SA health behaviour, participant contexts and acceptance to uptake such interventions. Recommendations for future practice and policy include the implementation of culturally appropriate mHealth interventions (i.e., text messaging) to better suit SA participants.

## Abbreviations

SA	South-Asian
CAM/T	Complementary and Alternative Therapies
FLO	Florence
LTC/LTCs	Long-term condition/Long-term conditions
QOL	Quality of Life
PAM	Patient Activation Measure
CKD	Chronic Kidney Disease
ESRD	End Stage Renal Disease
HTN	Hypertension
CVD	Cardio Vascular Disease
HIV	Human Immunodeficient Disease
TPB	Theory of Planned Behaviour
TAM	Technology Acceptance Model
ELM	Elaboration Likelihood model
TPB	Theory of Planned Behaviour
HBM	Health Belief Model
CS-SRM	Common Sense-Self-Regulatory Model
TTM	Transtheoretical Model
DH	Department of Health
NHS	National Health Service
WHO	World Health Organization
NICE	National Institute for Clinical Excellence
NMC	Nursing and Midwifery Council
RCN	Royal College of Nursing
RCGP	Royal College of General Practitioners
UK	United Kingdom
USA	United States of America

## Glossary of Terms

(Adapted from DH 2010; WHO 2019)

South-Asia	Southern part of Asia, region consists of Afghanistan, Bangladesh, Bhutan, India, Maldives, Nepal, Pakistan, and Sri Lanka.
South-Asian	Individuals from diverse populations of South-Asia, including nations Afghanistan, Bangladesh, Bhutan, India, Maldives, Nepal, Pakistan, and Sri Lanka.
Ethnic minority	A population group of a particular race or nationality living in a country or area where most people are from a different race of nationality.
Long-term Condition	One that cannot currently be cured but can be controlled with the use of medication and/or other therapies.
Diabetes	A life-long metabolic disease that causes high blood sugar, due to the body not producing enough insulin.
CKD	A life-long condition characterised by a gradual loss of kidney function over time. Also known as Chronic renal disease.
CVD	A general term associated for conditions affecting the heart or blood vessels.
Hypertension	A long-term condition also known as high blood pressure, in which the blood pressure is persistently elevated.
eHealth	Concerned with promoting, empowering and facilitating health and wellbeing of individuals, families and communities; and the enhancement of professional practice through the use of information management and information and communication technology.
mhealth	Also known as mobile health- involves the practice of public health and medicine supported by mobile devices such as telephones (mobile phones), tablets, personal digital assistants and other wireless infrastructures.
Text messaging	Composing and sending of electronic messages typically consisting of alphabetic and numeric characters, between two or more users of mobile, desktop, laptop or other computer devices.
User	In the context of the study, this term refers those using or operating the FLO text messaging system.
Non-user	Refers to those not using or operating the FLO text messaging system

## Chapter One

### Introduction

#### Introduction

This thesis brings together five year's work to generate new knowledge to answer a question originating from my observations of growing up within a South Asian (SA) community and later my experiences and knowledge as a health professional and researcher. The scene is set within this first chapter for the study of interest. It provides an overview of the researchers experience as an insider of a SA family, and witnessing poor adherence to treatment management amongst SAs with long-term conditions (LTCs). The aims and justification for the research are outlined, and the layout of the thesis presented.

#### The *'Insider'* Origins and Focus of the Thesis

As a member of the SA community, I have become increasingly aware of the poor management of health conditions amongst relatives and friends; including some showing a complete lack of knowledge of their condition or an understanding of the appropriate treatment regimen to follow. I would listen to conversations of people refusing to take medications properly or turning to alternative remedies for a 'cure'. Although, at the time I did not recognise what it meant, reflecting back members of my family and the SA community simply did not understand how to live with or effectively manage their health.

Once working in the healthcare sector, I soon realised that the problem was widespread amongst the SA population, wider than just the people I knew or associated with on a daily basis. Individuals candidly discussed their experiences of living with their conditions and the barriers they faced with the health care system. Evidence also suggested SA people being less likely to exercise, follow healthy lifestyles and adhere to their treatment regimens, leading to poor clinical outcomes (Liu et al, 2015; Sohal et al, 2015; Kumar et al, 2016).

My main role as a health care provider is to aid reducing symptoms of illnesses and encourage health promotion. The multiple health disparities existent amongst SAs in relation to the cultural and communication differences (Ramachandran et al, 2013), created a passion within me to help resolve this by finding a way to help people. As I started to examine the topic, I searched for interventions to help people remember what to do and how to manage symptoms, clinic visits and medication. I came across the use of short message service (SMS) (or text messaging). This has become a very popular and convenient platform for the delivery



of instant healthcare for a variety of conditions, by communicating health messages to educate, monitor health, promote self-care, and management (Badawy et al, 2017). However, the evidence base of whether or how such interventions influence or modify behaviour is limited particularly within ethnic groups (discussed in later chapters). Questions such as whether a text messaging system enhances positive behavioural outcomes for SA populations living with an LTC; what SAs think of such an intervention; why some engage and others do not, formed the focus of the thesis.

In the realm of social sciences, the researcher's perspective is not only concerned with the philosophical stances of objectivity or subjectivity, but also the position of the researcher with respect to the subject being researched (Dwyer and Buckle, 2009). Being an insider in a particular phenomenon refers to when the researcher conducts a study amongst a population or sample, which they are members or part of (Kanuha, 2000). This also suggests them having commonalities by sharing an identity, language, and experiences (Asselin, 2003). Bringing together my experience from the SA community and a health care professional provided a unique opportunity to undertake research, which interested me, and could potentially influence the way SA people manage LTCs. I was aware of a system implemented in the NHS called Florence (FLO). The FLO system has been used by over 300,000 people in over 70 health and social care organisations in the UK. The evidence base suggested it had helped thousands of patients with LTCs such as diabetes and hypertension since 2010 (The Health Foundation, 2017). I contacted the system managers and explained my ideas; they were keen to support the research, also identifying that they had limited evidence of whether it is successful in ethnic minority populations. They put me into contact with health care professionals utilising FLO in areas where SA populations were using the system, to locate a study site for the developing research. Eventually, I targeted clinics within the West midlands with a high populous of SA individuals, to facilitate recruitment from this specific community. Rabe (2003) suggests that the researcher gains insight into the lives of those studied by also living with them. Certainly, within this study having the role of an 'insider' allowed me a greater acceptance from the SA participants recruited from the community, providing a greater level of trust, openness, and depth to data, that would likely not have been evident otherwise. Participants were more willing to share certain events, comfortable discussing sensitive issues, possibly owing to the assumption of mutual understanding and shared distinctiveness. At times it felt like those on the outside would not understand (Dwyer and Buckle, 2009). I successfully explored SA preferences of self-management through a text

messaging system (for example, culturally tailored messages and translation), their understanding of their condition, treatment regime, and activation levels; creating unique evidence to inform practice.

### **Thesis Aim and Objectives**

The aim of this thesis was to explore and understand text-messaging in the SA community through FLO, an established text messaging system. The study examined the usefulness of text messages in enhancing positive health behaviours and self-management, with a particular focus on the influence of socio-cultural factors such as: health beliefs, cultural norms and religious customs, patient activation and engagement with text messaging.

The objectives were fivefold:

- Explore the perspectives and experiences of SA people living with a LTC and using technology to aid self-management or promote healthy behaviour.
- Investigate the experiences of those SA individuals not utilising the technology (this included those who had used FLO, but were no longer using it, or rejected the system in the first instance), to determine how the experiences of managing a LTC will differ to those using the technology.
- Examine how factors such as culture, religion and health beliefs influence the adoption of text messaging within a SA population.
- Assess whether patient activation measures provide a useful indicator of who would benefit or engage with a text messaging intervention.
- Extend the understanding of different theories by exploring whether the Common Sense Self-Regulatory Model and the Health Belief Model, provide appropriate frameworks for understanding individual beliefs, perceptions, how people make sense of and manage their illness using text messaging interventions within the SA culture.

### **Layout of the Thesis**

The thesis is comprised of nine chapters and reflects the PhD research journey of discovery, the acquisition and generation of new knowledge. This chapter has introduced the aims and objectives of the research study and at the outset exposed my heritage, a member of the SA community and an insider researcher.

Chapter Two provides a background of the research topic, including the exploration of key definitions of the particular terms relevant to this research study, such as LTCs and the

meaning of being 'South-Asian' in terms of culture and cultural norms. The focus then explores self-management within SA patients, factors associated to poor regimen adherence and the importance of patient activation. Furthermore, the chapter briefly outlines the uses of telehealth interventions, such as mobile phones and text messages, particularly providing a critique of the FLO system and relevance to the study.

Chapter Three, provides a critical synthesis of evidence and study methods employed in relation to the adoption of text messages and other forms of telehealth interventions, to enhance positive behavioural changes amongst ethnic groups. The chapter examines how text messaging as an intervention is perceived by such populations and identifies whether it provides any benefit to disease management or behaviour change. Extensive searches highlighted only two studies conducted within the UK particularly amongst SA people living with a LTC. SA patient experiences were found to differ to the general population in terms of cultural norms, customs and religious beliefs. However, current evidence provided limited understanding as to what and how these differences impacted on self-management behaviour, reinforcing the need for a focused research study.

Chapter Four introduces and discusses the theoretical concepts and constructs of health behaviour and *behaviour change*, as well as their definition in relation to healthcare. Exploring social cognitive and theories applied in health psychology, provides a better understanding of certain health behaviours along with the key determinants and components influencing behaviour change processes amongst SA participants. Together the exploration of the meaning of behaviour change, health behaviour, and existing evidence in health regarding the use of text messaging interventions, highlight evidence gaps with respect to understanding the use of text-messaging and self-management in SA populations.

Chapter Five sets out the research study central to the thesis, the aims and objectives, chosen methodology, data collection techniques and instruments, analytical frameworks and the operative aspects of the research. The literature identified an under-representation of SA patients, particularly those living with a LTC showing poor self-management (Shetty et al, 2011; Patel et al, 2012; Kumar et al, 2016; 2018; Pradeepa and Mohan, 2017). Therefore, the study was designed to explore the experiences and use of text messages to enhance health behaviours and self-management in a SA sample, using in-depth interviews for users and non-users of the system, and a patient activation measure (PAM) to understand their readiness to self-manage their LTC.

The initial study findings combine patient activation scores with the eleven core themes from the interviews and are presented in Chapter Six and Seven. Themes focus on: factors associated with adherence and self-management, varying patient activation levels measured using the PAM tool, patient experiences of using or not using the FLO system, and whether the FLO is an acceptable platform used to enhance and promote effective self-management.

The concluding part of the thesis Chapter Eight, brings together key research findings, generating discussion to corroborate and extend current knowledge within the wider existing literature. The strengths and limitations of the study are exposed, which includes the uptake of tele-health systems and embedding them within primary care services within the UK to further support self-management. Recommendations and guidance for best practice, policy, and future research emerge from the study findings; to optimise text messaging amongst SA populations promoting self-management, presented in Chapter Nine along with final remarks.

### **Summary**

This chapter provides a brief introduction to the focus of the thesis and PhD study, exposing the researchers background and passion for the topic. The gaps in current research evidence highlight the need for a study that examines the use and uptake of text messaging by the SA population when managing an LTC. Indeed, research that improves self-management for anyone with a LTC would help professionals understand which intervention works for whom, when and how. The next chapter examines LTCs policy and practice to develop a deeper understanding of technology-based health interventions (for example, text messaging), and identifying what we already know regarding key self-management issues faced by SA ethnic minority groups.

## Chapter Two

### South Asian, Self-management and Technology

#### Introduction

Chapter Two forms the basis of the PhD research by exploring the definitions of long-term conditions (LTCs), the term ‘South-Asian’ (SA), along with the meaning of culture and cultural norms. It also draws discussion on the challenges faced by the SA community in regards to self-managing their condition, defines self-management from a patient perspective, briefly outlines patient activation, and discusses the use of mobile phones and text messages, particularly the FLO system. The use of mobile health (mHealth) interventions and the behavioural outcomes of patients across the general population are reported, along with a lack of evidence identified within ethnic minority groups, specifically SA groups in the UK, underpinning the need and appropriateness of this research.

#### Long-term Conditions

Over 20 million people in England have one or more LTCs. The definition of LTC for the purpose of this study is offered by the Department of Health [DH], which states an LTC to be “one that cannot currently be cured but can be controlled with the use of medication and/or other therapies” (DH, 2010, p.4). LTCs account for 50% of all GP appointments, 64% hospital outpatient appointments, 70% hospital admissions and 70% of healthcare expenditure (Royal College of General Practitioners [RCGP], 2011; 2018). Examples of LTC’s are presented in Table 1.

**Table 1.** *Examples of LTCs (Adapted from Taylor et al, 2014, p.555)*

Examples of LTCs	
Allergy/Anaphylaxis	Ataxia
Asthma	Autism
Chronic Obstructive Pulmonary Disease (COPD)	Autoimmune Disorders (Lupus; Sjögrens syndrome)
Atrial Fibrillation	Blood disorders
Childhood Constipation	Brain Injuries (including stroke and TIA’s)
Congestive Heart Failure	Bronchopulmonary Dysplasia
Chronic Kidney Disease (CKD)	Burn Injuries
Chronic Pain	Cancer
Chronic Fatigue syndrome/ME	Cardiac Arrhythmias
Dementia	Cerebral Palsy
Depression	Chron’s Disease

Diabetes type 1/Diabetes type 2	Coeliac Disease
Endometriosis	Connective Tissue Disease
Epilepsy	Coronary Heart Disease (CHD)
Hypertension	Digestive conditions, stomach ulcers, oesophagus, reflux
Hepatitis B/Hepatitis C	Fibromyalgia/chronic widespread pain
Human Immunodeficiency Virus (HIV)	Gout
Inflammatory Bowel Disease	Gynaecological problems, chronic pelvic pain
Lower Back Pain	Haemophilia and other coagulation disorders
Migraine	Heart Failure
Multiple Sclerosis (MS)	Learning Disability
Osteoarthritis	Lung Fibrosis
Osteoporosis	Lupus
Parkinson's Disease	Malaria
Addictions (Substance and Alcohol)	Mood disorders (depression, mania and bipolar disorders)
Attention deficit hyperactivity disorder (ADHD)	Motor Neurone disease
Amnesia	Multi-morbidity
Angioedema	Multisystem autoimmune disease (MSAIDS; including lupus)
Arthritis	Muscular Dystrophies
Ankylosing spondylitis (and other arthritic conditions)	Neuralgias
Sickle Cell Disease	Hypothyroidism/Hyperthyroidism
Thalassemia	Obesity
Downs syndrome	Obstructive sleep apnoea
Anxiety and stress disorders (including complex and post-traumatic stress disorders)	Occupational lung disease
Aphasia	Peripheral Vascular Disease

### **The Definition of 'South-Asian'**

The term 'South-Asian' refers to individuals originating from India, Nepal, Bhutan, Sri-Lanka, Pakistan, Bangladesh, Maldives, Mauritius, Afghanistan, and Iran (Bhopal and Liam, 1998; Saikia, 2004). Whilst, Iran has middle-eastern influences it remains classified as part of the SA continent. This SA population as a whole is not a homogenous group but diverse and largely populous, as the culture is entwined in varied ethnicity, language, religion, customs, beliefs, attitudes and lifestyles (Penduduk, 2010).

LTCs such as diabetes, chronic kidney disease (CKD) and hypertension are four times more likely within this population compared to Caucasians (Ramachandran et al, 2013). Ethnicity-based research shows cardiovascular mortality to have declined considerably in the western world, whereas, people of SA origin are known to have an increased risk of developing cardiovascular diseases (CVD) (Gupta et al, 2016). Some studies revealed differences to exist in socio-economic and health-related outcomes within Indians, Pakistanis, Bangladeshis and European populations (Bhopal 1999; 2011). Bangladeshis and Pakistanis had the poorest health outcomes and were most disadvantaged in relation to varied coronary risk factors, whilst, Indians were the least.

Another factor contributing to the heterogeneity of SAs is generation, age groups and culture. There appears to be a subdivision between the SA populations within the UK, it constitutes of the first-generation individuals who have migrated and settled within the UK; and the second generation who are British born. The term 'South-Asian' has been used broadly in this research study despite the fact that majority of the sample identified, included individuals from Pakistan, India or Bangladesh. Adjustments were made during the quantitative and qualitative analyses within the current study to account for differences within the sample, in terms of self-management and adoption of mobile phones between generation and sub-ethnic SA groups.

Literature indicates cultural and communication differences mainly being noted in migrant SAs, which makes the delivery of healthcare more challenging and complications in the management of LTCs. As a result, this makes it difficult to study such diverse groups and understanding the complexity of cultural transmission, suggesting scarcity within SA specific research, as the differences between the two generations has not sufficiently been explicated (Patel et al, 2012).

Culture is a complex interaction of multitude factors giving people ethnic belonging, transmitted by passing on knowledge from certain beliefs, attitudes and behaviours from one individual or generation across another (Trommsdorff, 2008). Majority of first-generation SA migrants first arrived to the UK between the 1950s and 1960s. Individuals from these groups tend to be interdependent on their traditional values, cultural norms and religious beliefs, particularly those with Indian and Pakistani families (Mahoney et al, 2001; Iqbal and Golombok, 2017). In comparison, those born and raised in the host country easily adapt and develop in varied trajectories to the original generation. This can be due to parenting styles

and upbringing to be changing over time (Iqbal and Golombok). Literature suggests second-generation families in the UK to adopt traditional cultures and religious beliefs transmitted through family members from the first-generation, as well as adapting to the diverse UK culture in which they live in following migration (Dorsett et al, 2015). Religious identification and its intersection with cultural and ethnic identification, is an important part in influencing certain social behaviours, family structures and cultural norms. To grasp a better understanding of adherence behaviours, self-management and mobile phone use in SAs, it was important to define SA cultural norms. Cultural norms in the SA culture are the shared expectations, customs and attitudes that guide the behaviour of people from SA groups and communities. This included looking at the contextual, social, economic and cultural factors that influence health perceptions, beliefs and behaviours (Lucas et al, 2013), discussed below in more detail.

### **Adherence Behaviours of South Asian Population to Treatment Regime**

According to the most recent 2011 Census, the composition of SAs residing in England is 7.8%; making them the second largest population group after Caucasians (86% of the total population) (England and Wales, 2018). Studies have reported beliefs about medications and the perception of their illness to contribute to poor adherence and clinical outcomes (Kumar et al, 2016; DH, 2018). As the SA population continues to grow it is vital to address the increasing health needs. Indeed, common reasons of non-adherence amongst this population group have been listed below. Factors associated with poor adherence are examined in greater detail to generate a deeper understanding of how these aspects may influence the findings of the developing study (Shetty et al, 2011; Uzma et al, 2011; Patel et al, 2012; DeSouza et al, 2014; Kumar et al, 2016):

- Health beliefs about the need for and efficacy of medications;
- Toxicity of medications;
- The need of traditional medications over ‘western medicines’ (complimentary VS alternative therapies)
- Gender roles and cultural priorities
- Stigma and social support
- Communication



### *Health beliefs about the need for and efficacy of medications*

To understand the factors associated with taking medications, it is important to look into medicine-taking behaviours and health-related beliefs (Kumar, 2016). Majority of SAs have difficulty in identifying aspects of lifestyle that contribute to the development of diseases such as diabetes and obesity (Lucas, 2013). Studies found that SA participants lacked understanding of the relationship between lifestyle factors and disease, with many believing that disease is due to fate (Patel, 2012). A fundamental factor perpetuating this belief, was difficulty in explaining causation of disease amongst close friends and family. Even though many SA people have an awareness of diet and exercise contributing to reducing the occurrence of diabetes, they still felt there was not a sufficient enough explanation as to why members of the family had developed diseases such as CVD or diabetes (Patel, 2012; Lucas et al, 2013). This echoed my own experience belonging to a SA family.

Many patients of SA origin understood the importance of taking medications on a long-term basis, for the treatment of diabetes and CVD, and the dangers and risks involved with non-adherence (Kumar et al, 2016). Perceived effectiveness of medications varied dependent upon where they had been prescribed, with patients placing higher value on evidence-based medicine prescribed within the UK rather than India and Pakistan (Kumar et al, 2016).

However, traditional remedies and alternative therapies were still considered and practiced (Keval et al, 2009; Patel et al, 2015; Kumar et al, 2016). Whilst patients reported the benefits and effectiveness of medications, intentionally many patients reported missing dosages (Kumar et al, 2016), due to somatic cues such as “*feeling fine*” were given as reasons for not taking medicines, particularly in Pakistani female participants (Lawton et al, 2005, p.330).

Others believed there to be less benefit in taking lipid-lowering drugs due to noticing a difference in their symptoms (Stack et al, 2008). Some patients made conscious decisions not to take medications during social gatherings such as weddings and parties (Meetoo et al, 2004; Meetoo and Meetoo, 2005). Patients felt that the complications of disease were inevitable and unavoidable regardless of medications, whereas, others were influenced by the experiences of family members for taking medicine (Rafique et al, 2006; Kumar et al, 2016). Certain self-management strategies and life-style changes, such as increased walking and exercise, influenced the need for medication and sometimes a rationale for ceasing treatment regime (Fagerli et al, 2005; Kumar et al, 2016).

There is further evidence from SA studies suggesting there is a belief that much of life is in the control of a ‘higher power.’ Believing that God controls conditions such as diabetes,

CVD, CKD and lupus, commonly expressed in the older first generation, migrant British SAs (Lawton et al, 2005; Kumar et al, 2011; Lucas et al, 2013; Patel et al, 2015). A large number of SAs believed health problems to be the will of ‘Allah’ (Arabic term for God), genetics, change in climate and environment brought about by the migration of these individuals to the UK (Lawton et al, 2005).

Patients with LTCs have numerous complex co-morbidities and extensive physical, emotional and spiritual suffering, leading to higher mortality rate of 20-25% per year (Davidson et al, 2013). Fatalism, spirituality and religiosity, are viewed as important contributors for individuals coping with the limitations and burdens imposed by life-limiting conditions (Davidson et al, 2013). Ramirez et al (2012), identified the positive influences of religion and spirituality on physical health in SA people. Religious and spiritual beliefs have shown to be conducive in improving the quality of life (QOL) and satisfaction in patients with conditions such as CKD, compared to those with no religious beliefs who reported experiencing depression, fatigue and pain (Ramirez, 2012; Davidson et al, 2013). Muslims turn to Allah (God) for patience and strength which claims to enhance the ability of believers coping with difficult diseases (Cinar et al, 2009; Saffari et al, 2013). Cinar et al (2009) in a cross-sectional study looked at the different stressors and coping strategies of chronic haemodialysis (HD) patients, and found that turning to Allah and religion was the most common coping mechanism amongst Muslim patients with CKD. Saffari et al (2013), highlighted the importance of Islam in the Iranian and Pakistani cultures and identified that Muslims tolerate complexities in life and disease through their faith in Allah and the Holy Qur’an. The Qur’an which is Holy book of Muslims, states that: “*Be patient in difficulties you encounter*” (Holy Qur’an, 13:22) and “*rely on God in your affairs*” (Holy Quran 33:3). Moreover, the rituals and practices of Islam accentuates submission to God, and whatever individuals are faced with depends on God’s will. Muslim patients are recommended not to stand idle when a crisis occurs, instead they must devote to spiritual and religious practices, prayers and their family members, to enhance their ability to deal with their disease or illness (Rambod and Rafi, 2010). They are to pray for the improvement of their affairs, so God will help them (Holy Qur’an, 2:153; 7:128).

#### *Toxicity of Medications*

SA patients express concerns about the side-effects and toxicity associated with regular adherence to medication regime (Kumar et al, 2011; 2016). Those with diabetes were concerned about the increasing numbers of prescribed drugs being added to their regime. This

led to increased fears about the toxicity, as many considered taking too many medications would lead to death (Lawton et al, 2005; Kumar et al, 2016). Majority of their worries were associated with the potential side-effects of medicines and beliefs regarding toxicity (Wilkinson et al, 2012). This was similarly reported across SA patients with Rheumatoid Arthritis (RA) and their beliefs about the necessities of disease-modifying anti-rheumatic drugs (DMARDS) (Kumar et al, 2011). Main concerns included: long-term side effects; the apparent lack of efficacy of some therapies; changing from one drug to another; and the large variety of medications being consumed. The most common themes amongst SA patients with RA was the long-term damage that DMARDS may have on their general health and on specific organs (Kumar et al, 2011). Toxicity contributed to poor adherence amongst SA subjects, who suggested that taking many medications made them feel ‘dull’ and ‘dry’, some expressed anger and frustration when one tablet resulted in a complication to control, for which they had to take an additional medicine (Lawton et al, 2005; 2008; Kumar et al, 2016). This evidence indicates that patients need to be made aware of the dangers of missing important medications and its consequences on health-related outcomes. There is a need for further educational programmes creating better awareness and understanding of the benefits of medications, for symptom control, effective management of LTCs, and improved SA health behaviours and adherence (Kumar et al, 2016).

#### *Complementary and Alternative Medicines/Therapies (CAM/T)*

Complementary and Alternative medicine have been defined as “*Diagnosis, treatment and/or prevention which complements mainstream medicine by contributing to a common whole, by satisfying a demand not met by orthodoxy or by diversifying the conceptual frame works of medicine*” (Amin et al, 2015, p.36). They are treatments that lie outside the conventional health care system, examples include, homeopathy, acupuncture, osteopathic, chiropractic and herbal medicines (NHS England, 2016). Such remedies are an ancient method of healthcare, which is again gaining popularity amongst non-western samples, where they are being widely integrated into the modern medical system (Amin et al, 2015). CAM/T are highly associated with cultures and healthcare practices of settlers from SA groups (Pakistanis, Bangladeshis and Indians), being rooted in superstition, ignorance, lack of knowledge and education (Ahmed, 1992; Ali and Hussain-Gambles, 2005; Seet et al, 2020). CAM/T can be divided into three categories, these comprise of complementary therapies, alternative therapies and traditional remedies (Ali and Hussain-Gambles, 2005) (Table 2).

**Table 2.** *Differences Between Complementary, Alternative and Traditional Therapies*  
(Adapted from Ali and Hussain-gambles, 2005, p.42; Adams and Jewell, 2007)

<b>Term</b>	<b>Definition</b>
<i>Complementary Therapies</i>	These therapies are based on combining allopathic medical methods derived from alternative medical systems. Examples include: homeopathy, acupuncture and chiropractic medicine.
<i>Alternative Therapies</i>	These therapies are based on the exclusion of allopathic medications, replaced with other intervention (which are unproven formulas) such as essiac tea, shark cartilage, mistletoe and ancient Indian herbal remedies
<i>Traditional Medicines/Therapies</i>	These therapies refer to approaches and practices to health care incorporated with spiritual therapies such as prayers, manual techniques/methods, animal and mineral based medicines to treat, diagnose and prevent illnesses

Findings from Amin et al's (2015) study, reveal that 80% of participants expressed using some form of CAM/T, the most common being spiritual practices such as meditation and prayer for the cure of acute and chronic illnesses, as well as general well-being. Majority (98%) reported feeling satisfied with such remedies; some participants explained feeling dissatisfied by consultations with physicians, hence, visited homeopaths (referred to as *Hakim* in Urdu Language), herbalists, or spiritual healers.

Homeopathy is often confused with holistic medicine, and with herbal products, as most homeopathic medicines are derived from herbs (Frye, 2003). Females were most likely to visit and consult physicians, and when they felt dissatisfied with their consultations, they would turn to CAM/T to resolve symptoms from chronic conditions, like non-specific musculoskeletal pain, fibromyalgia and depression. Historically, CAM/T have a significant role when conventional remedies and physicians have failed to provide relief of symptoms (Wai et al, 1995). Furthermore, CAM/T were considered cost-effective even in developed areas, people preferred complimentary medicine over conventional therapies, due to the association of high costs (Amin et al, 2015). A concern was that 85% of participants did not feel the need to inform physicians about the use of complementary therapy, which led to

diagnostic confusion, abnormal test results and unexpected concentration of therapeutic contents of drug in the body due to herb-drug interaction (Amin et al, 2015). It can be dangerous for patients to be mixing allopathic or traditional remedies due to adverse effects, contrary to the belief that CAM/T are safe (DeAngelis, 2003; Amin et al, 2015; Seet et al, 2020). There is lacking evidence to support these remedies, further research is required to assess whether they are safe and effective (NHS England, 2016).

The preferences for traditional therapies have been recognised in the literature, where they are believed to improve and control LTCs, such as diabetes and hypertension. According to some SA samples, these remedies were associated with better health status and treatment control beliefs (Patel, 2015; Kumar et al, 2016). Certain therapies, such as food products were seen to improve diabetes control, with the combination of General Practitioner (GP) prescribed allopathic medication (Keval et al, 2009; Patel et al, 2015). Bitter melon which is referred to as '*Karella*' or '*Momordica Charanita*' is a popular food supplement taken by SA samples. Participants from studies believed that the bitter taste from this vegetable would improve glycaemic control by regulating sugar levels (Keval et al, 2009; Patel et al, 2015).

The theme of traditional remedies alongside prescribed 'western' regimes emanates across evidence on SA populations. Kumar et al, (2016) found this theme to be associated with beliefs regarding the need for and efficacy of medication. Many people were found to experiment with traditional remedies in parallel to western medicine, where traditional therapies were viewed as more necessary and effective. Some individuals described how these remedies were efficacious in controlling cholesterol control (Olliffe et al, 2010). Patients also described multiple benefits of alternative therapies, including the view that such treatments make a difference, have no adverse effects, provide balance (Keval et al, 2009), and are natural in comparison to western medications (Lewis et al, 2007). Others expressed traditional remedies as being better at managing long-term illnesses and controlling the adverse consequences of illness (Keval et al, 2009).

Individuals from the SA community were open about the fact that alternative traditional and herbal therapies were widely available (Kumar et al, 2016). Although, some argue that there is limited evidence supporting the use of such therapies, as sources of media amongst this population often portrayed these remedies in a positive light (Keval et al, 2009). The notion of family and friends was considered important in decisions to utilise alternative medications, and in some cases supplying them (Keval et al, 2009).

Although, traditional remedies have received positive credit from SA users, some patients placed more faith in western medications, they spoke of how they shifted from traditional supplements to accept medications prescribed by doctors, whilst others mentioned how traditional remedies contributed largely in the management of diabetes in SA countries (Kumar et al, 2016).

The use of CAM/T and traditional remedies over western medicine, appears to be a popular phenomenon amongst SA samples. Findings also reveal migrant SA communities within the UK, bringing with them their own traditional forms of medicine; although, profuse amounts of literature have explored this phenomenon, current evidence is lacking regarding the use of herbal/alternative therapies in the UK (Bhamra et al, 2017). Further research is required to gain an insight into the experiences of this group, and understand why they may prefer or rely on using traditional methods over conventional medicine.

#### *Gender Roles and Cultural Priorities*

Men and women have distinct and varied roles within the household. The traditional SA household has patriarchal influences where women are socially, culturally and economically dependent on men, who lead the household as the main breadwinners. Whereas, females are consumed within household chores and raising children (Patel et al, 2012). Due to societal beliefs and attitudes towards gender specific roles, some may argue, women to be in a subordinate position; which may lead to exclusion from making decisions with regards to health and healthcare (Fikree et al, 2004). In SA cultures, men are traditionally considered to be the main decision-makers of households, whilst women's decision-making autonomy is closely associated with that of their spouse (the husband), along with maternal and child health outcomes (Senarath et al, 2009). This was found to be evident in decisions-making, in relation to maternal healthcare amongst Bengali women in the UK (Ghose et al, 2017). Women from this origin, felt that the involvement of their husband/partners in decision-making, regarding reproductive outcomes is particularly important, as most families are 'male-headed', where male figures play the dominant role (Ghose et al, 2017). Similar views regarding reproduction in SA women, was also explored by Mann et al (2017), who argued that women with more egalitarian or open views reported fewer births, and felt they were able to make their own family planning decisions, jointly with their husband whilst doing so. However, decision-making tensions were described, where such women instead of their husbands, received and experienced community blame, familial nagging and meddling with decisions (Mann et al, 2017).

The concept of male-dominance also coincides with Patel et al's (2012), study on patients undergoing cardiac rehabilitation. Findings also reveal the SA household being male lead, where men exert influences over health-related factors, such as dietary decisions. Even if the female spouse is seeking to alter dietary changes to accommodate her husband's health needs, she is unable to do so as her husband refuses to sacrifice taste. Traditional SA diets present particular health problems, due to the amount of oil used in cooking, consumption of fried food, high sugar and popularity of Asian sweets (Lucas et al, 2013). Insight came from participants with diabetes and coronary heart disease (CHD), who felt they could not adapt to dietary changes or replace traditional recipes with less appealing "bland" food choices (Shetty et al, 2011; Lucas et al, 2013). These norms are viewed as barriers to encouraging lifestyle changes as a lack of knowledge was not seen as the main barrier across studies, but rather a complex value of hierarchy within the family system (Patel et al, 2012; Lucas et al, 2013). Cultural background and gender roles concur, to inform the ways that SA women think and reflect on their bodies and health (Ahmed et al, 2017). Women are less likely to make dietary changes even if they are the family member living with a health condition requiring diet modification. Instead, the family is expected to make changes for the male's medical condition (Patel et al, 2012).

In terms of cultural priorities, family ties are considered an important part of SA culture, where family is viewed as '*collectivistic*', promoting interdependence and social cohesion (Chadda and Sinha Deb, 2013). Ballard (1982), notes that most SA families have a broader network of familial-relations, in comparison to Caucasian families; in which the ideology of extended family, is common consisting of: husband, wife, children, older brothers and sisters, parents and grandparents. Elders and older siblings often have the most influence, even in terms of health-related outcomes (Patel et al, 2012). Some households where extended families are living together, are viewed to be dominated by the most senior or eldest persons living in the home; dietary decisions are therefore made by the eldest female member in the household (mother, mother in-law or grandmother). Younger women expressed difficulties making healthy dietary changes due to the resistance encountered by parents or grandparents (Kalra et al, 2004; Astin et al, 2008).

Adding to the theme of gender roles, both men and women have marital responsibilities, where health outcomes can be impacted when living with an LTC. Cukor et al (2007), explain that the development of chronic conditions within a couple may place strain on usual marital roles; spouses may experience depression and hostility. This was noted within SA

patients with end-stage renal disease (ESRD). Evidence presents, poorer quality of life in women with ESRD, decreased sexual functions and increased dependency upon family members and lower adaptability compared to men (Lessan-Pezeshki and Rostami, 2009). Another study amongst Indian patients receiving haemodialysis, indicated that couples in which one spouse has ESRD, also reported to have higher prevalence of depression, difficulty with sexual adjustment, perceptions of decreased intimacy, marital dissatisfaction and communication problems (Khaira et al, 2012)

Body Image and physical activity misconceptions was also an emanating theme in terms of cultural identity and gender roles (Patel et al, 2012, Lucas et al, 2013). In the SA cultures, larger body types are associated with sound health, which affects motivation levels to engage in behaviours linked to healthier lifestyles. Women were expected to be thinner when finding a suitor for marriage, and were expected to gain weight after marriage, not doing so was seen as a sign of unhappy marriages (Kishwar, 1995; Patel et al, 2012). Many SA women viewed weight gain as an inevitable path in every woman's life after having children and due to age, this was linked to fundamental beliefs of fate and destiny, which also contributed to their motivation to make changes (Lawton et al, 2008; Lucas et al, 2013). The absence of physical activity and exercise was very high amongst SAs, due to distinctive dislike for exercising at local gyms. Being healthy had little importance to such groups, instead social norms such as: socialising, the religious obligations to modesty, and the cultural rejection of sportswear for women was more important (Grace et al, 2008; Lucas et al, 2013). Cultural and social expectations, health issues and time constraints were seen to hinder the likelihood of performing physical activities (Lucas et al, 2013). These beliefs concerning healthy weight, body image and exercise are the main obstacles, that lessen the motivation towards diet control, exercise and positive health-related behaviours.

Current evidence provides a deeper understanding of the typical patriarchal family system, which is seen to be a tradition within the SA culture. Males hold primary power in roles of politics, moral authority, social honour and possession of property; whilst, women are viewed as the weaker member in the family. Interesting issues related to female health outcomes being over-ridden by male-dominance have been explored, where men also appear to make important decisions for their wives in regards to their health (Fikree et al, 2004). This view is mostly accepted by first generation immigrants who socialise family members, particularly children to their own values, norms, and beliefs in a western culture (Zaidi et al, 2013). In comparison, those from second generation seem to be leaving behind the stereotypes and



gender roles, as women's roles are evolving as they become more open to the western society by taking on employment within highly qualified occupations, and are more open to making their own life decisions particularly in relation to their health (Bandari et al, 2017). Gender roles are seen to contribute largely to health-related factors. However, there is not enough evidence looking into them, impacting self-management and the experiences faced by both men and women living with an LTC. Further research is required to learn more about the gender differences in terms of SA cultural norms and priorities, based on experiences related to disease management.

### *Stigma and Social Support*

Stigma in particular is a common barrier to health seeking behaviour, engagement in care, and adherence to treatment regimen in ethnic minority patients (Stangl et al, 2019). This is mainly due to an individual's fear of being labelled, discriminated, feeling socially unaccepted by their community and reducing their opportunities due to social inequalities experienced (Goffman, 1963). Consequently, this results to worsening health outcomes, undermines and hinders multiple processes such as social relationships, psychological and behavioural responses, resource availability and access to appropriate health and social care services (Hatzenbuehler et al, 2013). Stigma and social support have major influences on adherent behaviours and management in SA patients, particularly found in conditions such as cancer, diabetes, HIV and mental health illnesses (Karbani et al, 2011; Uzma et al, 2011; Chaudhry et al, 2016; Kumar et al, 2016; Syal et al, 2019).

Research identified that SA diabetic patients were reluctant to disclose their use of insulin to their friends, family and community, which made it difficult for them to adhere to medication during social occasions (Kumar et al, 2016). In some cases, individuals would ensure that insulin was taken before social gatherings in secrecy, as they felt that illnesses such as diabetes are not acceptable within SA communities. The social stigma was associated with embarrassment, acceptance and need for social support in society, which made patients reluctant to initiate insulin therapy. Social support contributed to the alleviation of the burdens of disease and good quality of life, due to patients having a sense of 'companionship' (Cukor et al, 2007).

These findings are consistent across studies conducted amongst SA patients with cancer (Hann et al, 2018). Cancer appeared to be a 'taboo' subject in this community, participants felt it was contagious, it was a stigma particularly in family, where SA subjects believed, it

could lead to ramifications on children's marriage prospects (Karbani et al, 2011; Hann et al, 2018). Mental-health illnesses were viewed in the same light (Chaudhry et al, 2016; Mann et al, 2017; Syal, 2019). SA women believed that words or terms such as depression were taboo and used by those who were isolated from society (Mann et al, 2017). Syal (2019), argues that these traditional views are imposed due to associations with shame, fear, secrecy around mental illnesses, lack of knowledge and understanding, isolation, social pressures to conform, feelings of not being valued and marriage prospects that may be damaged. Cultural views, beliefs and practices could be a potential key barrier to successful health related measures and the adoption of preventive measures. Further exploration of stigma and social support is needed to provide a clearer understanding of the term in a socio-cultural context, to understand its origins, meanings and consequences in SA populations. This can allow for non-adherence associated with stigma to be addressed and understood by healthcare providers.

### *Communication*

Good communication is an essential aspect and core feature of high quality and patient-centred care (Free, 2005). However, communication barriers exist, which are noted to be the main hindrance of poor adherent behaviours; this is evident amongst participants of SA origin, who are particularly non-English speakers (Kumar et al, 2011; 2016; Quay et al, 2017). Not only are language barriers a concern for individuals who come to an English-speaking country from overseas, with pre-existing language difficulties, individuals still experience barriers even after settling for numerous years (Ahmed et al, 2015; Meuter et al, 2016). Studies report that non-English speaking patients felt that language barriers between themselves and health professionals who were not able to communicate to them in their preferred language, was a fundamental hinderance (Kumar et al, 2011). Communication is an important element of patient experience, and contributes greatly to healthcare access and patient satisfaction (Gany et al, 2007; Brodie et al, 2016). However, those SAs who experienced language barriers showed to have very little information regarding their condition, symptom control and treatment regime (Bisell et al, 2004; Kumar et al, 2016), instead patients felt very limited to receive, impart and discuss their issues (Kumar et al, 2011). Communication styles with healthcare professionals influenced the ways patients viewed their disease process and medications (Rhodes et al, 2003; Brodie et al, 2016; Kumar et al, 2016). Some expressed a lack of engagement in the decision-making process, leading to poor understanding of treatment plan (Rhodes et al, 2003). Family members were also used

as a source of translation during consultations. However, this was not always successful, as some members were not able to fully grasp the information given, hence, there was failure to relay correct information to patients and the healthcare provider (Kumar et al, 2011). Some family members were also concerned about the lack of explanation provided from the professional regarding side-effects (Kumar et al, 2011).

These communication problems led patients to draw comparisons between receiving care for conditions such as diabetes, in countries such as the UK and SA countries including India and Pakistan, where treatment was costly and paying for medications was a barrier to adherence (Fleming et al, 2008; Kumar et al, 2016). Those who could afford treatment abroad felt they could receive better care from SA countries; whereas, others felt care in the UK was more beneficial and trustworthy. This view impacted the way SA patients communicated with UK doctors about medicines and followed advice (Lawton et al 2005; Kumar et al, 2016).

There is sufficient evidence to identify interpersonal barriers to communication results from language and cultural differences (Kumar et al, 2011; 2016; Ahmed et al, 2015). These contribute largely to poor adherence amongst SA patients living with an LTC, which in turn effects their health outcomes. However, these issues can be resolved through effective translation services in terms of patient preference, which can be examined through exploratory research (Ahmed et al, 2015). Encouraging language support for ethnic groups can improve patient care experiences, allow for effective, meaningful and informative communication during consultations and better relationships with their care providers.

In summary, the factors associated with non-adherence have been exposed. It is important to understand if and how these key concepts influence SAs mobile phone use and their engagement with a text messaging intervention. Furthermore, it can help address scarcity of studying SA samples within the UK and whether similar factors relate to their adherent behaviours, medication regimen, activation levels and self-management.

### **Self-Management of LTCs: A Patient-Centred Approach**

SA individuals experience a 50% higher chance of developing LTCs such as diabetes compared to the general population, which has significant ramifications on this population, as such LTCs are associated with a 2-4 times increased risk of CKD, myocardial infarction and stroke (Bhurji et al, 2016). These individuals, as well as those from the general populations have a key role in protecting, managing and choosing appropriate treatments, to best manage

their condition independently or in partnership with the healthcare system (NHS England, 2018).

Self-management has been described as:

*“...the individual’s ability to manage the symptoms, treatment, physical, and psychosocial consequences and lifestyle changes inherent in living with a chronic condition. Efficacious self-management encompasses the ability to monitor one’s condition and to affect the cognitive, behavioural, and emotional responses necessary to maintain a satisfactory quality of life”* (Barlow et al, 2002, p.178).

Health policies are aimed at creating self-management strategies to increase patient self-efficacy to effectively manage LTCs (Department of Health [DH], 2016; National Institute of Health and Care Excellence [NICE], 2020). Involving patients to take more responsibility for their health behaviours, partnered with guided support may lead to improved health promotion, patient empowerment, chronic disease management and reduced costs to health services (Stone et al, 2005; Reeves et al, 2014).

When studying self-management behaviours of ethnic groups more attention is needed than just language alone. Cultural differences and health beliefs need to be acknowledged and identified (Stone et al, 2005; Kumar et al, 2018). For example, literature reported SA patients attending outpatient appointments were less likely to agree with conditions such as diabetes, compared to Caucasian samples (Ahmed et al, 2015). A study amongst a SA group, identified particular beliefs and attitudes related to diabetes and it being perceived as occurring due to fate, divine planning, bad luck or genetics (Macaden et al, 2010); whilst, certain socio-economic factors (such as education, employment and income) were found to interplay with effective self-management and behaviour change (Shetty et al, 2011).

There are large gaps in understanding the self-management of LTCs amongst SA patient groups, perhaps the development of culturally adapted strategies can aid this. Studies enhancing diabetes education that was culturally tailored through the use of bilingual link workers (community members and/or healthcare professionals) who assisted with language translation, encouraged attendance at clinics and helped with further educational sessions based on self-management (Choudhury et al, 2009; Bhurji et al, 2016). Ahmed et al (2018), argues that healthcare professionals require a better understanding of SA patient perspectives, realities and the dynamic nature of their culture in the UK. For example, how customs and

traditions shift across generations, the importance of family support, and the interaction with self-management regimes.

The concept of self-management focused on patient-centredness, encompassing varied facets of contextual factors such as socio-cultural variables understood by the wider multi-disciplinary teams and a health care system responding to patient health needs. Studies suggest that a person-centred approach to developing an intervention should focus on user perspectives and be customised accordingly (Yardley et al, 2015). Studies utilising interventions for the self-management of SAs with LTCs such as asthma, were designed to reinforce knowledge and self-management behaviours (Griffiths et al, 2016; Ahmed et al, 2018). This included follow-up educational sessions, nurse clinics, written information leaflets as well as digital health platforms such as video format or picture messages sent via mobile phones. Educational videos incorporated cultural aspects such as cultural gestures through educational storytelling and social interaction for SA Hindi or Punjabi speakers. Patients reported such videos to facilitate their trust in the SA community member delivering the intervention (Poureslami et al, 2012; Ahmed et al, 2018). In contrast, modifying and tailoring interventions to language, ethnicity and cultural norms was seen to only influence information processing, rather than behaviour changes (Griffiths et al, 2016). SA studies that tailored information presented during educational sessions, were ineffective or insufficient to the needs of those facing barriers to their self-management regime. Instead, some SA individuals preferred messages to be relayed as a reminder via digital health platforms such as text messages or video formats which helped them remember taking medications on time. Others preferred interventions that were more tailored towards their condition rather than adherence behaviours alone, as an aid to adopt health behaviours to reduce symptoms related to diabetes (Prinjha et al, 2020). The majority of the interventions found to be tailored were preferred by SAs including the use of text messages sent via mobile phone devices (DeSouza et al, 2014; Prinjha et al, 2020). Subjects expressed messages that are culturally adapted (for example, translated messages) were relevant and more acceptable to them, than a generic message. This suggests that a tailored or personalised programme can optimise health outcomes and enhance behaviour change techniques compared to a fixed or 'one-size-fits-all' intervention (Bos-Touwen et al, 2015).

Self-management and patient involvement are key to behaviour change that enhances health-related QoL in LTCs (De longh et al, 2015). It aims to empower and support patients to take control, enabling them to manage their own health and well-being (Ogunbayo et al, 2017).

The potential gains from helping people manage their own health using individual and community-centred approaches can result in increased self-confidence, better QoL, improved clinical outcomes and greater achievement of health goals important to each individual (Pomey et al, 2015). Recent studies have examined the readiness or how activated a person is in their behaviour to perform self-management through their knowledge, skills and confidence, known as ‘patient activation’ (Hibbard et al 2014; NHS England, 2018; McCabe et al, 2018).

### **Patient Activation**

Strategies for improving quality of care focus on the role of the individual in managing their own health; there is a growing awareness that people should be more active and effective in managing their own health and well-being (Barker, 2018). ‘Patient Activation’ is a behavioural concept defined as “*an individual’s knowledge, skills and confidence for managing their own health and health care*” (Hibbard et al, 2014, p.7). Patients or people play a large role in determining their outcomes of care and well-being. Those with high levels of activation have a better understanding of their role in the care process and an increased capability of fulfilling that role. These individuals are more likely to engage in positive health behaviours to effectively manage their health and well-being (NHS England, 2018). Whereas, those with low levels of activation are more likely to feel (McCabe et al, 2018, p.1):

- Overwhelmed with the task of managing their health and would rather not think about it.
- Little confidence in their ability to have positive impact on their health and well-being.
- Misunderstand their role in the care process.
- Limited problem-solving skills, considerable experience of failing to manage their health, and becoming passive in managing their health.

Patient activation is considered to be a better predictor of health-related outcomes as well as socio-demographic factors such as age, ethnicities and health beliefs (Hibbard et al, 2014), which are relevant components to this research topic of interest. However, recent literature argues the need for further research to determine the impact of PAM (Patient Activation Measure)-tailored interventions on quality of care, as it is essential to understand how patient

activation can be better integrated into clinical practice to tailor care for patients with long-term illnesses, including enablers and barriers to implementation (Kearns et al, 2020).

Although, there is limited research particularly in the application of ‘patient activation’ in SA samples, certain factors (age, ethnicities and health beliefs) have shown importance to trigger occurrences of particular behaviours affecting adherence to treatment regime, which in turn, may affect the activation levels of SA patients (Kandula et al, 2020). Henceforth, this justifies the use of the Patient Activation Measure (PAM) within the research study, to assess self-management activities of SA participants.

Interventional studies have found patients who are more activated are more likely to attend screenings, check-ups, immunisations, adopt to positive health behaviours (for example, diet and exercise) and have clinical indicators within normal range such as Body Mass Index (BMI), blood sugar levels, blood pressure and cholesterol (Hibbard et al, 2007; Mosen et al, 2007; Becker and Roblin, 2008; Fowles et al, 2009; Salyers et al, 2009; Tabrizi et al, 2010; Gao et al, 2019), compared to those with lower activation levels. Research suggests SA patients facing major barriers in the ability to manage their own health and make changes to their lifestyle; they tried to make changes but when unable to perform all of them were more likely to make none due to illness-related beliefs, cultural norms and demographical factors as mentioned previously (Macaden et al, 2010; Patel et al, 2015; Kumar et al, 2016). Almost 70% of premature deaths are caused by detrimental health behaviours that could be altered (Spring et al, 2012). Therefore, increasing a focus towards the activation levels of those from ethnic minority groups can begin to address the racial disparities and health inequalities by adopting positive health behaviours and encouraging improved management of LTCs (Gwynn et al, 2016; NICE, 2016).

A persistent and central theme in this thesis is one of context, particularly in the context of mobile technology-based health interventions, delivered to patients to change and enhance positive health behaviours, activation levels and self-management. Consequently, the use of eHealth and mHealth are discussed below, which provides an introduction and rationale to study the FLO text messaging system amongst SA ethnic groups.

### **Advancements in eHealth**

The World Health Organisation [WHO] defines eHealth (also known as digital health) as a concept:

*“...concerned with promoting, empowering and facilitating health and wellbeing with individuals, families and communities, and the enhancement of professional practice through the use of information management and information and communication technology (ICT).” (WHO, 2019, p.1).*

Advances in eHealth often involves healthcare practice reinforced by electronic and communication processes, it predominantly includes database technologies, internet technologies and telecommunications, which are extending and transforming public healthcare services (Steinhubl et al, 2015; Nebeker et al, 2020). eHealth has the potential to improve individual health outcomes, and the performances of health providers; yielding improved quality, cost savings, and greater engagement by patients in their own health care (Bunting et al, 2011). In the UK, significant commitment has been paid by the NHS, in providing more convenient and wider public health services, with the delivery of information through a range of information communication technologies such as: telephones, television, computers, internet and touch-screen Kiosks (Sood and McNeil, 2017). Online technology offers the capacity to interact and communicate in a range of modalities including text, audio and video. These devices are able to deliver a more dynamic communication environment, with the potentials to have a more powerful impact on the recipients of health messages, compared to a single modality (Gray et al, 2016; Rubeis et al, 2017).

There is substantial evidence advocating the premise that when eHealth if appropriately deployed and utilised enables safer and high-quality care. This results in improved communication and better handovers through various tools; real-time monitoring of vital signs that can signal deterioration in a patient; and support in decision-making and rapid responses to tracking adverse events (Buntin et al, 2011; Reed et al, 2012; Cund et al, 2015; Sood and McNeil, 2017; Marcolino et al, 2018). A systematic review conducted by Buntin et al, (2011), demonstrated that the majority of the studies associate eHealth with improvements in multiple health outcomes, and increased effectiveness of care. This is consistent amongst diabetic patients, who found it helpful in improving their recognition and needs of greater drug treatments, as well as better management of disease-related risk factors amongst sicker patients (Reed et al, 2012). Kutney-Lee (2011), highlighted that those utilising comprehensive electronic health record systems report optimal care outcomes, and encountered fewer patient safety issues in relation to adverse drug reactions. eHealth was also found to be useful in intensive care settings, through remote monitoring which reduced



mortality rates by 68% and 46%, followed by a reduction in both average length of stay in the unit, costs and medication errors (Menachmi and Collum, 2011; Sood and McNeil, 2017).

Evidence supports the implementation of eHealth within the NHS, to guide healthcare providers in the provision of evidence-based treatments, delivery of safer, higher quality and more efficient care, to improve patient outcomes and experiences (Sood and McNeil, 2017). However, literature also demonstrates that integrating digital health systems can be challenging and overwhelming for both staff, research participants or patients. Examples include:

- Paper based systems being reformed into electronic systems, and the need to address training needs for users (Kostkova et al, 2015).
- Designing the app for multiple platforms, for example, android or iOS to maximise reach. However, users will only use the app if it is designed for their platform or operating system, which could potentially affect recruitment rate as some participants may be reluctant to take part in the study (De Redon and Centi, 2019).
- Barriers in relation to adoption and/or acceptance of technology for users- For example, language or cultural barriers, individuals requiring translated applications to understand their care processes (Lionarons et al, 2018).
- Ethical and Policy Challenge - For example, obtaining informed consent could impose challenges due to lack of basic and health literacy, local context of participants, cultural aspects and difficulties communicating complex protocols and algorithms (Kostkova, 2015; Vayena et al, 2018).
- Data Protection- Ensuring privacy and surveillance (Data Protection Act, 2018).
- Technological advances are currently the most influential driver of the rise in health-care spending. Hence, providers or organisations who have not yet adopted digital health systems (e.g., electronic health record systems, mHealth platforms) frequently cite financial reasons as barriers to adoption (Ehteshami et al, 2017).
- Economic disparities and limited access to healthcare services, hindering the implementation and promotion of digital health research, particularly for low- and middle-income countries. This results in a poor understanding of existing digital systems, how they function and the stages of maturity of digital interventions across developing countries and ethnic groups (Perakslis, 2018).

- Digital divide (The Office for National Statistics, ONS, 2021)- Although the internet is being used increasingly across all areas of life, and offering multiple benefits; there are those who are digitally excluded due to inequalities that act as barriers to access opportunities, digital knowledge and online services. Statistics from 2018 have found 5.3 million (10%) adults in the UK to have either never used the internet, or not have used it in the last three months. Reasons for this are associated with older age and socio-economic implications (for example, language barriers, income, low digital literacy and education levels) (ONS, 2021).

Nevertheless, the advances of eHealth interventions have shown promise when used with different patient groups, including those from ethnic groups (Patel et al, 2012; Vakili et al, 2015), to promote optimal self-management through the delivery of health messages. A common example of eHealth includes telehealth interventions defined as:

*“...the remote exchange of data between a patient at home and the healthcare practitioner, to aid in diagnosis and monitoring to support patients living with LTCs”*  
(Wootton et al, 2012, p.1).

The use and evaluation of telehealth over the last twenty years supports its introduction (Greenhalgh et al, 2012) with demonstrated findings shown to improve access to services. It is cost-effective, easy to use, saves time and increases patient satisfaction (De Jongh et al, 2012; McLean et al, 2012; Price et al, 2013; Dougherty et al, 2014; Cund et al, 2015; Dorsey and Topol, 2016; Salisbury et al, 2017). Smartphones (Mobile phones), health monitoring devices, wearable sensors and wellness systems are currently promoted as mechanisms to enhance self-management, check symptoms and empower healthy behaviour changes (Price et al, 2013; Dougherty et al, 2014). One of the simplest and most widely utilised telecommunication systems is short messaging service (SMS) or text messaging via mobile phones for supporting and monitoring multiple LTCs (Cund et al, 2015). The majority of interventions have been extensively used amongst the general population from Caucasian continents, compared to a few that have been employed amongst ethnic groups from SA areas such as India and Pakistan (Uzma et al, 2011; Rodrigues et al, 2012; DeSouza et al, 2014), suggesting mHealth interventions being understudied amongst SAs. Although, these few SA studies reported such platforms to aid SA patients through influencing positive behaviours and preventing health-related risks, there was limited evidence suggesting who may or may

not use such systems, why it may or may not be used, as well as the behavioural change processes, particularly across SA ethnic-minority groups within the UK.

### *Mobile Health (mHealth) Interventions*

Mobile health (mHealth) technologies are currently transforming the mode and quality of healthcare research on a global scale (Steinhubl et al, 2015). Such platforms involve the use of voice, SMS and applications which make the provision of health services deliverable. Usually delivered through consumer educational and behaviour change content, wearable sensors and point-of-care diagnostics, disease and population registries, electronic health records, decision-making support and provider tools for healthcare management (Peiris et al, 2018).

Mobile technologies are becoming an increasingly important platform for the delivery of health interventions, particularly in the management of LTCs and preventive health behaviours, and more recently in response to COVID-19. Text messaging can be beneficial by providing information to patients or carers regarding their condition, by monitoring of illness; improving adherence to treatment and/or medication or as peer-to-peer networking and support (Badawy et al, 2017). Evidence suggests messages being used as tools; encouraging physical activity and healthy eating; providing patients reminders regarding upcoming treatments, appointments and feedback on treatment success; symptom monitoring in asthma and heart diseases; smoking cessation interventions and a range of other health related issues (Klasnja and Pratt, 2012; Islam et al, 2019). Such interventions increase self-efficacy (Bandura, 1977; Bandura, 1982) and support mechanisms that may influence health behaviours and enhance self-management of chronic illness (De Jongh et al, 2012). De Jongh et al (2012), assessed the evidence of using text messages supporting the monitoring of LTCs such as diabetes, asthma and hypertension within a Cochrane review. Results demonstrated positive benefits in relation to primary outcomes of an individual's ability to self-manage long-term illnesses. However, some studies reported the opposite effect. In a Vietnamese study, participants identified messages to either contain limited information, or there was an overuse of medical terms than lay language (Sabin et al, 2017), these patients desired more information regarding their medication and treatment options. In a study by Suffoletto and Muldoon (2017), hypertensive patients demanded the need for interventions tailored to their health care needs. Similarly, Valerta et al (2017) reported findings where generic health messages for hypertension were not direct enough to address the needs of each individual user, hence, they were less adherent to the texts sent. Others reported messages to be

repetitive, disruptive or predictable due to them being sent at a time outside the patients' availability or the tone in which they were sent, some felt messages were 'nagging' them to perform certain behaviours (Horner et al, 2017). For optimal adherence to messages, one should receive messages to support them on the basis of the individual's personal schedule (Suffoletto and Muldoon, 2017). The lack of attention to personal preferences, led to participant drop-outs and fewer people up taking text messaging interventions (Ramirez et al, 2016).

Text messaging services are employed for preventive health behaviours such as smoking cessation, increasing physical activity behaviours, dietary intake as well as LTC management such as diabetes, hypertension, and adherence to anti-retroviral (Lester et al, 2010; Uzma et al, 2011; Shetty et al, 2011; Dick et al, 2011; Lin et al, 2012; Rodrigues et al, 2012; Mbuagbaw et al, 2012; Jennings et al, 2013; Osborn and Mulvaney, 2013; Xiao et al, 2014; Prinjha et al, 2020).

Table 3 (Appendix 1), shows a data extraction sheet summarising and presenting studies utilising mobile phone interventions for the management of LTCs, and Table 4 (Appendix 2) presents those within preventive health behaviours, reviewed from the last ten years. Many studies were also found and explored within systematic reviews discussed in the next chapter (De Jongh et al, 2012, Badawy et al, 2017; Marcolino et al, 2018). All studies reported positive effects on health outcomes. Firstly, for those individuals living with LTC such as diabetes, hypertension, and asthma. Messages were sent to provide support through medication reminders and information regarding treatment regime; results showed improvement to adherence and patients self-efficacy (Petrie et al, 2011; De Jongh et al, 2012; Hamine et al, 2015). For those receiving messages for preventive health behaviours, messages for smoking cessation, sexual behaviours, alcohol misuse and increased physical activity were developed (Free et al, 2013; Whittaker et al, 2016). Messages were designed to reduce negative behaviours, to prevent substance or alcohol consumptions, promote weight-loss and safe sex (for example, condom use). Findings showed some text messages enhanced lifestyle outcomes and empowered individuals to adopt safer health practices (Bacigalupo et al 2013; Free et al, 2013).

Although, much of the evidence verifies the benefits of using text messaging interventions in healthcare, to enhance positive behaviours and self-management; they were only utilised short-term within each study. Various text-messaging systems explored, have not been

replicated across research studies conducted amongst samples with similar conditions or health outcomes making them unreliable. In addition, majority of the studies cited are based in Europe or USA, focusing particularly on European or American populations (ethno-centric samples). This suggests either limited access to ethnic minority population or lack of uptake of text messages, making it difficult to generalise across such samples, that are often non-adherent to their treatment regime due to challenges faced with their self-management (Osborn and Mulvaney, 2013).

If mHealth is being used more widely moving forward, further research is required to understand the cultural barriers and challenges faced by ethnic minority groups living with LTCs, and whether a mobile health intervention would assist with self-management. This PhD study aims to explore the experiences and use of text messages to enhance health behaviours and self-management in SA patients. This will be achieved by utilising and evaluating the Florence (FLO) text messaging system. However, prior to that, different types of text messaging systems used in healthcare within the UK have been outlined and compared to FLO, justifying the rationale for its inclusion to the study.

Table 5, summarises the functions of other popular platforms currently being used in mHealth and text messaging. Majority of the text messaging services focus on mental health or younger samples, there is also limited literature supporting the use of other interventions adopted in a SA population. Whilst, ‘Patient Knows Best’ was a service known amongst SA samples in a Birmingham NHS trust, it reported no behaviour changes or continuous support for self-management of LTCs. FLO is the only text messaging system that provides robust evidence of positive behaviour changes in numerous studies previously performed. This includes use within the SA group with chronic illness and making it of interest to this study (Cund et al, 2015; Boath et al, 2016; De et al, 2016; Poole et al, 2016).

#### *Florence (FLO) text messaging system*

There is growing interest in the use of the Simple Tele-health NHS Florence system or “FLO”, well known within NHS groups, as a tool that can encourage effective nurse/clinician-patient interactions. It supports self-management from patients in the longer term as it is already embedded in practice (Cund et al, 2015). This system provides a platform to access potential research participants. FLO is a text messaging system developed by a team at NHS Stoke on Trent in 2010, where messages can be adjusted by health care providers for each patient dependent on the condition, defining when messages should be sent, what

information they are asking for and how the system should respond. FLO then sends regular text messages to patients helping them to monitor their health, sharing any information sent back by the patient with the health care provider that is managing their care. Gathering deeper evidence of SA patient preferences and cultural influences, would be beneficial to the future development of this system in clinical practice.

The FLO system has been used by over 300,000 people in over 70 health and social care organisations in the UK, and has helped thousands of patients with LTCs such as diabetes and hypertension since 2010 (The Health Foundation, 2017). A generic literature search was performed to provide a wider review on the usage of FLO, to identify possible sites for the study proposed, as well as demonstrating the growing evidence of the utilisation and the effectiveness of the FLO text messaging system. Table 6 (Appendix 3), presents a summary of studies that were retrieved.

A total of eight studies were found to utilise the FLO system for the management of various conditions, all conducted within the UK. Studies monitored a variety of LTCs such as diabetes, hypertension and wound care using the FLO text messaging service (Cottrell et al, 2012; Cund et al, 2015). Common findings were discovered, revealing improved medication compliance and healthcare outcomes through the use of technology and tele-medicine. Also, it demonstrated that a majority of patients found the service easy to use, reassuring, saved time, effective in the management of an LTC and reduced number of contacts they had with their GP (Cund et al, 2015; Boath et al, 2016; De et al, 2016; Poole et al, 2016). Majority of the studies (n=6) reported the system to be effective, flexible, affordable, acceptable, and in many cases preferable to usual care. Two suggested the system allowing clinicians to monitor conditions such as hypertension more closely and immediately if needed (Cottrell et al, 2012; 2015). Limitations included studies to be conducted amongst small samples affecting generalisation of results (Cund et al, 2015; Boath et a, 2016; Poole et al, 2016); and failure to identify barriers faced by patients whilst engaging with the system, as one study found patients to use FLO but not fully engage with system or their treatment regime (Cottrell et al, 2012). Only one study was identified to employ ethnic minority samples, assessing the effect of FLO to empower and enhance adherence to diabetes treatment (De et al, 2016). However, insufficient details were provided on the study design, data collection, analyses and the type of ethnic minority groups used. Suggestions were made regarding the need for further longitudinal studies and qualitative research, to assess the long-term effect on behaviour change across larger samples (Cottrell et al, 2015; Poole et al, 2016) including those from

ethnic minority groups (De et al,2016). Furthermore, there was also a need to provide greater insights into the barriers faced by patient and professional users, the potential solutions and ideas for future developments.

This developing evidence based in the UK, reinforces the use of innovative methods to assess, support and monitor LTCs as well as offering an insight into patient experiences (Cund et al, 2015). Although, there is scarce evidence as to whether it is useful and effective for ethnic minority patients such as those from a SA population. Cund et al (2015), suggests that embedding the 'Simple Telehealth Florence' within primary care services within the UK, would complement and aid in developing tele-health systems adapted to support the self-management needs of SA patients with LTCs.

**Table 5. Overview of Text Messaging Platforms**

<b>Platform</b>	<b>Functions and Messaging Content</b>	<b>Comparisons to FLO and reasons for exclusion</b>
<b>ChatHealth</b>	<p>Text messaging service designed for young people, to anonymously get in touch with health care professionals.</p> <p>Texts offer information, advice or details of relevant services regarding self-harm; stress and anxiety; bullying; sex, relationships and contraceptives; alcohol and drugs.</p>	<p>Messages are focused on younger populations and are based on social issues, compared to the FLO which focuses on the self-management of LTCs sent to all age groups including adults suitable for the study. There is also no evidence of this service being used in SA or ethnic minority groups.</p>
<b>Solent Pulse</b>	<p>Text messaging platform that is also being used amongst younger populations (children and adolescent, parents or carers) to receive health support from qualified nurses.</p> <p>Predominantly used for health visiting and school nursing. Messages focus on similar concepts to ChatHealth, including: health, sex, drug and alcohol use, relationship advice, bullying, and self-harm.</p>	<p>Messages are created for younger samples within schools or universities. Platform is not designed for self-management of LTCs.</p> <p>No evidence of its use across SA sample.</p>
<b>Patient Knows Best</b>	<p>An app that offers text messaging services and allows patients access to health or medical records. Patients also receive up-to date treatments, medication and allergies.</p> <p>Has been used to monitor LTCs such as diabetes, hypertension and CKD (De et al, 2016)</p>	<p>Messages have been developed to manage LTCs which are relevant to study of interest. However, no evidence exists on how this system influences behaviour changes, whereas, FLO does (Cund et al, 2015)</p> <p>Has been used across SA sample in the UK (Birmingham), however, patients preferred FLO due to messages tailored and individualised to their condition and self-management needs (De et al, 2016).</p>
<b>FireText SMS</b>	<p>A text messaging service sending individualised messages or large-scale communication campaigns to patients and health care professionals with FireText SMS.</p> <p>Provides appointment reminders, instant test results and information.</p>	<p>Messages developed for the general population, no indication on who the system has been used on or not. Also, intervention does not particularly focus on behaviour change or self-management of LTCs.</p>



<b>Shout</b>	<p>A 24/7 text messaging service also known as a crisis text line.</p> <p>Messages are developed and sent by volunteers to help individuals coping with negative emotions, experiencing bullying and mental health issues</p>	<p>Messages are designed to mainly target those with mental health issues. Is not appropriate to support self-management of other LTCs most common in SAs (for example diabetes and hypertension).</p>
<b>Mind text service</b>	<p>Also, a platform focusing on mental health issues such as depression and anxiety.</p> <p>Messages are tailored dependent on the needs of the person with mental health problems.</p>	<p>Messages are created to support patients with depression and anxiety, and aim to promote positive emotions. However, this intervention is not deemed appropriate to the study, as the focus of the thesis is on physiological LTCs that SA patients struggle to self-manage, rather than just psychological LTCs.</p>
<b>MJOG</b>	<p>An automated text and email messaging system developed to increase attendance to appointments and adherence to important uptake of clinics such as flu vaccinations. Patients are sent informative/educational messages as well as appointment reminders.</p>	<p>The system is rather generic, similar to other systems outlined, it does not focus on long-term issues and self-management behaviours. Also, there is no evidence of such systems being adopted or used by ethnic minority groups.</p>
<b>accuRX</b>	<p>A text messaging and video-call system offering patients virtual consultations or health messages from their doctor or nurses.</p> <p>Case studies from NHS sites, highlight the benefits of this system (NHS, 2018) to include: reduced waiting times between appointments and consultations, spending less on paper mail/postage, reduced medication errors and personalised messages.</p>	<p>The system offers support for LTCs and offers personalisation of messages. However, no evidence of who has or has not used system (i.e., use in SA groups)</p>

## Summary

With SAs being one of the largest ethnic minority populations within the UK, there is increasing impediments to multiple health-related problems they face, particularly diabetes accompanied with other LTCs (such as hypertension, CKD, CVD) if not managed appropriately. These increase demands on current health services that are required to deliver effective treatment strategies, and education programmes for optimal self-management of LTCs. Understanding the barriers and facilitators discussed in this chapter regarding this ethnic minority group's self-management behaviours, illness-related perceptions, health beliefs, cultural norms and customs, gives rise to the need of care interventions that meets expected health outcomes and SA patient needs.

The study has been designed through exploration and understanding of existing theory behind behaviour changes, concepts involved in behavioural change processes and what it means to SA groups. Given that mhealth features so strongly worldwide and has become a central and effective provision of immediate care, makes it pertinent to explore amongst this group, where and how it is used and what they expect from such interventions. Reflecting upon this extensive journey of discovery and exploration, the next chapter (Chapter Three) identifies the gaps in the literature in regards to employing text messages across SA ethnic minorities within the UK. It provides a critique of the findings and the study methods utilised to explore the uptake of text messaging interventions, to enhance behavioural change processes amongst ethnic groups living with LTCs.

## Chapter Three

### The Use of Text Messages in Ethnic Groups with LTCs:

#### A Systematic Literature Review

##### Introduction

Mobile health (mHealth) is a growing avenue within healthcare amongst health professionals, the increased use of SMS shows potential for health promotion and behavioural change interventions (Fedele et al, 2017). Much of the work performed in health to explore text messaging as a tool for the management of LTCs, adherence to medication regime, or improving health behaviours extensively focus on patients who are Caucasian and from the western parts of the world such as USA and Europe (Hall et al, 2015). This suggests a dearth in the literature on ethnic minority groups living with LTCs in the UK. The purpose of this literature review was twofold:

- To identify and describe text messaging interventions that have been utilised by individuals within the ethnic minority population living with LTCs.
- To determine the factors and models that influence positive behaviour changes within this population group, and examine whether they found this intervention to be of any benefit to help them adhere to their treatment regimens and adopt healthier lifestyles.

To accomplish the aims of the review a systematic search of current literature was conducted. The search strategy employed is described as well as the critical appraisal methods adopted, to determine the quality and relevance of the studies retrieved. The narrative synthesis of the review provides an overview of the different ways' researchers have utilised text messaging interventions, within ethnic populations living with LTCs in other countries (Uzma et al, 2011; Rodrigues et al, 2012; Leon et al, 2015; Chen et al, 2018; Bartlett et al, 2019). However, limited studies were found to exist with the same methods being utilised amongst ethnic minority patients with chronic conditions in the UK. A number of factors were addressed in the evidence focusing on treatment regimens, encompassing poor adherence amongst this target group. Findings from these ethnic groups has shown to draw parallels with ethnic minority patients facing similar issues within the UK, which reinforces the importance to tackle them.

## Framing the Review

It is important to frame a comprehensive literature review within a clearly defined objective. Most guidelines for evidence-based practice use the acronym PICO (Population, Intervention, Comparison and Outcome) to help practitioners develop a well-worded question to facilitate a search for evidence (Table 7). Therefore, owing to an emphasis placed on the use of tailored text messages, enhancing positive behavioural changes in ethnic patients with LTCs; the nature of enquiry will use a mixed methods approach. A demonstration of how the PICO tool divides up the parts of the study focus has been provided below.

**Table 7.** *Application of the PICO tool (Poilt and Beck, 2014, p.29-31)*

Population	ethnic patients (including minorities within UK, European regions and USA)
Intervention	Tailored SMS
Comparison	Individuals who are not using the intervention (control group)
Outcome	Enhancing positive behavioural changes towards adherence to medical regime

Accordingly, the following literature question was put forward: ‘How do tailored text messages enhance positive behavioural changes within ethnic minority patients with long-term conditions?’ In addition, further sub-topics/questions were examined:

- The use of tailored SMS to support patients living with LTCs;
- How the experiences of this patient group differ in terms of cultural norms, customs and traditions, demographic factors e.g., age, ethnicity, religion, gender, marital status etc.;
- Whether behaviour change models are used to aid in the enhancement of positive behavioural outcomes for improved adherence.

## Definition of Terms

To address the above question, or any other research topic it is necessary to specify the relevant counterparts of the question. This was done firstly by defining the term ‘ethnic minority’. Ethnic minority is defined as a group of people of a particular race or nationality living within a country or area where most the population are from a different race or

nationality (Cambridge Dictionary, 2016). Attention will also be paid on individuals with chronic conditions, a definition of this term is provided in Chapter Two, along with examples presented in Table 1 (Chapter Two). Lastly, the context of tailored text messages will be focused on patients living with these conditions who own mobile phones and are receiving them.

### **Inclusion and Exclusion Criteria**

An inclusion and exclusion criteria were applied to ensure that only those papers relevant to the questions to be addressed were included. Limitations were first set to retrieve studies within the last ten years. Only peer-reviewed articles were considered as they are ensured to provide improved quality of research, and those studies written in English language due to the time scale and cost issues associated with translation (Table 8).

**Table 8.** *Inclusion and Exclusion Criteria*

<b>Inclusion</b>	<b>Exclusion</b>
<ul style="list-style-type: none"> <li>• Published between 2010-2020</li> <li>• Peer-reviewed</li> <li>• English Language</li> <li>• Adult patients; Ethnic minority populations</li> <li>• Patients with any long-term conditions, the most commonly considered included patients with diabetes, hypertension, long-term viral diseases such as HIV, and interventions tackling obesity i.e., increasing physical activity. Factors also associated with adherence and behavioural outcomes/ health management strategies</li> <li>• The use of tailored text messaging, SMS/short service messaging interventions</li> </ul>	<ul style="list-style-type: none"> <li>• Professional/ specialist opinion, Dissertation, Non-academic Journal i.e., Nursing times</li> <li>• Caucasian population from within Europe/USA or Paediatric patients/adolescent</li> <li>• Patients with cancer and acute conditions. Other conditions such as smoking cessation, non-chronic conditions</li> <li>• The use of other tele-health technologies or interventions e.g., websites, phone calls, Video calls, emails etc.</li> </ul>

There was no limitation applied to country of study as this would limit the search. Only two studies were found to originate within the UK regarding these population groups. The main focus of the research was on ethnic populations with LTCs. Therefore, papers that were presented as dissertations, professional opinions or part of non-academic journals were not included. Other reasons for exclusion included recruitment of paediatric or adolescent samples, those with acute conditions or cancer, and studies focusing on general or Caucasian samples.

### **Search Strategy**

A systematic search strategy using a range of databases (CINAHL, MEDLINE, British Nursing Index (ProQuest) and PSYCHINFO) were used to identify focused evidence-based literature spanning from the last ten years. Before identifying the papers, potential search terms were identified, refined and used, as listed in Table 9. This included keywords from the PICO framework and common terms that were entered in each of the databases used to yield papers.

**Table 9.** *Search Terms*

<b>Population</b>	<b>Intervention</b>	<b>Comparison</b>	<b>Outcomes</b>
Ethnic minority	Text messages	Not specified	Well-being
Minority group	Short messaging service - SMS		Adherence
Ethnic minority population	Tailored text message		Disease management
Racial minority			Health management
Long-term conditions			compliance
Chronic conditions			
Chronic diseases			

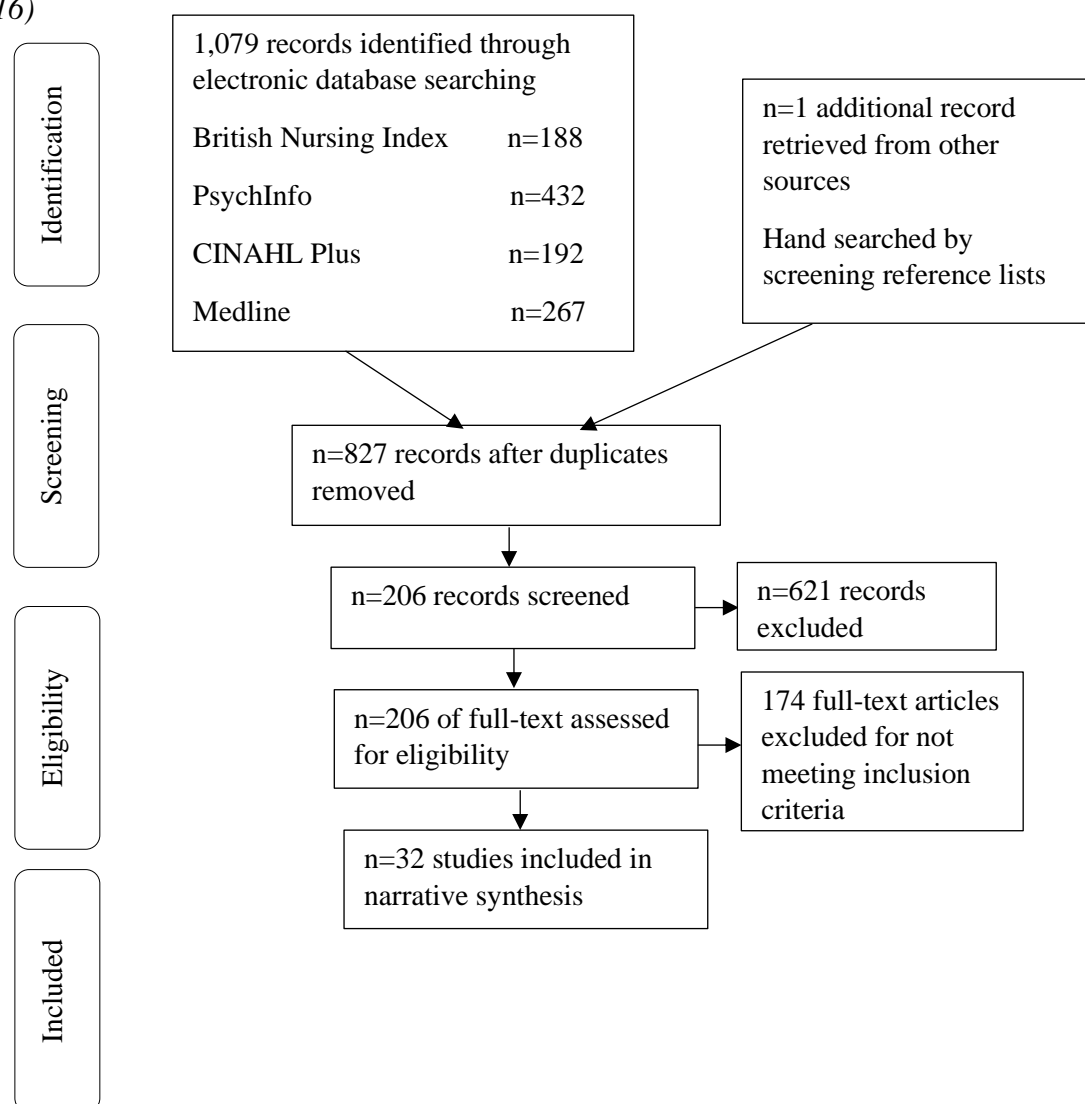
Terms were used in combination with ‘Boolean operators’, to expand or reduce search parameters resulting in a more focused and productive search. The AND was used to maximise search results by retrieving articles containing relevant keywords, whilst, truncations [\*] were used to search for words with common stem, also allowing words of variable endings.

The data extraction and screening of titles and abstracts was performed by one author (the researcher). Many potentially relevant articles were retrieved and also excluded under further scrutiny; numerous combinations were trialled in order to retrieve the most relevant papers. For more consistent results, it would be favourable to use the same search terms in each electronic database (Aveyard, 2010). Although this was the case, 0 results were obtained frequently when search terms were combined. Hence, some of the terms were altered in databases such as CINAHL and Medline as shown above in Table 9. A robust search strategy was performed where amendments had to be made to the search terms before relevant papers were obtained. Adjustments were required to yield a more suitable number of articles applying limitations and selecting them dependent on the inclusion and exclusion criteria shown in Table 10 (Appendix 4). After papers were retrieved reference lists were screened for any other relevant papers that may have been missed, only one study was attained by Steinberg et al, (2013). This paper focused on enhancing weight loss amongst obese Black-African women. Although, obesity is an example of chronic conditions put forward by DOH (2016), this paper was not found under search terms including “Long-term condition”, “chronic condition” and “chronic disease” within any of the databases used. 21 papers were retrieved during the search.

### **Updated Search**

The initial search took place in 2016 from which papers that informed the research area of interest were retrieved. However, it was necessary to update the search to ensure the most current evidence was presented in the wider literature review discussion. The updated search strategy was rerun from 2016 to 2020, using the same search terms and journals shown above (Table 11, Appendix 5). As a result, 257 references were yielded after removing duplicate items across the four data bases. The titles and abstracts of each reference were screened using the same inclusion/exclusion criteria. Consequently, 11 relevant papers were collated. A combined Search strategy performed from 2010-2016 and 2016-2020, has been shown below in a PRISMA flow diagram (Diagram 1). All studies gathered are presented in a data extraction sheet in Table 12 (Appendix 6).

**Diagram 1.** PRISMA Diagram Presenting Overview of Search and Papers Retrieved (2010-2016)



### Critical Appraisal

All studies were subject to a critical appraisal using the Critical Appraisal Skills Programme (CASP) tool (Table 13, Appendix 7), a well-recognised tool aimed to develop an evidence-based approach in health and social care, which assists individuals to analyse the best available research (Glasper and Rees, 2013c; Hek and Moule, 2007). The CASP framework was used alongside the NICE (2016) methodology checklist, for a more focused critique of the evidence on the topic (Table 14, Appendix 8). Both qualitative and quantitative studies were scrutinised separately due to the nature of the methodologies. This helped to make sense of the research evidence applied in practice, and identified a dearth in literature concerning this topic of interest.



Sample judgement was based on: sampling framework, methods of participant selection, recruitment methods, number of participants recruited and representativeness of target population; whilst, method judgement on methodology, description of fieldwork, data collection methods and analysis framework. In line with NICE (2016) quality assessment indicators, each of the sections was given a judgement of good (++), appropriate/adequate/average (+), or poor (-) dependent upon the quality of the paper and description provided. Table 15, presents some examples (continued in Table 14, Appendix 8) of key papers extracted, how they were scored and why they were considered in the review.

**Table 15.** *Example of Quality Summary*

<b>Author</b>	<b>Sample rating</b>	<b>Method rating</b>	<b>Positive</b>	<b>Negative</b>	<b>Relevance to study and review aims</b>
2. Jennings et al (2013)	Good (++)	Good (++)	<ul style="list-style-type: none"> <li>Views of gender-tailored text messages are explored amongst all participants and genders.</li> <li>Good explanation provided of the qualitative methods and interviewing techniques used to elicit participants' perceived benefits and challenges.</li> <li>Adequate description of sample variables.</li> <li>Appropriate recruitment method to suit the study design (purposive technique).</li> <li>Translation of intervention considered.</li> <li>Ethical Approval considered.</li> </ul>	<ul style="list-style-type: none"> <li>Interview guide not provided any clarity on the type of questions asked during interviews.</li> </ul>	<ul style="list-style-type: none"> <li>Differences between gender influences the sampling method.</li> <li>Clear variables of sample to consider for example, age, education, marital status, employment status, phone ownership, and prior experience sending and receiving SMS.</li> <li>Methods explain how patient experiences were captured.</li> <li>Enhancement of positive behavioural outcomes and improvement in communication through SMS intervention.</li> </ul>
11. Rodrigues et al (2012)	Good (++)	Good (++)	<ul style="list-style-type: none"> <li>Quantitative methods used to record adherence to Anti-retroviral treatments (ART).</li> <li>Appropriate statistical techniques used for analysis.</li> <li>Fairly large purposive sample.</li> <li>Ethical approval attained.</li> </ul>	<ul style="list-style-type: none"> <li>Perhaps interviews would be a better method to capture patient experiences of being involved in a SMS intervention.</li> <li>Patients' awareness of being under study could lead to Hawthorne effect on adherence; hence recruitment strategy may need to be reconsidered.</li> </ul>	<ul style="list-style-type: none"> <li>Likert-scales/instrument useful to measure and/or rate patient acceptability and views of SMS intervention.</li> <li>Barriers associated with adherence were revealed, 'forgetfulness' was found to be the most common cause of non-adherence in Indian sample.</li> <li>Improvements in medication adherence through text message reminders to take medications on time.</li> </ul>

12. Liu et al (2015)	Good (++)	Average (+)	<ul style="list-style-type: none"> <li>• Large and representative sample.</li> <li>• Stratified random sampling technique to select study subjects.</li> <li>• Valid rationale provided for not masking/blinding staff and patients.</li> <li>• Ethical approval obtained.</li> </ul>	<ul style="list-style-type: none"> <li>• Not enough information or details provided regarding data collection methods and data analysis techniques.</li> </ul>	<ul style="list-style-type: none"> <li>• Good findings-show improvements in medication adherence through an SMS intervention for patients with TB.</li> </ul>
13. Müller et al (2016)	Good (++)	Good (++)	<ul style="list-style-type: none"> <li>• Mixed method approach used to address research aims.</li> <li>• Combined sampling technique used-random sample and convenience sampling technique.</li> <li>• Randomization methods explained in adequate detail.</li> <li>• Good description of quantitative and qualitative analyses.</li> <li>• Ethical approval obtained.</li> </ul>	<ul style="list-style-type: none"> <li>• Sample size was small to determine the intervention effect within a RCT design.</li> <li>• The study was also limited by lack of statistical power to represent quantitative results.</li> </ul>	<ul style="list-style-type: none"> <li>• Good findings with respect to elderly patients and their frequency of exercise, associated with weight management. Results reflect on other studies discussed within the review.</li> <li>• Relevant themes emerged from interviews (for example, exercise program, SMS text message content, effects of the SMS text).</li> </ul>
14. Uzma et al (2011)	Good (++)	Good (++)	<ul style="list-style-type: none"> <li>• Randomized controlled trial.</li> <li>• Random sample selected appropriately.</li> <li>• Good clear description of data collection methods.</li> <li>• Appropriate quantitative analysis approach adopted.</li> <li>• Development of validated instruments to assess adherence of medication.</li> <li>• Ethical approval obtained.</li> </ul>	<ul style="list-style-type: none"> <li>• No clarity of whether study participants/staff members identified within RCT.</li> <li>• Small sample size obtained making it difficult to make generalisations.</li> </ul>	<ul style="list-style-type: none"> <li>• Good findings providing evidence of SMS intervention to have improved compliant rates within the Pakistani population receiving anti-retroviral therapy.</li> </ul>
15. Dick et al (2011)	Good (++)	Good (++)	<ul style="list-style-type: none"> <li>• Mixed method approach used to strengthen rigor of data collected.</li> <li>• Voluntary sampling used to retrieve sample appropriate for the qualitative phase of the study.</li> <li>• Findings reflect upon results of larger studies.</li> <li>• Surveys and interviews used for data collection.</li> </ul>	<ul style="list-style-type: none"> <li>• Study could be performed within a larger sample size to increase and enhance reliability.</li> </ul>	<ul style="list-style-type: none"> <li>• Interviews were useful to gain feedback on the experiences of participants to make amendments to their tailored text messages.</li> <li>• Identified aspects to consider for changes to diabetic patients' self-management behaviours.</li> <li>• Enhancement of positive behavioural outcomes for improved diabetes care.</li> </ul>

			<ul style="list-style-type: none"> <li>• Sufficient details provided regarding surveys and interviews guide (close-coded and open-ended questions used).</li> <li>• Good description of quantitative and qualitative analyses.</li> <li>• Qualitative analysis involved interviews being transcribed verbatim, thematic analysis adopted and performed by two randomly assigned reviewers.</li> <li>• Ethical approval obtained.</li> </ul>		
16. Vakili et al (2015)	Good (++)	Average (+)	<ul style="list-style-type: none"> <li>• Development of validated instruments to assess eating habits-translated in the Persian language.</li> <li>• Intervention carried out by external expert research team, reducing potentials for biases.</li> <li>• Random sample selected as suitable for study.</li> <li>• Quantitative data analyses procedures described adequately.</li> <li>• Ethical approval attained.</li> </ul>	<ul style="list-style-type: none"> <li>• Not enough information provided on sampling method. Although, it was random further details regarding their technique could be included and discussed.</li> <li>• No clarity on blinding procedures to reduce further biases.</li> </ul>	<ul style="list-style-type: none"> <li>• Good study identifying mobile phone usages and short messages intervention to improve healthy food choices and increase the consumption.</li> <li>• Enhancement of positive behavioural outcomes to make better food choices.</li> </ul>
27. Moyano et al (2019)	Good (++)	Good (++)	<ul style="list-style-type: none"> <li>• Qualitative study methods outlined adequately.</li> <li>• Study aims stated clearly.</li> <li>• Appropriate sampling technique (convenience) used to fulfil aim of study.</li> <li>• Interviewing techniques and analysis of themes well outlined.</li> <li>• Application and reference to behaviour change model- HBM and its determinants (for example, risk perception)</li> </ul>	<ul style="list-style-type: none"> <li>• 24 middle-aged participants were selected for the study in Argentina. Sample size may not be representative of the wider population in Argentina.</li> </ul>	<ul style="list-style-type: none"> <li>• Findings suggest a strong association between receiving text messages and having a better patient-physician relationship.</li> <li>• Text-messages found to improve health outcomes amongst diabetic patients.</li> </ul>

## **Overview of Papers Extracted**

After combining papers from the two search processes, a total of 32 studies were retrieved and included. Although, the search was limited to ten years, the relevant papers included were published between 2010-2020. All the papers were research studies, nine of which adopted a mixed methods approach; seven studies were qualitative and 16 studies used a quantitative approach. Out of the 16 quantitative papers, two studies assessed the same intervention which is the SMS-Text Adherence Support (Star) trial created to improve treatment adherence for hypertensive patients (Bobrow et al, 2014; Leon et al, 2015). Nine studies used a cross-sectional design, administering questionnaires and surveys for data collection; 15 studies utilised a randomized controlled trial design, and 12 used interviews as the main exploratory method of data collection, particularly within the six qualitative studies found. In-depth interviews are the most common method of data collection encouraging participants to define important dimensions of a particular phenomenon (Polit and Beck, 2014). Eleven studies were conducted in Asia; one Taiwan, three India, one Pakistan, one Iran, four in China and one in Malaysia. Eight studies were conducted in African regions; two Kenya, three South-Africa, one Cameroon, one Ethiopia and one in Uganda. Two took place in the UK, one in Argentina and one in New Zealand. The remaining nine were performed in United States of America (USA). Seven studies report the completion time; five took between 1-6 months and the two remaining were performed greater than a year, with the maximum being a year and six months.

## **Study Aims**

The studies have combined various aims to investigate the use of text messaging interventions. The aims of the 30 studies resemble and overlap one another; six main chronic conditions can be drawn out from the studies examined. There was a clear focus on the management of LTCs, particularly to aid patients with diabetes (10), HIV (10), tuberculosis (TB) (2), chronic kidney disease (CKD) (1), hypertension (3) and obesity (6). Eighteen studies aimed to particularly improve adherence to medication and 14 focused on behavioural modification and management strategies; to explore the gaps within patients' perception of their condition, and to assess whether text messages provided support to improve health management strategies. Tailored text messaging interventions were used in all the studies (32) to address the needs of individuals with particular health conditions. Such messages helped develop improved self-management strategies. According to Woolford (2010), individually tailored information has been shown to be an effective and patient-centred

approach to promote health-related behaviour change. Text messages in each study were created to improve adherence to various medications used to self-manage common LTCs such as diabetes, TB, HIV, and CKD; and promoting healthier lifestyles by tackling problems faced by individuals with obesity and hypertension.

### **Tailored Text Messaging Intervention**

With respect to the topic of mHealth and use of text messages to improve health behaviours of ethnic groups with LTCs; all 32 studies have directly reported the positive effects of tailored texts on behavioural changes within such populations. All studies solely focused on patients with LTCs, predominantly HIV, diabetes, hypertension, obesity, TB and CKD patients (Liu et al, 2015; Bartlett et al, 2019; Musiimenta et al, 2020). The studies all designed messages that were tailored dependant on the conditions, patients with HIV received messages regarding adherence with antiretroviral medication (Lester et al, 2010; Uzma et al, 2011; Rodrigues et al, 2012; Mbuagbaw et al, 2012; Jennings et al, 2013; Xiao et al, 2014; Endebu et al, 2019; Evans et al, 2019; Govender et al, 2019; Mayo-Wilson et al, 2019); whilst, diabetic patients received messages regarding medication adherence, diet control, foot care, and blood sugar monitoring (Shetty et al, 2011; Dick et al, 2011; Lin et al, 2012; Osborn and Mulvaney, 2013; Chen et al, 2018; Dobson et al, 2018; Moyano et al, 2019; Prinjha et al, 2020). Patients with hypertension and obesity received messages that focused on improving adherence to antihypertensive medication, increasing physical activity and considering healthy eating (Lin et al, 2012; Patel et al, 2013; Steinberg et al, 2013; Bobrow et al, 2014; Desouza et al, 2014; Leon et al, 2015; Vakili et al, 2015; Buccholz et al, 2015; Müller et al, 2016). Seventeen studies used interviews that explored the experiences of this patient group and how this intervention was perceived by them, whereas, the other 15 papers were experimental, investigating the effects of this intervention. Results showed improvements in compliance to medication regime and positive behavioural changes for healthier lifestyles (30). Barriers were also identified in adherence behaviours, with common ones being lack of information about medication, cost of medication and fear of side effects as well as psycho-social stressors and health service issues in disadvantaged areas (Osborn and Mulvaney, 2013; Leon et al, 2015; Hincapie et al, 2017). Messages in all studies differed, five reported them to be tailored and culturally appropriate in terms of cultural norms, customs, traditions, language and demographic factors (Lin et al, 2014; Xiao et al, 2014; Vakili et al, 2015; Chen et al, 2018, Endebu et al, 2019; Prinjha et al, 2020).

### **Patient Modality**

All 32 studies involved patients with one of six chronic conditions being either: HIV, CKD, TB, diabetes, obesity or hypertension. This may suggest limited evidence of utilising this intervention in patients with other chronic conditions such as arthritis, COPD, multiple sclerosis, Alzheimer's disease and many others. Fifteen million people within just England alone are accounted to have a single or multiple LTCs, most commonly being COPD, diabetes mellitus, rheumatoid arthritis, coronary heart disease, dementia, and stroke (DOH,2012; The Kings Fund, 2016). It would be worthwhile studying the effects of this intervention tailored to address the needs of individuals with such conditions. Due to the nature of the research topic, a close focus was drawn upon ethnic groups and minority populations. Therefore, patients were found to be included from different parts of the world. Samples were pre-dominantly Black or Hispanic in 16 studies, with eight included from African regions and eight from within USA. Eleven studies employed Taiwanese, Indian, Pakistani, Iranian, Chinese and Malaysian patients. Patients were all selected from sectors providing health care, which were accredited healthcare centres or chronic disease outpatient centres. Although, the studies retrieved were found from a range of settings utilising various ethnic samples, only two were carried out in the UK, one using a SA sample (Prinjha et al, 2020). This suggests insufficient evidence amongst minority populations living in the UK. Therefore, the findings of this study will contribute to the current and much wider literature based on ethnic minority groups and the use of text messages to monitor and improve self-management.

### **Ethical Approval**

Where ethics is concerned, 25 studies out of the 32 report having obtained ethical approval for their study from recognised authorities including university, hospital or their local research ethics committees (Dick et al, 2011; Shetty et al, 2011; Uzma et al, 2011; Mbuagbaw et al, 2012; Jennings et al, 2013; Osborn and Mulvaney, 2013; Rodrigues et al, 2012; Patel et al, 2013; Steinberg et al, 2013; Bobrow et al, 2014; Buccholz et al, 2015; Leon et al, 2015; Liu et al, 2015; Vakili et al, 2015; Müller et al, 2016, Hincapie et al, 2017; Chen et al, 2018; Dobson et al, 2018; Evans et al, 2018; Bartlett et al, 2019; Govender et al, 2019; Mayo-Wilson et al, 2019; Moyano et al, 2019; Prinjha et al, 2020; Musiimenta et al, 2020). The process of obtaining informed consent from participants prior to recruitment was described in 28 studies, but in the other four it was not discussed. Consent was presumed on distribution of information sheets amongst patients and return of questionnaires and surveys in three

studies, where participants were asked to provide contact details as well as acceptability of healthcare interventions delivered via mobile phones. For the remaining four studies it was unclear whether ethical approval was obtained or ethical issues considered.

### **Sample and Sampling Methods**

The number of patients recruited within the 32 studies varied from five (Bartlett et al, 2019) to 4,292 (Liu et al, 2015). Ten studies recruited samples less than 50 subjects (ranges 18-45), and 13 consisted of samples ranging from 50-366. The remaining six studies recruited samples greater than 400 patients (ranges 488-4,292). Twenty-six studies focused on recruiting patients from a single site, whereas, the remaining six chose participants from more than one centre or study site.

On the whole, sample selection and recruitment varied across the 32 research papers. Thirteen of the studies used random sampling methods, where patients were selected from a pre-determined list of random numbers. In comparison, non-random participant selection such as a purposive sampling technique were used by twelve. Others targeted the whole population (1); however, sampling methods were unclear and not defined in detail (Desouza et al, 2014; Chen et al, 2018). Two studies used self-selection techniques where participants volunteered to take part; whereas, others adopted an opportunistic approach to conveniently recruit appropriate patients from particular outpatient clinics or local community organizations, to study the use of text messaging interventions (6). Out of the 32 studies, two incorporated sampling methods. Lin et al, (2014) and Mayo-Wilson et al (2019), first self-selected patients by advertising their studies via leaflets and flyers in local neighbourhoods, hospitals, health centres, and commercial buildings. After attaining a sample, they used a random sampling technique to randomise individuals to either an intervention or control group. Leon et al, (2015), also combined methods (purposive and convenience sampling) to conveniently recruit their South-African sample who were attending an outpatient chronic disease centre.

### **Data Collection**

The most popular field-work method was questionnaires, surveys and validated instruments. Sixteen studies used them to collect demographical data, baseline anthropometrics and Likert-scales to assess patient experiences of taking part in text messaging interventions. Sixteen studies performed face-to-face interviews, where eight used focus groups (Mbuagbaw et al, 2012; Jennings et al, 2013; Buccholz et al, 2015; Leon et al, 2015;



Hincapie et al, 2017; Chen et al, 2018; Endebu et al, 2019; Prinjha et al, 2020); and five used in-depth semi-structured interviews (Osborn and Mulvaney, 2013; Müller et al, 2016; Bartlett et al, 2019; Moyano et al, 2019; Musiimenta et al, 2020). A mixed method approach was adopted by four studies in which face-to-face interviews were utilised to inform the development and administration of questionnaires and surveys (Dick et al, 2011; Lin et al, 2012; Osborn and Mulvaney, 2013; DeSouza et al, 2014). One study used quantitative methods of data collection; however, methods have not been specified making it unclear how data was collated (Liu et al, 2015).

### **Researcher Bias**

The researchers were external to the text messaging intervention or separately trained and certified researchers. Research assistants or nurses were employed to conduct the study fieldwork within majority of the research papers (14). However, six of the studies posed the potential for researcher bias including the internal researchers and healthcare providers of patients. Having the researcher or healthcare professional as the main person responsible for delivering the text messaging intervention, collecting data or working within the research setting, could possibly preconceive patient experiences and ideas (Lester et al, 2010; Rodrigues et al, 2012; Jennings et al, 2013; Lester et al, 2015; Lin et al, 2015; Liu et al, 2015; Müller et al, 2016). In the study conducted by Steinberg et al (2013), although, trained staff was mentioned it was unclear whether they were internal or external researchers, and insufficient detail was provided to determine whether research bias existed.

### **Analysis**

Twenty-eight of the 32 studies provide an adequate and comprehensive description of the data analysis processes performed. In the remaining four studies the description was very limited and insufficient. For example, stating the degree of engagement with messages was correlated with weight loss, or applying the intention-to-treat, to frame the analyses but not providing enough information of how this approach has been applied (Lester et al, 2010; Lin et al, 2012; Osborn and Mulvaney, 2013; Bobrow et al, 2014; Lin et al, 2014). Majority of the research studies being quantitative used statistical methods for analysis (20). Although, brief details were given, it was not difficult to establish the nature of the study and type of methods used for analysis in some studies (Lin et al, 2012; Osborn and Mulvaney, 2013; Liu et al, 2015). Of the fifteen studies utilising questionnaires as a data collection method, appropriate statistical tests for analysis were adopted. The most common software used for analyses by quantitative research was SPSS, used in ten of the studies; the remaining ten provided no

information on the type of software used. From the information provided, eleven studies used a thematic or content analysis, or a combination of both to study qualitative data. They all had interviews transcribed and translated, including six of them verbatim. Six of the eight papers explained their process of attaining rigour and accurate data process through reflexivity. Out of the seven qualitative studies, three used a mixed method approach of analyses, both qualitative and quantitative data analysed separately (Dick et al, 2011; Bartlett et al, 2019; Endebu et al, 2019). Four studies outlined using NVIVO (Musiimenta et al, 2020; Prinjha et al, 2020) and ATLAS.ti (Dick et al, 2011; Moynao et al, 2019) to transcribe and analyse interviews. The remaining three studies provided no information on qualitative analyses.

### **Summary of Quality**

Generally, the quality of the studies was high. Critical appraisal assisted with the classification of both the quality and rigour of each study, using three categories- low (-), medium (+) or high quality (++). Qualitative and quantitative designs were critiqued separately. From the 32 studies, 29 studies were judged to be of high quality, three medium and one low. Table 14 (Appendix 7) and 15 provide a summary of the quality ratings.

The study that was judged to be of low quality was by Lin et al (2012) due to not being completely applicable to the topic of interest, as it did not employ a text messaging intervention to assess the improvements in behavioural outcomes in relation to adherence. Although this was the case, it met important aspects of the inclusion criteria by focusing on compliance, behavioural outcomes and health management strategies of LTCs within ethnic patients. The findings of this study corroborated with all the other papers especially those who studied similar samples in China (Xiao et al, 2014; Lin et al, 2015; Chen et al, 2018). Barriers and challenges experienced by Chinese populations were unveiled, which in turn highlighted the need for tailored services and educational interventions to help improve self-management and promote health behaviours for people with diabetes as well as other LTCs. These aspects provide a justification for including this study within the review.

Studies adopting a single approach with qualitative interviews or quantitative instruments/surveys were useful in obtaining patient experiences of engaging with text messaging interventions to improve adherence. Those adopting a mixed method approach where both methods are combined, strengthened the rigor of the data collected, leading to increased meaningfulness and credibility of findings (Dick et al, 2011; Lin et al, 2012; Osborn and Mulvaney, 2013; DeSouza et al, 2014; Endebu et al, 2019). This allowed

researchers to address and measure issues relating to poor adherence; whilst, exploring attitudes of ethnic samples with LTCs and their involvement in text messaging interventions (Dick et al, 2011; Lin et al, 2012; DeSouza et al, 2014; Prinjha et al, 2020). Likewise, validated instruments developed and adapted as culturally appropriate, were useful in collecting large amounts of data regarding medication adherence and behavioural outcomes (Uzma et al, 2011; Lin et al, 2015; Vakili et al, 2015; Musiimenta et al, 2020). There was a range of tools utilised by other studies that effectively measured and identified similar factors (Shetty et al, 2011; Rodrigues et al, 2012; Patel et al, 2013; Xiao et al, 2014; Bobrow et al, 2014; Dobson et al, 2018). However, patient experiences of living with LTCs, aspects surrounding behavioural factors, adherence, and preferences of using text messages were better captured within qualitative focus group, semi-structured and in-depth interviews (Dick et al, 2011; Jennings et al, 2013; Osborn and Mulvaney, 2013; Leon et al, 2015; Müller et al, 2016, Chen et al, 2018, Prinjha et al, 2020). Never the less, this time-consuming method restricted the size of the sample and in turn the quality of findings (Buccholz et al, 2015; Bartlett et al, 2019).

Although, most studies were conducted within a single site (26), findings could be generalised due to the relevance and similarity of the results suggesting text messaging to be an acceptable intervention, to help improve medication adherence, and enhance positive behavioural and health outcomes. Many studies presented large and representative samples (Lester et al, 2010; Xiao et al, 2014; Bobrow et al, 2014; DeSouza et al, 2014; Liu et al, 2015; Dobson et al, 2018; Endebu et al, 2019), including five studies that recruited a multi-site sample (Lester et al, 2010; Jennings et al, 2013; DeSouza et al, 2014; Xiao et al, 2014; Liu et al, 2015). All research papers focused on text messages that were designed and tailored dependent on the conditions or diseases the ethnic groups presented with. When the details of specific text messages designed to address a certain disease, findings could be translated to those study sites where similar interventions were performed (Dick et al, 2011; Shetty et al, 2011; Osborn and Mulvaney, 2013). For those studies where sufficient quality and rigor existed, the results on the whole could be generalised to populations with LTCs such as HIV, TB and hypertension (Bobrow et al, 2014; Xiao et al, 2014; Liu et al, 2015). Similarly, despite small sample sizes in some research papers, results were considered reliable, as they were found to correlate with more rigorous studies with larger samples (Dick et al, 2011; Osborn and Mulvaney, 2013; Leon et al, 2015; Buccholz et al, 2016; Bartlett et al, 2019; Moyano et al, 2018).

As a whole, a number of different issues were highlighted, identified and emphasized across a variety of different studies within the review. The 32 studies focused on ethnic/ethnic minority patients with LTCs and the use of a text messaging intervention, to enhance positive behavioural outcomes. Nineteen studies described medication regime in relation to certain conditions and the use of text messages to improve medication adherence and behavioural outcomes; whereas, 13 focused on other management strategies such as lifestyle changes including physical exercise and eating habits. Ten studies drew upon factors affecting patient adherence (Dick et al, 2011; Rodrigues et al, 2012; Osborn and Mulvaney, 2013; Lin et al, 2014; Leon et al, 2015; Hincapie et al, 2017; Chen et a, 2018; Bartlett et al, 2019; Musiimenta et al, 2020; Prinjha et al, 2020), whilst, others focused mainly on behavioural change goals, psycho-social factors, health service and organization factors, patient experiences and perceptions of engaging with text messaging.

### **Key Themes Extracted**

From all the studies (32) reviewed themes were identified pertinent to the self-management of LTCs, behavioural outcomes relating to health and the uptake of technology-based or text messaging interventions amongst ethnic groups (Box 1).

**Box 1. Key Literature Review Themes**

- Demographics (age, gender, education level, psycho-social factors)
- Barriers to Adherence
- Health Beliefs and Experiences
- Behavioural Goals, Psychological Affects and Outcomes
- Patient Education and Information Seeking
- Content Provision and Use of Text Messages

**Demographics***Age and Gender*

Demographic factors such as age and gender were addressed within all studies (32). Four studies focused on female populations with LTCs and the use of a text messaging tool to enhance positive behavioural outcomes (Jennings et al, 2013; Steinberg et al, 2013; Vakili et al, 2015; Moyano et al, 2019). Gender differences were explored by Jennings et al (2013), along with the development of a safe, comprehensive, and gender-tailored platform that would be acceptable for the participants under study. The study addressed the challenges faced by women and their partners, in supporting the prevention of mother to child transmission of HIV, and how mobile phones could be utilised to mitigate these challenges, through gender-tailored messages. Male involvement reflected women's desires to address partner disclosure and to promote better partner support, suggesting that text message reminders can be a useful channel to initiate a dialogue with male partners (Jennings et al, 2013). Both Steinberg et al (2013) and Vakili et al (2015) examined the use of text messaging to promote weight loss and healthier lifestyle choices in ethnic minority women. Findings were supportive of such intervention, suggesting mobile phones can be a useful self-monitoring tool for weight control and to improve healthy food choices. DeSouza et al (2014), examined a large proportion of participants from which they were able to identify certain gender differences existing within a typical Indian family. Women were often responsible for all household chores as well as the health and hygiene within their family. They were less likely to be employed, making their schedules more flexible and conducive, and ensuring improved medication adherence compared to men. Female participants were more likely to communicate directly with healthcare professionals regarding the management of health issues when assistance was needed. While, valuable findings were retrieved gender differences were not explored in other studies, in relation to perceptions of living with a LTC

and how the behaviours may vary between men and women (Shetty et al, 2011; Uzma et al, 2011; Rodrigues et al, 2012). The literature presents findings in favour of females having better health behaviours compared to men, however it fails to acknowledge why men have poorer outcomes and are less adherent.

Age was another variable disclosed within the eligibility criteria, as all studies included adults aged 18 and above. Younger patients were found to be better engaged with the intervention within all the studies, due to having better knowledge and skills of using technology (Xiao et al, 2014). This suggested age contributed to engagement and acceptance of technology-based interventions, as older adults were late adopters to mobile phone technology (Xiao et al, 2014; Prinjha et al, 2020). Two studies employed older samples to appropriately address the aims of their studies. Vakili et al (2015), used a sample aged between 40-60 years; whilst, Müller et al (2016), recruited subjects between the ages of 55-70. The two studies demonstrated text messages to be an acceptable platform to enhance positive life style changes, increasing exercise frequency and promoting healthier eating amongst participants (Vakili et al, 2015; Müller et al, 2016). Age did not influence the use of text messages, as seen by Xiao et al (2014). Older subjects faced barriers due to not being able to read messages compared to other participants (Vakili et al, 2015; Müller et al, 2016), who suggested education and literacy levels being pertinent and important to be able to receive adequate health care to self-manage with such interventions.

#### *Education and Literacy levels*

Education and level of literacy was found to be consistent with mobile phone use, positive behavioural outcomes, adherence and being able to read and understand text messages regarding treatment regimen across all studies. Educational text messages were designed and sent dependent on the condition patients presented. They successfully aided patients to adapt to positive lifestyle change and improve adherence. Variations were shown to exist between participants' education level, adherence and ability to use and understand texts sent to mobile phones. Eligible participants in some studies were educated, more likely to respond to the intervention and self-manage their condition effectively, as they were able to read messages. This was an important factor to consider, as low literacy was shown to lead to rejection to text messages, poor self-management of LTCs and health outcomes in regions such as China, Africa, India and Pakistan (Shetty et al, 2011; Uzma et al, 2011; Mbuagbaw et al, 2012; Xiao et al, 2014; Chen et al, 2018; Mayo-Wilson et al, 2019). Limitations of mobile phone communication included how to relay complex text messages and verifying that the

recommended tasks given via texts were completed. Participants who experienced difficulty with the intervention required support from their partners, families and healthcare workers to help them read and understand what messages were telling them to do.

Text messages improved patient education, adherence to clinic visits and treatment of hypertension for all patients through additional educational messages, providing information on blood pressure control and adherence to antihypertensive medications (Bobrow et al, 2014). Similarly, patients who were better educated acquired better self-management techniques through regular monitoring of blood sugars and attending clinics periodically when advised (Shetty et al, 2011).

Region of residence was found to affect literacy and education levels in some studies. SA patients living within the rural regions had lower levels of education impacting treatment, care and support they received, which in turn led to poor adherence, reduced benefits of treatment and limited therapeutic options (Uzma et al, 2011; DeSouza et al, 2014). Similarly, individuals in rural China, and those with less than a primary education found it difficult to read messages and were less willing to accept them. Poor adherence existed amongst the Black African-American population, due to a lack of knowledge regarding self-management guidelines to effective glycaemic control being a major challenge (Dick et al, 2011). Attention to factors such as English literacy and education within such samples would only serve to improve the efficacy of mHealth and aid in treatment adherence.

Predominantly, in terms of patient education the mobile phone is a useful device delivering text messages to educate individuals from different countries of the world, along with motivating and prompting various self-management activities to improve self-management of LTCs (Lester et al, 2010; Dick et al, 2011; Mbuagbaw et al, 2012; Patel et al, 2013; Steinberg et al, 2013; Vakili et al, 2015; Hincapie et al, 2017).

### **Barriers to Regimen Adherence**

There are copious barriers related to treatment compliances and non-adherence amongst the ethnic minority groups discovered, such as: communication issues, social issues (for example, costs of treatment), forgetfulness, lack of understanding or education on treatment regime, health beliefs related to taking medicine or adhering to healthy changes and views on side effects (Uzma et al 2011; Mbuagbaw et al, 2012; Rodrigues et al 2012; Liu et al, 2015; Hincapie et al, 2017). Forgetfulness was identified to be the most recurring theme in many studies, where participants had a hard time remembering to take medication, which led to

missing doses (Lester et al, 2010; Dick et al, 2011; Mbuagbaw et al, 2012; Osborn and Mulvaney, 2013; Xiao et al, 2014; Bobrow et al, 2014). Therefore, mobile phones were utilised to provide tailored messages to inform patients of the benefits of improved adherence and to prompt and remind them of what to do. For example, to take medication to assist with self-management of various conditions (Shetty et al, 2011; Osborn and Mulvaney, 2013; Chen et al, 2018; Dobson et al 2018; Bartlett et al, 2019), or to increase exercise frequency (Steinberg et al, 2013; Buccholz et al, 2016; Müller et al, 2016), promote screening of TB and HIV testing (Uzma et al, 2011; Evans et al, 2018; Govender et al, 2019; Mayo-Wilson et al, 2019; Endebu et al, 2019; Mussimenta et al, 2020); and encourage healthy eating (Lin et al, - 2014; Vakili et al, 2015).

Reduced finances and social circumstances influenced regimen adherence within ethnic patient groups (Dick et al, 2011; Mbuagbaw et al, 2012; Jennings et al, 2013; Hincapie et al, 2017; Moyano et al, 2019). Despite the availability of effective treatment, many patients felt that inadequate resources and high costs of medications contributed to poor adherence (Dick et al, 2011; Uzma et al, 2011; Osborn and Mulvaney, 2013). Disadvantages for using mobile phones, to assist patients to take medications on time, included lack of sufficient funds for purchasing airtime or charging phones when multiple text messages were initiated (Jennings et al, 2013).

Some studies also identified psychosocial components to be associated with medication adherence and desires of using text messages or mobile phones. Participants described how the stressors of daily living made it difficult to adhere to treatment regimen and adopting to technology-based interventions (Leon et al, 2015), This included: poverty and material deprivation, emotional stress due to competing demands of care giving roles, bereavement, unemployment, living in fear and discomfort from perceived side effects and certain health beliefs about medications. Consensus across studies highlighted the most common challenges associated with medication adherence were fear of side effects, lack of social support, knowledge deficits and low self-efficacy (Dick et al 2011; Uzma et al 2011; Rodrigues et al 2012; Osborn and Mulvaney, 2013).

### **Health Beliefs and Experiences**

Health beliefs of the different participants within different regions were shown to influence medication adherence and acceptance of mobile phones (and text messaging interventions)



(Mbuagbaw et al, 2012; Osborn and Mulvaney, 2013; Xiao et al, 2014; Leon et al, 2015; Evans et al, 2018).

Patients believed that using mobile phones to aid in medications did not benefit their health but were rather harmful and unimportant (Osborn and Mulvaney, 2013). Some also complained about the complexity of receiving messages and then having to adhere to information regarding diabetes care, influencing patient beliefs about their self-management and acceptance of text messages (Chen et al, 2018). However, some patients believed messages to be useful and helpful to follow through medications, foot care and appointment schedules (Dick et al, 2011). Similarly, text messages helped with adherence to HIV treatment which was experienced as a complex phenomenon amongst SA and Chinese participants due to complicated dosing, patient characteristics, healthcare systems, treatment regimen and environment (Uzma et al, 2011; Rodrigues et al, 2012; Xiao et al, 2014).

Cultural beliefs affected participants' attitudes and beliefs about medical care, their understanding of managing and coping with the course of an illness, the meaning of a diagnosis, the consequences of the medical treatment and the acceptance of technology. People originating from SA and Middle Eastern regions believe illnesses to be the result of super-natural phenomena (Uzma et al, 2011; Vakili et al, 2015). Pakistani participants regarded religion to be an important coping mechanism to their condition. They believed that turning to God for patience and strength claimed to enhance their ability of coping with difficult diseases such as HIV rather than relying on a text-messaging system. Similarly, Vakili et al (2015) identified the notion and importance of religion within the Iranian culture, where individuals dealt with complexities in life including those of disease through their faith in God rather than the benefits of medications or modern technology-based interventions (mobile phones). Cultural and religious aspects play a major role in patient adherence. Whilst, text messages within the interventions were designed in terms of the condition and translation of language, they were often not tailored to address cultural and religious needs, which were a vital aspect of daily life for many individuals (Uzma et al, 2011; Xiao et al 2014; DeSouza et al, 2014; Vakili et al, 2015; Bartlett et al, 2019; Mussimenta et al, 2020).

Disease burden impacted on health-related outcomes and acceptance of using mobile phones. This was evident in participants' living with CVD, who showed poor adherence to taking anti-hypertensives and not complying with messages sent to support their self-management. Patient attitudes were affected due to "unfair labelling" as "non-adherent" (Bobrow et al,

2014) when they were unable to keep up with their regime and the health messages delivered. This resulted in subjects turning away and feeling less motivated towards text messages. HIV-related stigma in some studies caused participants to feel ashamed and fear negative beliefs, feelings and attitudes from society (Uzma et al, 2011; Mbuagbaw et al, 2012; Endebu et al, 2019). Patients from African and Pakistani regions felt unhappy with text messages as they felt constantly reminded of having the “shameful disease” (Uzma et al, 2011; Mbuagbaw et al, 2012), it was more important to keep their condition private as they feared being labelled and members of their community finding out. However, Xiao et al (2014), identified regional differences stating that participants living within rural areas had higher acceptance of the text-messaging intervention due to HIV being less stigmatized in comparison to urban regions. This view suggests the importance of reputation and self-respect within certain cultures, as particular samples facing such conditions experienced loss of hope, reputation, and feelings of worthlessness, leading to poor self-management and adherence to text messages.

### **Behavioural Goals, Psychological Affects and Outcomes**

Patient behaviour was seen to be the major cause of non-adherence to medication regimen (Shetty et al, 2011; Mbuagbaw et al, 2012; Xiao et al, 2014; Leon et al, 2015). This particularly included negative behaviours where some participants felt taking medication was a burden, and believed it not to be important, which accompanied feelings of laziness, tiredness and lack of motivation when engaging with the text messages. Others dreaded side effects of medications and believed it to be harmful rather than helpful in the management of their condition (Dick et al, 2011; Osborn and Mulvaney, 2013). Hence, some patients ignored messages to avoid taking prescribed medicine. Therefore, behaviour goals were seen as an important component influencing positive behavioural change in many studies (Lin et al, 2012; Steinberg et al, 2013; Lin et al, 2014; Vakili et al, 2015; Müller et al, 2016). A series of personalized behaviour change messages were sent to assess and ensure patient goals were met in terms of their self-management and monitoring strategies. With regards to obesity, patients answered questions that determined their need and self-efficacy to change behaviours associated with weight management (Lin et al, 2012; Steinberg et al, 2013; Lin et al, 2014).

Participants described how major life stressors such as being involved in abusive relationships or undergoing a divorce were the backdrop for readiness to change adherence behaviours (Leon et al, 2015). Such individuals described how such events led to depression and acts of self-blame resulting in poor adherence to medication. For this reason, they felt

that text messages had restored their confidence, ‘*nudged*’ them in the direction of better self-care and reinforced positive changes (Leon et al, 2015). Findings demonstrated a long-term impact for several subjects who report the SMS intervention being beneficial, and described their methods for organizing, routinizing and sustaining their new and improved adherence behaviours (Leon et al, 2015).

Participants felt empowered by the prompts provided by text messages and improvement in adherence and attitudes towards self-monitoring behaviours (Steinberg et al, 2013). They felt a greater sense of control and understanding of the seriousness of their condition, and the importance to make improvements to their health practices. They noted text messages to increase their awareness of taking more responsibility for managing their own health through regular self-monitoring which enhanced self-efficacy (Leon et al, 2015). High self-efficacy impacted on patient motivation in positive ways. Therefore, text messages were used to motivate and encourage participants to adhere to behavioural goals (Dick et al, 2011; Vakili et al, 2015; Müller et al, 2016). Some participants affirmed the value of text messages, describing them as very important, encouraging and inspiring. On the other hand, promoting high self-efficacy in many other participants with LTCs, low self-efficacy was evident where samples experienced an incentive was needed to encourage them to learn more about their condition (DeSouza et al, 2014). Consequently, patient education and information seeking were a vital component to improve adherence to regimen (Shetty et al, 2011; Jennings et al, 2013; Leon et al, 2015; Govender et al, 2019).

### **Patient Education and Information Seeking**

Patients’ with LTCs confirmed that information and patient education increased their adherence to treatment (Dick et al, 2011; Lin et al, 2012; DeSouza et al, 2014; Dobson et al, 2018; Moyano et al, 2019). Indeed, people managing LTCs reinforced that being knowledgeable about the disease and overseeing aspects of their treatment facilitated their survival, and also assisted in utilising text messages to aid with their self-management process (Shetty et al, 2011; Jennings et al, 2013; Bobrow et al, 2014).

Patients suggested information and education assisted in the self-management of diabetes (Dick et al, 2011; Prinjha et al, 2020). Automated text messaging reminders were feasible and a useful means for improving self-management amongst varied diabetic racial groups. Daily reminders helped them avoid missing their medications, to regularly check their feet for

wounds and attending arranged appointments (Dick et al, 2011; Shetty et al, 2011; Chen et al, 2018; Moyano et al, 2019).

Educational texts motivated patients to collect and take medication as well as providing information regarding hypertension and its treatment (Bobrow et a, 2014). Informative text messaging interventions had a positive effect aiding to prevent mother-to-child transmission of HIV (Jennings et al, 2013). Appropriate education informed women regarding specific services that would provide extra drugs, information on early infant testing, as well as the benefits and risks of breastfeeding versus mixed feeding (Jennings et al 2013). Some suggested education to be a continuous process providing opportunities to improve health outcomes (Buccholz et al, 2016, p.66). Educational interventions can be useful to aid in improving self-monitoring and self-efficacy for individuals with LTCs. The information and support provided can lead to the development and implementation of a '*meaning-centred*' philosophy (Lin et al, 2012). To elaborate, this would facilitate comprehensive integrated primary care focusing on the delivery of personalised care, also identify and enhance patient knowledge in terms of their own information and educational needs, which in turn would support them to live an independent and fulfilling life (Lin et al, 2012; RCN, 2016).

### **Content Provision and Use of Text Messages**

The content, comfort and timing of delivery of messages directly impacted on the behaviour of participants and influenced their education and information needs. Participants experienced motivation and a greater sense of social connectedness. They valued the supportive content and polite tone of text messages, which appeared to have generated a sense of recognition, respect, value and care (Leon et al, 2015). Messages were translated into the local languages of the region in which the studies were conducted to prevent language barriers. This was proven to be effective as subjects were able to read, understand and follow messages (Mbuagbaw et al, 2012; Xiao et al, 2014; DeSouza et al, 2014; Bobrow et al, 2014; Vakili et al, 2015; Bartlett et al, 2019). Having a choice of languages, for the SMS content, was appreciated by some individuals (Leon et al, 2015). Participants felt the need of an intervention that would aid them and protect the family environment from the burdens of the disease (DeSouza et al, 2014). Subsequently, they were permitted to specify additional messages that they believed would benefit them (Osborn and Mulvaney, 2013; Buccholz et al, 2016; Dobson et al, 2018).

The content of messages from all studies provided information that was relevant to their illness, condition or current situation (Dick et al, 2011; Jennings et al, 2013; Osborn and Mulvaney, 2013). Majority focused on the goal planning techniques for self-monitoring, repetition and substitution, social support and information on natural consequences of LTCs (Steinberg et al, 2013; Bobrow et al, 2014; Lin et al, 2014; Govender et al, 2019). For diabetic patients, texts were generated to help reduce barriers to medication adherence, to successfully promote self-management and care which aided with blood sugar monitoring reminders and foot care (Dick et al, 2011; Shetty et al, 2011; Osborn and Mulvaney, 2013). Similarly, for those participants living with hypertension and HIV, reminder messages were sent to take medications on time, information regarding blood pressure monitoring and prevention of HIV transmission was provided (Lester et al, 2010; Mbuagbaw et al, 2012; Bobrow et al, 2014; Xiao et al, 2014; Leon et al, 2015). Generally, participants felt comfortable using the technology, accessing and reading text messages with no technical difficulties when messages were received (Leon et al, 2015; Govender et al, 2019; Endebu et al, 2019). Some reported difficulties or unease with the technology due to not being confident phone users, particularly older patients (Leon et al, 2015; Liu et al, 2015; Prinjha et al, 2020). Thus, participants were not able to engage with text messaging systems. Some individuals found it inconvenient to receive text messages when not given a choice to choose the timings of receiving them, particularly during work (DeSouza et al, 2014; Leon et al, 2015). Majority of those who were older participants, or men and women with lower literacy level not being able to read, suggested other platforms such as voice-mail, video-calls or telephone calls to be considered (Xiao et al, 2014; Leon et al, 2015; Chen et al, 2018). Participants felt that these alternative interventions could allow for easy access to care where they could converse and receive detailed feedback from healthcare professionals regarding their treatment regimen and self-management goals.

It was important to ensure that information enabled participants to maintain a sense of normality, through minimal disruption in maintaining factors most valuable to them such as their lifestyles and daily routines. As a result, study subjects were often given a preference of the frequency of text messaging delivery. The timing of the text messages provided them with the opportunity to change not only their adherence behaviour, but to also tackle their stressors more positively (Leon et al, 2015; Govender et al, 2019). Receiving text messages everyday was most appropriate as it helped patients to remember taking medications on time and enabled behaviour change techniques to increase self-efficacy (Osborn and Mulvaney,

2013, Müller et al, 2016). Those receiving texts every day felt they were well looked after, their self-management regime and health outcomes improved (Osborn and Mulvaney, 2013, Müller et al, 2016, Hincapie et al, 2017). However, male participants that were employed full-time, preferred messages to be sent outside of working hours to prevent disturbances, compared to female samples who did not have a preference of timings due to being at home with a more flexible schedule (Uzma et al, 2011, DeSouza et al, 2014). Low adherence was evident in those participants who received three or fewer messages in a week. Non-adherent participants were not prompted as often and felt that in order to be successful in behavioural change, and improving effective treatment adherence daily text messages would be more useful (Steinberg et al, 2013; Vakili et al, 2015).

### **Summary**

The review was valuable in identifying and describing topic areas in relation to ethnic minority groups living with LTCs, and highlighting factors influencing the management of LTCs with the aid of a text messaging intervention. However, a number of gaps within the literature reinforced the need for further research on this topic area (Box 2).

The concept of ‘tailored interventions’ requires further clarification from a patient-centred point of view. Recommendations and preferences are suggested to improve health text messages, to personally aid the health care needs of patients from ethnic minority populations. Whilst, there is developing evidence based on text messaging programmes influencing health behaviours, there is scarce evidence in their use within ethnic minority communities in the UK, particularly the SA population. It remains unclear as to whether similar outcomes exist across different cultures. Literature outlines this being due to translation and language barriers (Patel et al, 2013; Kumar et al, 2018). However, other factors such as self-efficacy, acceptability and health beliefs regarding technology have not been explored. Chapter Four, will explore SA health behaviours, preferences, use and adoption of text messaging interventions in SA ethnic minority populations.

**Box 2. Summary of Key Research and Gaps in Evidence**

- Research studies conducted within the UK across ethnic minority groups were limited (2).
- Culturally-relevant text messages sent to recipients increased the uptake of interventions, and nudged individuals towards self-management behaviours, increasing access and recruitment of people from ethnic-minority populations (Evans et al, 2018; Prinjha et al, 2020).
- Despite patient experiences of engaging with a text messaging intervention to improve self-management of LTCs being investigated (Vakili et al, 2015; Musiimenta et al, 2020), there was limited evidence examining factors cited to affect self-management of ethnic minority groups, such as cultural norms, customs, and traditions (Shetty et al, 2011; Kumar et al, 2016).
- Further research is needed to examine and explore how cultural norms and traditions may influence self-management behaviours.
- Demographical and psychosocial variables such as education levels, age and gender roles were found to influence mobile phone usage and impact self-management behaviours (DeSouza et al, 2014; Xiao et al, 2014). Although, current research evidence was ambiguous as to how these factors correlate with one another and influence behaviour change processes within ethnic minority groups.
- There was limited use and discussion on behaviour change models and how theoretical concepts can be incorporated to demonstrate acceptance and adoption of text messages, mhealth technologies and interventions.
- The application and understanding of theoretical contexts in ethnic minority groups needs further exploration.
- The review highlighted messages being created accordingly, with conditions patients presented with, or translated in a language of their choice. However, there was limited evidence showing the effects of messages being tailored to suit individualistic needs and priorities.

## Chapter Four

### Behaviour Change and Use of Mobile Health Interventions

#### Introduction

Changing individual behaviour is progressively at the heart of healthcare. The study of behaviours influencing health and factors determining which individuals will and will not perform particular behaviours, has become a key area of research in healthcare (Dixon-Fyle et al, 2012; Conner and Norman, 2015). There is fundamental change in healthcare, which is currently driven by an ageing population and the rising incidence of behaviourally induced chronic conditions. Healthcare is evolving towards patient-centredness, prevention and ongoing management of LTCs, where health systems are revolutionising the delivery of healthcare needs to meet these challenges (Chadborn et al, 2018). Alongside this, an equal concern involves changes required and those being made once a disease has been diagnosed (Newsom et al, 2011). Understanding individual lifestyles and how changes in behaviour occur has become important, particularly the occurrences of positive changes towards managing LTCs amongst ethnic groups. Indeed, exploring why and how individuals from such groups perform a variety of behaviours, can inform the design and improvement of an intervention to change the prevalence of health behaviours. This in turn will increase longevity and improve health outcomes and quality of life amongst these individuals (Abraham et al, 2016).

Evidence suggests that people may make alterations to their behaviour after being diagnosed with a chronic health condition. This could be due to the fact that the features and impact of LTCs do not resemble one another (Goodwin et al, 2010; DH, 2016;). Thus, behaviour change may vary because of differing perceptions of illness and health outcomes (Saarni et al, 2006; Newsom et al, 2011). Behavioural theories and models have been at the forefront of research, predicting and explaining certain health behaviours, based on individual beliefs regarding the behaviour, in terms of a psycho-social context, perceptions and representations (Rutter and Quine, 2002; Conner et al, 2017). Chapter Three briefly presented evidence on the occurrences of behaviour change and self-management of LTCs, through the use of mHealth interventions, particularly text messages. However, further research is required to gain a complete understanding of how individuals from different socio-demographic groups change their health behaviour in response to their diagnosed conditions through technology-based interventions (Bhurji et al, 2016). Indeed, whether these changes are maintained or



whether certain health conditions are more likely to lead to changes (Chen et al, 2018). Numerous theories are rooted to establish a clearer understanding of the cognitive determinants contributing to the development, maintenance, and change of health behaviour patterns (Abraham et al, 2016). However; a more appropriate understanding is needed to evaluate the underpinning of the theoretical processes involved in illness perception and behaviour change, as well as to effectively assess the adequacy of prevention measures within ethnic minority groups, particularly those of SA origin (Armitage and Connor, 2000; Ramachandran et al, 2013; Cockerham, 2014).

Therefore, this chapter explores aspects associated to behavioural changes, the prominent theories and models in health care psychology, as well as their application to the understanding of health behaviours. It places emphasis on factors associated with behaviour change processes and those influencing health promotion through mHealth (and text messaging). An overview of the definitions of health behaviours and behaviour change, critically evaluate and extrapolate key determinants of relevant models and theories, for the identification of an appropriate health behaviour model pertinent in depicting behavioural changes within SA ethnic minority groups using mHealth.

### **Definitions and Overview of Health Behaviours**

Health is identified with the state of being free of illness and injury. Behaviours associated with health constitute a habitual, and stable pattern of conduct which directly or indirectly affect human health and well-being (Bąk-Sosnowska and Skrzypulec-Plinta 2016). The definitions of ‘*health behaviour*’, overlap with that of which is provided by Gochman (1997, p.16):

*“It is the activity undertaken by individuals for the purpose of maintaining and/or enhancing their health by preventing health-related issues or disease.”*

The term affiliates with individuals with chronic diseases who seek to manage, minimize or contain their condition through positive forms of health behaviour such as diet, exercise and smoking cessation (Spring et al, 2012; Cockerham, 2014; Bąk-Sosnowska and Skrzypulec-Plinta 2016). Health behaviours can be divided into those that promote health, or those that threaten health. Health risk or unhealthy behaviours are detrimental actions that impede recovery of an illness. Spring et al (2012, p.i10), elaborates on five categories of behaviours that consistently correlate with increased morbidity and mortality:

- 1) Consuming diet high in fat and calorie, and low in nutrients;

- 2) Reduced levels of physical activities and increased levels of sedentary activities;
- 3) Smoking habits;
- 4) Misuse of illegally or illicit drugs and high consumption of alcohol;
- (5) Engaging in risky sexual behaviours.

The basis of health consists of beliefs, emotional reactions and behaviours linked with the maintenance and improvements in one's health (Bąk-Sosnowska and Skrzypulec-Plinta, 2016). In addition, other factors in relation to medical regimen and non-adherence in ethnic minority groups are also directly associated with poor treatment outcomes in patients with LTCs such as: diabetes, epilepsy, AIDS, HIV, asthma, tuberculosis, hypertension, and organ transplants (De Geest and Sabaté, 2003; Kumar et al, 2016). Adherence varies across differences in behaviours and is affected by certain factors. Key barriers associated with non-adherence to treatment plans amongst SA patients include: illiteracy, financial issues, health beliefs, unawareness of missing doses and reasons for taking medications, fears and experiences of side-effects, and low self-esteem (Manobharati et al, 2017).

### **Definitions and Overview of Behaviour Change**

From the Oxford English dictionary (OED), the earliest use of the word 'behaviour' is a late middle English noun, dating back to the late 15<sup>th</sup> century essentially from the word behave ending in the now obsolete term '*haviour*' meaning "possession". The term is altered from 'aver'; a noun derived from an old French verb 'aveir' which means "to have". Therefore, the term '*behaviour*' has been defined as the way in which one acts or conducts one self, especially towards others. Synonyms include: *conduct, act or way of acting, practice or way of practising deportment, bearing, etiquettes, manner, actions doings, demeanour* (OED, 2016; The Cambridge English Dictionary, 2017). The term *change* is a verb which has been used alongside behaviour, defined as to make or become different (OED, 2016). The two words put together suggests altering and modification of individuals' decisions and the way someone acts or responds.

Change is an essential objective in health interventions with increased attention on prevention prior to onset of disease (WHO, 2008; Glanz et al, 2015). Many health conditions are caused by risk behaviours such as non-adherence to medication, problems drinking, substance use, smoking, over-eating and unsafe sex. Individuals vary in their ability to adapt to changes in environmental conditions (Michie et al, 2011). Therefore, a key question in behaviour

research is how to predict and modify the acceptance and maintenance of healthy behaviour (Ryan, 2009; Conner and Norman, 2017). There are various methods and theories encouraging behaviour change in human beings who have control over their conduct, which allow health compromising behaviours to be eliminated by self-regulatory efforts and health enhancing behaviours to be adopted instead, such as: adhering to medication, increase in physical exercise, weight control, preventative nutrition, improved dental hygiene or safe sex through condom use (Johnson and May, 2015). Health behaviour changes refer to the motivation, desires and actional process of abandoning certain health-compromising behaviours and instead to adopt and maintain health-enhancing behaviours (Abraham et al, 2016). However, to maximise the potential efficacy of interventions it is necessary to understand the factors that influence and determine certain behaviour, and the theoretical constructs of behaviour changes involved in SA patient groups.

### **Behaviour Change and Acceptance of Technology-based Interventions**

Following the consideration of important definitions and dimensions of health behaviours and behaviour change, the social and cognitive determinants of health behaviours are examined. An extensive discussion presents relevant theories that could be pertinent to the SA population to determine and understand their behaviour change patterns, as well as their acceptance and adoption of mHealth and text messaging interventions. Chapter Three examined the use and acceptance of mobile phones and text messaging, to expose causal effects on the relevant constructs pertinent to behaviour change processes in SAs. Some studies showed such interventions to alter negative behaviours in SA participants that resulted in positive effects on behaviour, leading to improvements in adherence and self-management (DeSouza et al, 2014; Prinjha et al, 2020). Others reported a lack of acceptability of mHealth interventions, and non-adherence to treatment regimens in similar samples (Islam et al, 2015; Kamal et al, 2015). In spite of the advancements and rapidly increasing use of mobile phone-based applications, it remains unclear as to whether such interventions are acceptable across SA subjects (Mohamed et al, 2011). Thus, the technology acceptance model, outlining determinants involved in accepting and using technologies, such as mobile phones may offer a way of understanding uptake.

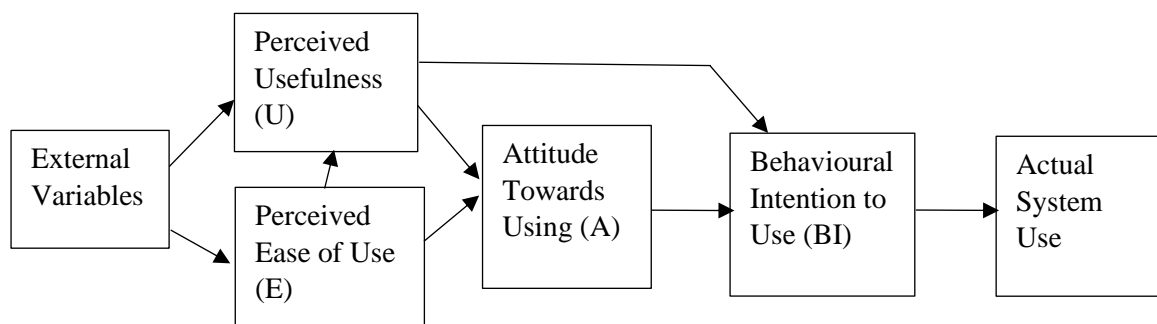
### **Technology Acceptance Model (TAM) (Davis et al, 1989)**

In health care, technology adoption is a process that involves embracing technology and considering it as an essential part of life, for the utilization of health information which takes place through acceptance (Garavand et al, 2017). The TAM (Diagram 2) shows how users

come to accept technology, it comprises several variables, some of which overlap with other theories discussed later, including Health Belief Model (HBM), Social Cognitive Theory (SCT) and Theory of Planned Behaviour (TPB). These concepts include perceived usefulness, persuasion, perceived ease of use, perceptions and attitudes towards technology, motivation, subjective norms and self-efficacy (Schepers and Wetzels, 2007).

Perceived usefulness (U) is the degree to which an individual believes that using a particular system (for example, text messages) would enhance their performance (or in this case, their health outcomes) (Davis et al, 1989). Perceived ease of use (E) refers to whether the technology is easy or not to use, to help them achieve their desired outcome. As a result, this will impact the individual's attitude (A) negatively or positively, for instance if it is difficult to use people will have negative attitude towards it and not use the system (Venkatesh and Davis, 2000). Although, the model has not previously been used amongst ethnic minority samples such as SAs, determinants such as attitudes and intentions (also outlined in TPB and HBM) are directly influenced by the perceived technology usefulness and ease of use.

**Diagram 2.** *Technology Acceptance Model (Davis et al, 1989, p.986; Venkatesh and Davis, 2000)*



Socio-demographic variables have shown impact on SA patients' behaviours to adopt such interventions. Evidence suggests that mobile phones were adopted by those SAs who received messages tailored to their health needs and self-management regime (Bhurji et al, 2016). Tailoring appears to be linked to perceived usefulness (U) and ease (E). Individuals found such messages useful (U), as tailored text messages, for example, translated content to preferred language, were easier (E) to follow, persuade and motivate patients to adhere to medications and improve their health-related outcomes. Although, older participants were seen to be later adopters compared to younger participants, due to the complexities of modern technology (Muller et al, 2016). Mohamed et al (2011), highlighted patients who are well-informed through mHealth interventions have an increased intention to use the system or

intervention. Useful text messages related to health condition were more significant to the intention to engage with text messaging systems and the perceived ease of using such systems. Other factors such as motivation, persuasion and self-efficacy are also important determinants evident in the acceptance of text messages in SA samples, explored below in more detail (Kamal et al, 2015; Balhara and Anwar, 2019).

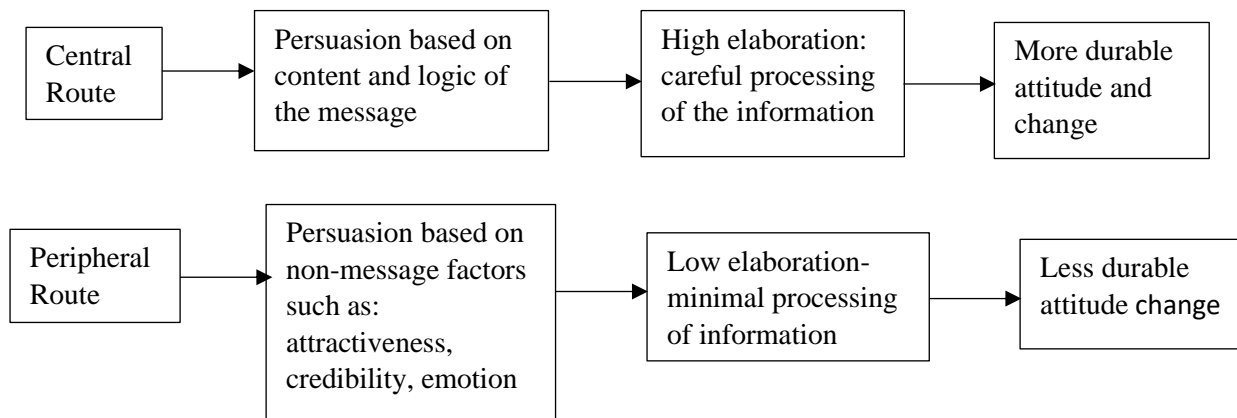
### **Motivation and Persuasion**

Individuals are involved in supporting and encouraging behavioural modifications and may seek the support in doing so, thus, it is important to identify approaches and strategies that motivate change (Hardcastle et al, 2015). The term '*motivation*' is used to refer both an individual's reasons for action and their enthusiasm for doing so (Dixon, 2008). Although, information presented in text messages influences change, alone it is not sufficient to motivate behaviour change. For change to occur and be effective, information needs to be persuasive (Buhi et al, 2012). Therefore, alongside motivation, persuasion is an important component that can also influence and motivate an individuals' beliefs, attitudes, intentions and behaviours to change and improve (Abraham et al, 2016; Thompson et al, 2018). The process of health promotion, facilitates the protection and improvements of the health status of individuals, groups, communities, or populations. To achieve this, health promoters utilise contextual influences such as motivation and persuasion, through goal-directed and purposeful behaviours that encourage individuals and groups to take health-promoting actions to accomplish long-term goals (Swindell et al, 2010; Sandler et al, 2011).

The conceptual factors to motivation discussed in a number of relative theories tend to assume a degree of motivation for change, to promote actions by converting motivation into action (Rosenstock, 1974; Ajzen and Fishbein, 1980; Prochaska and DiClemente, 1983; Rogers 1983; Bandura, 1993; Deci and Ryan, 2000). Some theories focus on cognitive antecedents of motivation such as knowledge attitudes and beliefs, such as the HBM (Rosenstock et al, 1988). This model suggests that a person would be motivated to change their general health values due to specific beliefs about their susceptibility to a particular disease and its likely severity. Whereas, the TPB recognises components such as subjective norms (perceived social pressures) to be important motivating factors that suggest beliefs about outcomes of a particular behaviour (Ajzen and Fishbein, 1985). Another exemplary model based on motivation is the Transtheoretical model (TTM), which identifies a series of motivational stages through which individuals progress and relapse in order to achieve certain health goals for particular behaviours associated with smoking cessation, condom use,

alcohol/drug abuse, weight-loss, and stress management (Prochaska and DiClemente, 1983). Although, important theoretical constructs have been identified to motivate positive behaviours, the element of persuasion is missing, which is also likely to influence and result in changes in attitude, and providing an important basis for the motivation to change one's behaviour to adopt technology and text messaging (Corcoran, 2011; 2013).

**Diagram 3.** *Elaboration Likelihood Model (Adapted from Cacioppo and Petty, 1984, p.674)*



Simons (1976), defines persuasion as *'human communication that is designed to influence others by modifying their beliefs, values, or attitudes'* (Simons, 1976, p. 21). Cacioppo and Petty (1984), suggest two ways in which individuals are persuaded to make decisions, through the concepts outlined within the Elaboration-likelihood model (ELM) (Diagram 3), by informing an individual's understanding of behavioural influences through the acceptances of engaging with technology (which in this case are mobile phones and text messages). The ELM is a dual process theory that is associated with two routes, the central route and the peripheral route, which differ in the level of information processing or *'elaboration'* demanded by individuals to change their behaviours and attitudes (Cacioppo and Petty, 1984; Van Lange et al, 2012).

Central route processing involves high level of elaboration, where the user is able to scrutinize and pay attention to the message, due to high levels of motivation. This route allows for logical, conscious thinking to decision-making, where the user focuses on the pros and cons of the message and a decision to agree with it (Petty et al, 1981). Successful persuasion and adoption of mobile phones within SA patients, was dependent on how recipients perceived and responded to the persuasive messages, those who had a higher acceptance of engaging with a text messaging intervention had improved medication adherence (Ershad-Sarabi et al, 2016). This route allowed for permanent changes in attitudes

and behaviours, as the SA users were seen to act and elaborate upon the persuasive messages to achieve optimal self-management goals. On the other hand, the peripheral route involves low levels of elaboration, where the user is not scrutinizing or paying attention to the message for its benefits or effect. Instead, other factors can influence the user, such as distractions, general impressions and external characteristics (Cacioppo and Petty, 1984). Evidence on SA patients demonstrated that external sources such as other forms of mass media (for example, television, computers, Internet), friends, family and peers shaped the perceptions of SA users, which thereby influenced their acceptance behaviour to text messages (Venkatesh et al. 2003; Karasz et al, 2016). SA communities emphasise on the importance of family cohesion, conformity, co-operation and interdependence on one another when faced with an illness and its management. Therefore, change through this route is temporary as decisions to change are made in groups or within family which are valued more than the individual's perception, making them susceptible to further change (Karasz et al, 2016).

The ELM has also been used to inform health behaviour interventions including mHealth tailoring which has become a widely used platform. Evidence suggests this process to increase persuasiveness of a message for supporting preventative health behaviours (Krebs et al, 2010; Jensen et al, 2012).

### **Tailored Text Messages**

Tailored information to form messages, use information adapted for individuals, usually matched to personal characteristics, social and psychological factors such as demographics, attitudes and beliefs (Corcoran, 2013). Customizing communication ensures the relevance of information for target audiences, which can influence positive use and adherence of a message (WHO, 2019). The term '*tailored*' seems to be concerned with '*patient-centredness*', which is regarded as the care or information that is respectful and responsive to the individual patient preferences, needs and values rather than those of the service (Barry and Edgman-Levitan, 2012; RCN, 2017). Supporting evidence recommends that the '*personalization*' or tailoring of health information can be used as strategies to improve and promote positive behavioural changes (DH 2016).

Messages can be tailored to address the needs of individuals rather than the general populations through the use of theoretical constructs making information more relevant to an individual person or group of people (Campbell and Quintiliani, 2006; Baker et al, 2015). The mechanism of tailoring has been explicated using the ELM, which suggests that

personalization can result in central processing of information that implies that the information is considered more thoroughly by the receiver or user, making behaviour change more likely (Cacioppo and Petty, 1984; Skovv-Ettrup et al, 2014). Tailored interventions and targeted information demonstrate to deliver essential behaviour change constructs such as reminders or encouragement to perform certain actions to enhance self-efficacy by reinforcing the adoption of healthy behaviour, social support for patients, informing individuals about the options for best treatment, screening tests and diagnostic procedures, shared decision-making processes and the provision of better patient understanding through their values and preferences of their illness management (Lawrence and Kinn, 2012).

Literature suggests that tailored information is beneficial in enhancing positive behaviour changes in comparison to non-tailored information, and text messages that were created and sent to patients in accordance to their personal characteristics (Woolford et al, 2010; Head et al, 2013). Messages were used and designed to prompt patients for chronic disease management, illness-related and non-illness related medication adherence, unhealthy behaviour modifications and preventative behaviours such as smoking cessation, increasing physical activities and healthy eating behaviours (Woolford et al, 2010; Head et al, 2013; Spohr et al, 2015; Lewis et al, 2018). This correlates with studies conducted amongst patients of ethnic minority populations with LTCs such as: hypertension, diabetes, obesity and renal disease (Dick et al, 2011; Shetty et al, 2011; Osborn and Mulvaney, 2013; Kamal et al, 2015; Lin et al, 2015; Mooney et al, 2017). In these studies, messages were tailored in terms of the conditions patients presented with, preferred language, culture, religion and certain health beliefs. The utilisation of such SMS interventions enhances positive behavioural outcomes of various target groups. Patients felt more involved in their care, particularly through personalised messages that included details unique to the recipient such as their name and appointment details (Fjeldose et al, 2009; Head et al, 2013). Findings from racial minority groups also indicate that culturally tailored and translated messages, into a language preferred by a target group overcome language barriers. Indeed, having choices and preferences makes participants feel motivated and better supported that their needs are being addressed, which creates a greater sense of recognition, belonging, respect and care (Leon et al, 2015).

Despite there being evidence amongst ethnic minority groups favouring tailored text messaging interventions and strategies, inadequate medication adherence still exists. Many patients fail to achieve optimal disease control due to non-adherence, reported to be a particular problem in SA patients (Kumar et al, 2016; 2018), reinforcing my own observation



within my community. Approaches influencing mobile technology have emerged. However, the use of text messaging applications assessing behavioural change, is at an early stage of research within the SA population (Gatwood et al, 2016). Efforts to improve adherence to treatment within SA groups has had limited effect as evidence often focuses upon text messages aimed at Eurocentric samples. Tailoring mobile phone SMS or text messages is a novel way to address non-adherence and health beliefs amongst ethnic groups. A similar approach such as ‘nudging’ or nudge steers individuals in certain directions, which may also achieve behavioural changes and improved health outcomes in SA patients (Perry et al, 2015).

### **The Concept of ‘Nudge’**

Most of the significant challenges in SA healthcare has been associated with non-adherence to evidence-based guidelines (Manobharati et al, 2017). Hence, recent policies have been enthused to show an interest in encouraging individuals to lead healthier lives by ‘*nudging*’ them towards making better decisions for their health (Vlaev et al, 2016). The term ‘*nudge*’ is used to describe an aspect which involves choosing to make decisions (known as *choice architecture*), that alters or changes an individual’s behaviour in a predictable way without restricting any options or significantly changing their economic incentives (Thaler and Sunstein, 2009). It conceptualizes that the behaviour is shaped, constructed and influenced by the context within which it is placed (Quigley et al, 2013). The 2010, UK House of Lords, examined interventions in behaviour science and technology to influence behaviour for achieving policy goals implemented through the nudge theory. They considered text messaging interventions to be an adaptive and persuasive system that shows promise to tackle poor health outcome, encourage patients to attend appointments, and steer individuals from ethnic groups as well as the general population towards healthier behaviours and lifestyles (Michie and West, 2013; DH, 2016).

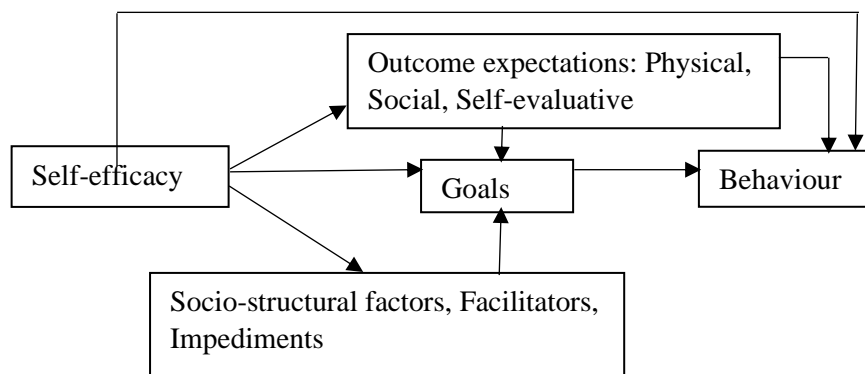
Overall, persuasive and motivational factors lead to goal-setting (Locke, 1996; Fenner et al, 2013), self-monitoring (Miller and Thayer, 1988), action planning (Schwarzer, 2014) and implementation of intentions (Gollwitzer, 1999; Hagger and Luszczynska, 2013). Models such as the ELM and TAM, help inform concepts such as tailoring and nudging which further aid to depict behavioural constructs that focus on binding behaviour change through effective persuasive and motivational techniques through text messages that influence and impact individual perceptions and behavioural changes. Subsequently, there is limited evidence as to how such approaches are adapted my ethnic minority patients (particularly SA patients) to

sustain and adopt healthy behaviours. Therefore, the intended study will explore how text messages and their frequency to nudge influences certain types of behaviours (for example, motivational behaviours and enhanced self-efficacy) within this population group.

### Enhancing Self-Efficacy and Control

Comparable and interconnected concepts to consider alongside motivation, persuasion and personality, are self-efficacy and locus of control (Wilson, 1999). Self-efficacy beliefs are commonly associated with motivation, which in turn determines how individuals think and behave (Bandura, 1994). It is a belief based on an individual's innate ability of achieving goals, and has been defined by Bandura (1982), as a personal judgement of "*how well one can execute courses of action required to deal with prospective situations*" (p.122), determining whether an individual is able to exhibit coping behaviour through sustained efforts when facing obstacles. Those with high or strong self-efficacy, exert sufficient effort of setting higher goals, and display greater commitment and motivation for successful outcomes. Particularly amongst SA patients with LTCs (samples with diabetes and asthma) a feeling of self-efficacy enhances self-management and coping skills, compared to those with low efficacy, who are likely to cease effort and under-perform (Bhurji, et al, 2016; Griffiths et al, 2016). Individuals with high assurance in their capabilities to control threats and challenges, are less susceptible to cognitive issues including stress, depression and anxiety (Bandura, 1994).

**Diagram 4.** *Social Cognitive Theory (Bandura, 2004, p.146)*



Bandura's Social Cognitive Theory (SCT) (1977; 2004) outlines a number of crucial factors influencing behaviour. It explains how individuals acquire and maintain certain behavioural patterns, while also providing a basis for intervention strategies in behaviour change (Glanz et al, 2002; Conner and Norman, 2005). Along with '*perceived self-efficacy*', another core

construct of the SCT, is '*outcome expectancies*' which are concerned with an individual's beliefs about the possible consequences of their actions (Conner and Norman, 2005).

Diagram 4, illustrates the interplay between the variables throughout the behaviour change process.

The SCT (Bandura 1977; 2000) is a comprehensive theory that takes human behaviour, cognition and environment into account. The model has been applied to behaviour change interventions such as tailored text messages, where the socio-structural determinants of the SCT demonstrate the effects on preventative health-related behaviours, leading to significant increase in self-efficacy, outcome expectations, motivation and action in relation to better health (Bandura 1998; Skovv-Ettrup et al, 2014). The constructs of the model appear to be relevant to the TAM and ELM, as self-efficacy interlinks with persuasion, and factors such as reinforcement and punishment, effecting motivation to attain certain goals (Ormrod, 2014). Ensuring high perceived control and self-efficacy are crucial in the maintenance of motivation and the translation of intentions into actions within such groups (Abraham et al, 2016).

The model however, minimises emotional responses, and fails to address full complexities of human differences beyond acknowledging that they exist. Tyng et al (2017), argue that certain behaviours are a result of emotional responses determined by biological factors, controlled by evolution and not so much with conditioning or observation. For example, jealousy, sadness or resentment may lead to an individual to behave in a particular way that is not consistent with their normal behaviour. Further criticism of the SCT is that the constructs of the model are too broad, and 'loosely structured', lacking a unifying principle and structure (Ormrod, 2014). Individuals are viewed as being dynamic which makes it difficult to implement the theory in its entirety. Instead, the theory focuses on implementing concepts such as self-efficacy alone rather than other concepts related to health behaviour and personality factors such as motivation, attitudes, norms and fear which have determined SA behaviours in previous literature (Kumar et al, 2016; Potthoff et al, 2019).

### **Variables and Determinants Influencing Behaviour- Behaviour Change Theories**

Many factors integrate with one another to affect individual health behaviours, such as socio-demographic, environmental and individual characteristics all contributing to health-related behaviours (WHO, 2018). From the literature explored it was clear, that many behavioural components amongst the SA community contributed to non-adherence, lacking understanding

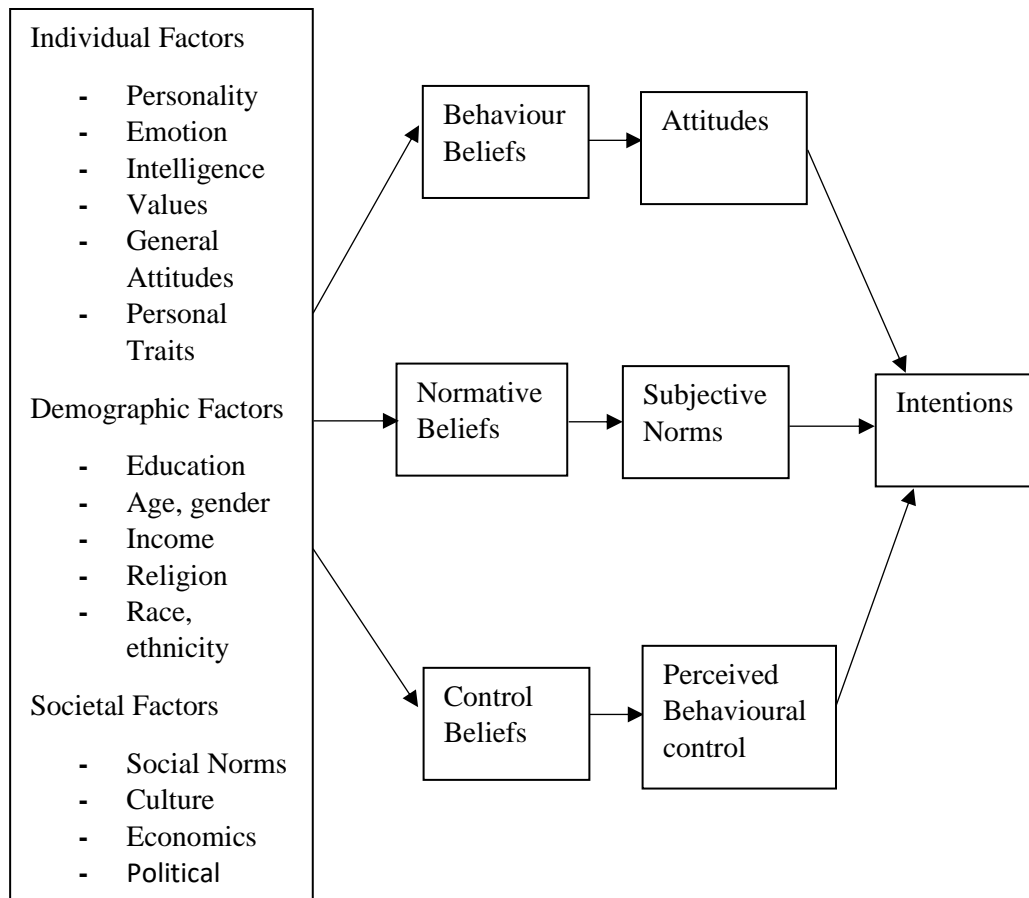
of treatment regime and poor health outcomes (Uzma et al, 2011; DeSouza et al, 2014; Kumar et al 2016; 2018; Patel et al, 2015; Manobharati et al, 2017). Fundamental determinants such as attitudes, subjective norms, health beliefs and perceptions, were also found to contribute to self-management and uptake of text messaging interventions. However, the reasoning behind certain behaviours in relation to inadequate self-management and acceptance of text messaging was not explored. Overlapping determinants of key behaviour change models (attitudes, subjective norms, health beliefs and perceptions), are explored further, to illustrate health behaviours related to and influential for the adoption and acceptance of mHealth interventions in SA populations.

### **Attitudes**

The term attitude is defined as “*relatively enduring organization of beliefs, feelings and behavioural tendencies towards socially significant objects, groups, events or symbols*” (Hogg and Vaughan, 2005, p.150). Attitudes are the overall evaluations of the behaviour change process performed by the individual, whether it is a positive or negative outcome (Ajzen 1991; Abraham et al, 2016). The Theory of Planned Behaviour (TPB) (Diagram 5) focuses on the connection between intentions, behaviours and perceived behavioural control which claims that individuals tend to perform behaviours they intend. The TPB can be a useful model to understand how behavioural interventions such as text messages attempt to alter SA behaviours, influence their attitudes, which in turn encourage their intentions and beliefs (Ajzen and Fishbein, 2005).

Factors such as knowledge, understanding and beliefs were seen to form certain attitudes within SA patients regarding consequences of their illness, as they felt more confident that their LTCs can be minimized through adequate management through better knowledge and awareness regarding the condition (NICE, 2017; Moosa et al, 2019). Digital health literacy was seen to positively affect their engagement with text messages, and shift attitudes towards self-management behaviour amongst a diabetic SA sample in Sri-Lanka. This led to greater awareness of prevention, and enabled participants to interact with health care practitioners to learn more about the consequences of poorly managed diabetes, through action planning and improved self-efficacy, via face-to-face appointments with healthcare providers or via educational text-messages (Islam et al, 2015; Herath et al, 2017).

**Diagram 5.** *Theory of Planned Behaviour (Adapted version from Ajzen and Koblas, 2013, p.215; ter Keurst et al, 2016, p.123)*



However, other studies exposed SA attitudes towards adherence, to be negatively affected through cultural beliefs regarding traditional alternatives to prescribed medications due to toxicity and side-effects, interactions with healthcare providers and stigma attached to illnesses which lead to poor adherence and health outcomes (Rodrigues et al, 2012; Patel et al, 2015; Kumar et al, 2016). Majority of these attitudes were seen to form due to normative values, which in turn determined adherence behaviours (Ajzen, 1991; Lucas et al, 2013).

### **Subjective Norms**

Subjective norms are “*the perceived social pressure to perform or not to perform the behaviour*” in question (Ajzen, 1991, p.188), suggesting the individual’s beliefs are influenced by significant others (individuals or groups) whose preferences about a person’s behaviour are important. There is vast evidence stating SA normative values to be closely influenced through family and social support networks (Patel et al, 2012; 2015; Kumar et al, 2016; Sharma et al, 2019). Social support is the perception and veracity that one is cared for, through continuous assistance available from others as part of a supportive network

consisting of family, friends, neighbours and organizations (Shiba et al, 2016). Patients who utilised or adopted mobile phones and engaged with text messages, felt that messages offered social support as they were seen to have improve their self-esteem and emotional well-being (Guillroy et al, 2015). Aspects of social support can include emotional tangible, informational and companionship (Cukor et al, 2007). Gallant et al (2010), explored this phenomenon amongst older African-American and Caucasian individuals. Results demonstrated strong social connections to exert positive influences on behaviour and self-management activities for example, monitoring dietary intake, providing medication reminders, monitoring important parameters such as blood pressure and sugars, and attending important appointments (Gallant et al, 2010).

Further evidence from cross-sectional studies conducted amongst SA patients living with ESRD, receiving Haemodialysis reported social influences from close friends and family led to positive behavioural outcomes, greater satisfaction in life and an enhanced ability of coping with stressors associated with their condition (Rambod and Rafi, 2010; Anees et al, 2011, Sharma et al, 2019). Other studies revealed familial norms to exert negative pressure on SA individuals as some patients made decisions to not take medications or to cease their treatment due to stigma attached to disease, experiences of other family members who had similar condition or during social gatherings to fully participate in events such as weddings and parties (Lucas et al, 2013; Rahaei et al, 2015; Kumar et al, 2016).

The TPB is a useful model that can be used to understand the intentions to manage and/or predict behaviours associated with self-management and the use of text messages amongst a SA sample. However, the theory assumes that human beings are rational and make systematic decisions based on available information; unconscious motives and irrational determinants of human behaviour have not been considered (Gibbons et al, 1998; Abraham et al, 2016). It does not focus on cognitions or factors that may influence certain health-related beliefs or emotions regarding disease in ethnic minority groups (Patel et al, 2012). Ajzen and Fishbein (2005), note that emotions could be relevant to a range of health behaviours, and may be expected to place influence upon behaviour through the impact on beliefs and attitudes.

### **Health Beliefs and Perceptions**

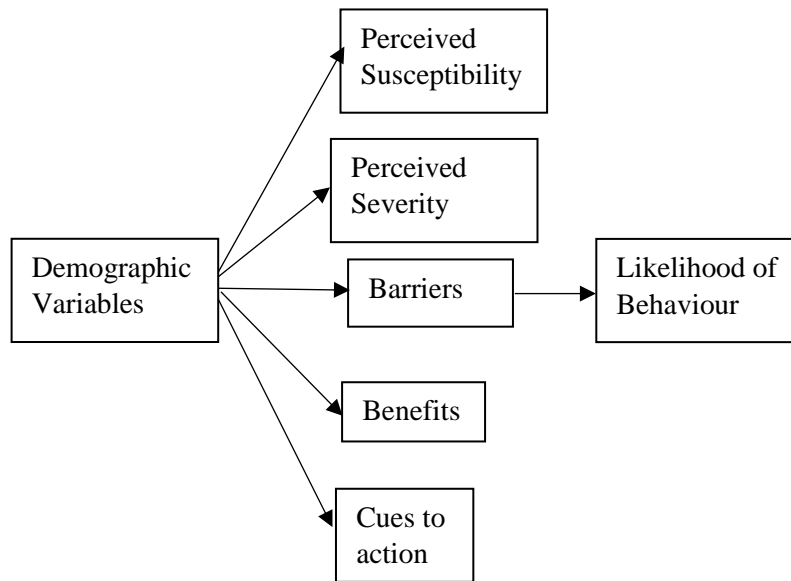
Attitudes and social norms are formed by particular health beliefs regarding severity of disease and patient adherence, within certain communities (Abraham et al, 2016). It is an important aspect for healthcare professionals to understand patient healthcare beliefs,

perceptions, values and preferences for the delivery of patient-centred care (Kennedy et al, 2017). An individual's beliefs about health, (for example, cause of disease, controlling symptoms, and perceptions of different treatments) helps predict health behaviours related to medication adherence, lifestyle behaviours and use of health care systems (Fishbein and Cappella, 2006). Studies show cultural health beliefs to play a part in SA self-management, they shape how prescribed medication regimens are perceived as well as their adherence or non-adherence to them (Horne et al, 2013; Kumar et al, 2016). Many health beliefs were associated with negative behaviours including: efficacy and toxicity of medications, stigma and stereotypes that were seen to be the main contributors to poor self-management and health-related outcomes.

Theories such as the Health Belief Model (HBM) (Diagram 6), was developed to understand why patients do not engage in behaviours related to disease prevention and their views regarding symptoms and adherence to prescribed treatment regimens (Janz and Becker, 1974). Unlike the TPB, the model focuses on aspects of individuals' representations of health and health-related behaviour being the 'threat perception' and behavioural evaluation, by proposing that individuals' behaviour can be predicted based on how vulnerable they consider themselves to be (Conner and Norman, 2005; 2017).

Constructs such as the perception of risk or threat were found to be positively associated with preventative health behaviour in some SAs (Patel et al, 2017), along with their perceived susceptibility to illnesses or health-related issues, and perceived severity of the consequences of the illness (Cummings et al, 1979; Corcoran, 2011). Those who perceived their illness to be a threat acknowledged that they were the ones who are responsible for protecting their own health, and recognised that disease was preventable by making healthier lifestyle choices (Netto et al, 2007; Patel et al, 2017). Individuals that adopted text messaging interventions were seen to improve the awareness of the risks associated with patient illnesses and provided useful information and reminders to tackle any issues to reduce the severity of disease. Patients from Pakistan and Bangladesh viewed messages to be positively correlated to improve glycaemic control and medication adherence to reduce risk factors associated with stroke (Islam et al, 2015; Kamal et al, 2015).

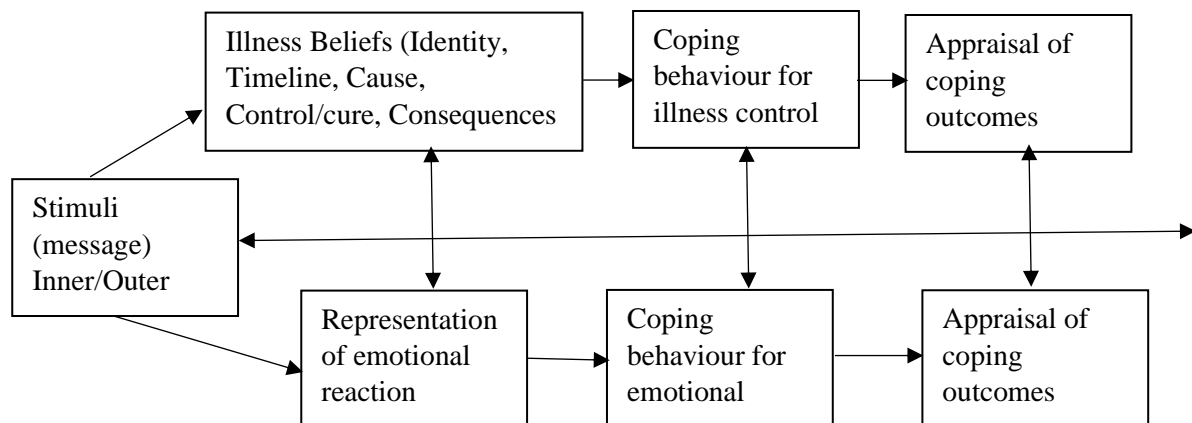
**Diagram 6.** *Health Belief Model (Adapted version from Fish-Ragin, 2015, p.11; te Keurst et al, 2016, p.123)*



Similar to the TPB and SCT, the HBM has been useful in predicting adherence to treatment regime and informing text messaging interventions to promote adherence to medication (Islam et al, 2015; Kamal et al, 2015). The HBM accounts for health beliefs, whilst, subjective norms and perceived self-efficacy outlined in the TPB and SCT, are also integral components in adherence behaviours. Perhaps these concepts can be applied in conjunction to obtain more detailed findings on SA behaviours and outcomes in relation to self-management and acceptability of mHealth interventions. However, these components alone would not be enough to grasp a full understanding of behaviour change occurrence in SAs. All three models (HBM, TPB, SCT) have been criticised for not studying the impact of emotions related to health behaviours or managing a chronic condition. Evidence suggests that emotions such as fear and consequences may be a key factor in predicting health behaviours (Glanz et al, 2008).



**Diagram 7.** *Common Sense Self-Regulatory Model (Leventhal et al, 1980;1997; 2016; Callaghan et al, 2008, p.326)*



Unlike the TPB, HBM and SCT, the Common Sense Self-Regulatory Model (CS-SRM) (Diagram 7), considers the emotional processes related to health beliefs. It is a useful model for this research study, as it considers socio-demographic determinants of health behaviours related to those facing an illness and the acceptance of text messages. Furthermore, it will draw upon factors associated within SA patients' behaviour change process, such as their: stigma, fears, anxieties, cultural norms and values, to create a clearer idea of their feelings, experiences and perceptions. The application of the model has been supported in empirical studies conducted amongst SA populations with LTCs such as heart disease, diabetes (Darr et al, 2008; Grewal et al,2010; Patel et al, 2012; 2015; Ghio et al, 2018), and terminal illnesses such as cancer (Grunfield and Kohli, 2010). Furthermore, it also acknowledges emotional responses such as coping behaviours and psychological factors, which are also important and can be useful to determine and identify health behavioural styles of SA patients.

### **Coping Behaviours**

Coping with a chronic illness encapsulates psychological and emotional aspects when living with a LTC (Potter et al, 2017). Dominant approaches for understanding coping, focus on the individuals affected by the illness for example, their personal attributes (Taylor and Armor, 1996) or their abilities to make behavioural or cognitive changes towards coping (Moskowitz et al, 2015). Youngkill et al (2002), advocate that the more an individual's fundamental life goals, for which they may require information to achieve are threatened by an illness, the more stress the individual experiences, influencing their coping abilities and self-management. Recent literature has found managing stress and coping to be underlying focus

on behavioural goals (Ludwig et al, 2011; Lawrence et al, 2013; Sharma et al, 2019). Misconceptions and lack of understanding has been evident in SA patients with CHD, leading to increase in stress and issues with coping (Grewal et al, 2010). Therefore, the provision of information must be tailored to the context of specific needs, beliefs and circumstances, to assist with coping within ethnic groups and the general population (Mooney et al, 2017). This was evident in studies employing text-messages tailored to the patient's needs dependent on the condition they presented with to improve coping behaviours (Shetty et al, 2011; Kamal et al, 2015).

Acknowledgement of one's illness or condition has been recognised as a central aspect of coping, which signifies that once a change in health status has been recognised, a range of resources can be mobilised to address its effects (Ahmad et al, 2014). Folkman and Lazarus (1986; 1988), elaborate on this, by stating that; when faced with a stressful encounter an individual first considers the situation with respect to what is at stake, what coping mechanisms and resources are required, and what choices are available. Difficulty in identifying aspects of lifestyle factors contributing to the development of diseases, such as diabetes and obesity makes coping a challenge. Majority of studies found that SAs lacked understanding of the relationship between lifestyle and disease, and the resources available to aid them (Lucas et al, 2013; Kumar et al, 2018). Therefore, those diagnosed with a lifestyle-related condition were often unconvinced of the effect their lifestyle choices had on health, with a majority of participants not knowing the cause of their condition due to limited access to informational resources, resulting in poor coping strategy and non-adherent behaviours. Personality traits are evident to reflect upon an individual's pattern of thoughts, feelings and behaviours, which influences how individuals perceive their disease and self-management regime (Hepworth et al, 2003; Kirby, 2016). These characteristics may vary dependent on situation, a major life event, age, health beliefs, seen in SA groups (Ramirez et al, 2012; Saffari et al, 2013), or due to physical factors such as tiredness or laziness; affecting motivation (Ormandy, 2008; Olgiati et al, 2016). In a study by Kumar et al (2016), the Satisfaction with Information about Medications (SIMS) tool was used amongst SA individuals to identify different personality types, in relation to their treatment regime for managing Rheumatoid Arthritis. Subsequently, four personality types were categorized and identified as; agreeable, passive, sensitive and balanced. This indicates personality traits (including religion and cultural traits) to encourage and influence SA attitudes and behaviour related to health (Santoshi et al, 2010).

### **Religion and Fatalistic Beliefs**

The notion of religion and fatalistic beliefs has been noted to contribute to coping behaviours related to illness or disease. They have been found to be interlinked with SA cultural and religious beliefs, as studies reveal SA patients to perceive illness as a natural part of suffering that is predestined upon them by God (Choudhry et al, 2016). Such beliefs were found to influence physical activity and dietary choices, as individuals believed that turning to God will help them cope better and give them hope, as God is ultimately responsible for their health (Darr et al, 2008; Lucas et al, 2013). This contributed to improved health outcomes and quality of life (Büssing et al, 2010). However, some studies reported that even if God was responsible for their health and condition, the individual still had the responsibility to look after their well-being; as disease was an indication from God that they did not manage their health, hence, lifestyle and behavioural changes needed to be made (Farooqi et al, 2000; Ramirez et al, 2012; Saffari et al, 2013). Although, this concept motivated SA patients to adopt healthier behaviours, some expressed anxiety, depression and hopelessness due to their lack of understanding of their condition leading to loss of control over their self-management (Patel et al, 2015; Sharma et al, 2011; 2015).

### **Psychological Impact**

Psychological, behavioural and cognitive variables can also interplay with coping styles and health-related behaviours. Despite patients being well informed regarding treatment and management of LTC's, many still fail to achieve optimal disease control due to non-adherence; which is reported to be a particular problem amongst SA patients (Kumar et al, 2018). Factors such as level of knowledge, outlook on life, attitudes, feelings, experiences, stereotype, prejudices, preferences, self-perceptions, emotions, interests/hobbies, memories, intuition, motivations and personality influence how illnesses are perceived and presented (Ankem, 2006). It is evident that psychological conditions such as anxiety and the presence of depression contribute and affect health-related behaviours (Patel et al, 2015). Its prevalence remains high amongst ethnic minority groups, particularly those of SA origin (Karasz et al, 2016; Mooney et al, 2016). Findings reveal that individuals from this ethnic group are less likely or unwilling to access information from mainstream services due to health beliefs, stigma and feelings of shame that influence reluctance to search for help, causing negative behaviours such as depression and feelings associated with loss of control (Wynaden, 2005; Sharma et al, 2015; Mooney et al, 2016). Others have further examined the

predictors of depression and similar psychological conditions, concluding that; older age, literacy, financial difficulties, gender roles, perceptions of illness, social isolation, and poor physical health are contributory factors to not having health care needs met (Xiao et al, 2014; Jacob et al, 2017; Mooney et al, 2017).

Adding to psychological and cognitive factors, an individual could experience cognitive uncertainty manifested as anxiety, resulting from their attitudes and judgements of the knowledge needed to overcome the challenges or problems faced (Ormandy, 2010). A view prevalent amongst the older SA generation was that the management of health should be left to qualified health-professionals, due to language barriers and multiple health problems described as reasons for lack of or inability to understanding their own condition (Lucas et al, 2013). This resulted in an increase of uncertainty for those patients with diabetes, hypertension and obesity (Lucas et al, 2013). It was also noted that patients from this sample group experienced feelings of insecurity, pessimism, and lack of control over their health; whereas, younger participants expressed a higher value on education and interest in increasing their control over their health (Lucas et al, 2013; Shin and Kang, 2014).

Demographical variables such as education, literacy levels, and others including age, gender, social and economic status, marital status, ethnicity, health status and diagnosis determine behavioural changes greatly (Jacob et al, 2017; Borek et al, 2019). The CS-SRM does not take such factors into account, whereas TPB and HBM have considered these components to be behavioural modifying factors, particularly within SA samples discussed below (Lucas et al, 2013; Kumar et al, 2018).

### **Demographics**

With regards to SA patients, the research area of interest looks at demographic factors associated with disease management, and discusses differences in demographics in relation to self-management, mobile phone usage and adopting positive behavioural changes.

In terms of ethnicity, most ethnic minority groups often experience higher morbidity and mortality than majority of populations for various long-term illnesses (Ford and Harawa, 2010). For example, individuals of SA origin in the UK have a higher prevalence of diabetes, which therefore, requires management of complications such as coronary artery disease, ESRD, hypertension, stroke, retinopathy, neuropathy, and lower limb amputations (Gonzalez-Zacarias et al, 2016). Amongst the SA population, younger patients show to have a better understanding compared to older participants (Kumar et al, 2018). They were also more

likely to engage with text messages compared to older patients, due to being familiar with recent and modern technology (Xiao et al, 2014; Balhara and Anwar, 2019). Older SAs were found to be more reliant on healthcare providers and lacked motivation resulting in poor medication adherence; whereas, younger SAs reported to access a wider range of educational resources to improve self-management (Khaira et al, 2012; Lucas et al, 2013; Kumar et al, 2018).

Income and education were also found to be positively correlated within SA patients and text message use. Higher levels of education and English literacy were found to be associated with improved self-efficacy amongst this group, as individuals were able to read messages, respond and act upon them (Shetty et al, 2011; Muilwijk et al, 2017). These findings coincide with other ethnic minority groups, such as Black-African patients with diabetes, who reported educational text messages to assist with self-management and positive behavioural outcomes (Dick et al, 2011).

Evidence suggests gender differences between men and women to be emanate (Bandari, 2017). Familial roles and gender differences within a SA community garners much attention within healthcare, decision-making and adherence to treatment regimens (Bandari et al, 2014; Gaveras et al, 2014). As discussed previously, men and women have distinct roles within the typical South-Asian household (Patel et al, 2012). For example, within a typical Indian or Pakistani home, women are often responsible for household chores and are less likely to be employed, compared to the men, who are the main breadwinners. Women were found to seek more information regarding health issues, due to having flexibility within their schedule and were conducive to ensuring better medication adherence behaviours in comparison to men when needed (DeSouza et al, 2014). However, both genders experienced the burdens and pressures of disease to interfere within their parental role, due to the possibility of not providing support for their children (Nijjar, 2012).

There is consensus across studies, regarding the burdens of illnesses with in ethnic-minority groups and risk factors that accompany them. Comparable findings explore various socio-demographic factors across the SA ethnic minority, and its contribution to the self-management of their LTCs (Siegel et al, 2014; Kumar et al, 2018). There are a range of differences in the awareness levels of LTCs, access to care, limited human/infrastructural resources (dependent on situation and context) and limited understanding of what may work for them. Literature presents multitude of challenges in trying to identify, address and

understand these socio-demographical factors in relation to disease management (Siegel et al, 2014), and the need for further research to explore patient experiences, in relation to these characteristics (gender roles, familial issues, marital status) with respects to SAs behavioural, self-management needs and adoption of technology-based interventions, such as text messages.

### **Key Theoretical Constructs**

Theories related to acceptance of technology and general health behaviours were explored, critically compared and discussed. Key determinants were exposed which could potentially influence SA self-management behaviours and uptake of text messaging interventions. An overarching objective of the proposed research is to extend the understanding of appropriate theories; such as CS-SRM and the HBM which have previously been used in SA samples. As a result, additional determinants identified and outlined (Box 3) from other theories (TAM, ELM, SCT and TPB) have also been drawn out as constructs which may influence SA health behaviours.

### **Box 3. Key Theoretical Determinants Pertinent to Behaviour Change Processes in SA Population**

- Demographics (e.g., age, literacy and education, familial role and social networks)
- Attitudes (e.g., cultural beliefs)
- Subjective Norms (e.g., cultural norms; gender roles)
- Health Beliefs and Perceptions (e.g., stigma)
- Coping Mechanism/Behaviour (e.g., tailored messages, religion, fatalistic beliefs)
- Psychological Impact (e.g., depression, anxiety, fears)
- Persuasion and Motivation (e.g., concept of tailored interventions, nudging, cultural and social support)
- Self-Efficacy and Control (e.g., confidence and interest to self-manage)

### **Summary**

This chapter provided an overview of the definitions of health behaviour, behaviour change, its relevant theories, and their application to understand the behavioural change process amongst SA populations. Key theoretical constructs were critically evaluated to depict SA health-related behaviours in relation to non-adherence which included lack of understanding, knowledge and health beliefs associated with treatment regimens. Other social and cognitive

factors were also acknowledged and discussed which were relevant to positive behavioural outcomes amongst SA groups, including: stress and coping, psychological impact and demographics.

In addition, the use and adoption of text messaging interventions was emphasised, which provides the main focus of this thesis and the proposed study. There is ample evidence supporting the use of mHealth and text messaging/SMS interventions, which aid in health promotional measures for example: to educate, motivate, prompt, and assess various health care activities. The ELM and TAM appropriately examined factors such as motivation and persuasion associated with SA patients' level of use and acceptance of mobile phones and text messaging to improve adherence and self-management of chronic conditions. Models including the ELM also informed elements of patient-centredness, tailoring information and messages, which were empirically effective and essential to 'nudge' individuals to achieve optimal self-efficacy, health promotion and behavioural outcomes, specifically amongst non-adherent ethnic groups.

Evidence suggests cultural barriers, attitudes, norms and beliefs to be possible contributors to non-adherence within SA groups (Patel et al, 2015; Kumar et al, 2016;2018). Many criticisms were outlined from the health behaviour models discussed, which focused solely on causal beliefs rather than how people actually assess and evaluate symptoms, adhere to their treatment, take active responsibility for their illness and the influences of societal and cultural context for disease management. From the evidence collated above multiple constructs that were relevant, were identified and drawn together for a better understanding of behaviours relevant to self-management and uptake of text messages (Box 3).

In addition, there are key theoretical elements of behaviour change amongst SAs associated with the use of text messages that can be taken forward within this study (Box 4).

Research to better understand the notion of behaviour change processes, to explore and understand the experiences, and behaviours of SA ethnic minority communities is needed. This may involve examining behaviour changes in relation to medication adherence or investigating the effects of text messaging interventions, tailored to the needs of this group as a strategy to positively change behaviour, aid in optimal health promotion, and improve health outcomes. Chapter Five examines different methodological approaches relevant to the research study and presents the aims, objectives, and chosen methodology.

**Box 4.** *Key Research Elements of Behaviour Change Theories Associated to Text Messaging in SAs*

- Factors such as stigma, fears, anxieties, cultural norms and values are key determinants that are associated with negative health-related behaviours.
- The idea of religion and fatalistic belief contributes to coping behaviours and health beliefs in regards to dealing with LTCs within SA communities.
- The term ‘*tailored*’ is interconnected with ‘*patient-centredness*’, and is responsive to individual patient preferences, needs and values. SA patients who received messages tailored in terms of their illness, preferred language, culture, religion and certain health beliefs, felt more involved with improved behavioural outcomes (Fjeldose et al, 2009; Head et al, 2013).
- The concept of *nudge* can be applied to text messaging interventions as a persuasive system that directs individuals to adopting healthier behaviours (DH, 2016).
- The CS-SRM is a useful model for this research study as it considers emotional processes and health behaviours that are excluded from other cognitive models, which will allow for a deeper understanding of SA feelings, experiences and perceptions of their illness and their use of text messages.
- Combining theories such as the HBM and CS-SRM can help to better inform SA health beliefs and their understanding of disease from a more socio-cultural perspective, as well as their acceptance of text messages.
- There is need for further empirical evidence to explore the usefulness and appropriateness of text messaging interventions, to aid the behaviour change process of SA ethnic minorities within the UK to overcome poor adherence and improve self-management of LTCs.
- Multiple theoretical determinants were identified to play a part in the behavioural change processes of SA patients using text messages (summarised in Box 3).



## **Chapter Five**

### **Research Methods**

#### **Introduction**

The evidence of methods used to examine patient experiences, feelings, attitudes, activation levels of engaging with text messages and living with a LTC is limited, particularly amongst SA groups. This creates the need for further investigation in this field of research, and provides the opportunity to examine the strengths, limitations and appropriateness of available methods that influenced the selection of the methodology for this study.

The choice of methodology was dependent upon the topic, the research question, the philosophical paradigm, thoughts and perspectives of the researcher; all critical components which informed study decisions. The study idea originated from an interest to address the gap in research knowledge that identifies the barriers and hindrances contributing to poor adherence to treatment regime and the acceptance of mHealth amongst SA patients.

Fundamental to the research was to respect, understand and explore SA participant health beliefs, cultural norms, religious values and their perspective of their illness. In addition, how they view and use text messages, to generate a deeper understanding of their experiences and barriers, and to identify appropriate support programmes to foster LTC self-management.

Therefore, this chapter presents the aims and objectives of the study, a brief overview of the research paradigms, the differing approaches exploring SA patient experiences of living with an LTC and the justification of the chosen approach to address the research aim.

#### **Study Aim**

This study aimed to understand the use of text messaging in the SA population and whether it was useful to promote positive health behaviour, increase and support self-management of a LTC. It explored the experiences of SA people, and investigated whether health beliefs, cultural and religious customs contributed to self-management, patient activation and engagement with a text messaging service. Health text messages delivered to SA patients using the NHS text messaging FLO system were examined, and behaviour resulting from the text messages recorded and interrogated.

The objectives were fivefold:

- Explore the perspectives and experiences of SA people living with an LTC and using technology to aid self-management or promote healthy behaviour.
- Investigate the experiences of those SA individuals not utilising the technology (this included those who had used FLO, but were no longer using it, or rejected the system in the first instance), to determine how the experiences of managing an LTC will differ to those using the technology.
- Examine how factors such as culture, religion and health beliefs influence the adoption of text messaging within a SA population.
- Assess whether patient activation measures provide a useful indicator of who would benefit or engage with a text messaging intervention.
- Extend the understanding of different theories by exploring whether the Common Sense Self-Regulatory Model and the Health Belief Model, provide appropriate frameworks for understanding individual beliefs, perceptions, how people make sense of and manage their illness using text messaging interventions within the SA culture.

### **Philosophical Perspective of the Researcher**

The principles of whether ‘experiences’ in the field of healthcare, is objective (external) or subjective (internal) appear divided. To understand the epistemology behind this particular study it is important to briefly revisit the theoretical underpinning of behaviour change to promote self-management of LTCs in SA patients presented in Chapter Four.

Dolan (2012) suggests that human decisions are strongly influenced by environmental and personal factors that lead to changes in behaviour. Many behavioural theorists argue behaviour change to be triggered through constructive processes, which allow active learning through individual attitude, beliefs, perceptions, fears, emotions, intentions, knowledge, norms, openness, motivation and goals (Rogers, 1983; Rosenstock, 1988; Ajzen, 1991; Bandura, 1997). This confers with the ideology that an individual’s behaviour, attitude and outcomes of those behaviours are influenced by observing others, gaining information, learning and forming ideas of how new behaviours are performed and on a later occasion this information is coded and created by us, that serves as a guide for action, which is subjective and internal (Bandura, 1982; 1993). Within the realms of a naturalistic and constructivist view, the methods advocated by behavioural theorist such as interviews, have been used to study phenomenon and the occurrences of everyday behaviour (Frey et al, 2005; Abraham

and Michie, 2008). Multiple studies included in the literature review (Chapter Three), employed such methods to gain insights into SA patient experiences of using text messages to support their self-management (Osborn and Mulvaney et al, 2013; DeSouza et al, 2014; Prinjha et al, 2020). The constructivist perspective has gained wide acceptance in the field of healthcare and psychology, where emphasis is placed upon the perspectives, attitudes and experiences of the individual patient or client, what they believe and what is real for the ones with impeding health outcomes. The view that individuals construct their own ideas, knowledge and experiences gives rise to different interpretations, along with implications in practice. Many constructivist principles have originated from psychological, sociological and philosophical perspective, which cannot be '*transplanted*' into reality (Gordon, 2009, p.41).

However, due to the nature of the study focus, to explore the patient experience, reality is accepted as a construct of the human mind, perceived to be subjective. Current evidence shows little changes in patient health outcomes, as many continue to experience difficulties in diagnosis, accessing information about their condition, receiving appropriate co-ordinated care and access to appropriate treatment regime (DH, 2016). There lacks insight into a patient's reality. Interacting and recognising an individual's mental activity or patient experience in a world real to them, is a reality of its own (Elkind, 2005). Papert (1991) extends and describes constructionism, as a '*learn-by-making*' formula, which concerns learning as an iterative, active process, through which we reconstruct actions and experiences in to meaningful products, through "*knowledge structures*" (Papert and Harel, 1991, p.1). This theory focuses on education needs of the learner, which in this study is the patient, and other elements such as the individuals, context, situation, motivation, readiness to engage, and in terms of the study participants, cultural norms, health beliefs and tackling barriers that hinder optimal health (Ramachandran et al, 2013; Patel et al, 2015). The changing nature of knowledge and adaption to these changes, are central to the theory, as it draws on how people think differently, when faced with alternative views that form attitudes and ideas that expand their version of their world and their experiences (Shetty et al, 2011; Prinjha et al, 2020). This is particularly relevant to SA patients, who are faced with multiple barriers to appropriately self-manage their illness; their view of the world changes as they are learning-by-making sense of what is happening to them and having the appropriate support available, to facilitate effective coping and self-management of their condition (Kumar et al, 2018).

This excursion focusing on the learning theory discussed, was not to divert attention from the epistemological basis but to strengthen the constructionist (interpretivist) stance adopted to

investigate how human beings create systems for meaningfully understanding their worlds through their experiences (Raskin, 2000). To achieve the aim of the study the exploration of patient experiences of living with a LTCs, and how SAs make sense of their illness through the role of health beliefs is important, to better understand their health behaviours and the use of text messages to aid optimal self-management.

The philosophical basis of this study originates from the assumption that human experiences are subjective, bound by human cognitions, emotions and behaviours; whilst at the same time acknowledges that experience can also be measured objectively (Denzin and Lincoln 2005). An inductive or qualitative approach would be useful to gather an in depth understanding of human behaviour and the reasons behind such behaviour. It would enable the researcher to gain rich knowledge and insight about human beings, focusing on their experiences often in their natural environments and taking into account how socio-demographic and cultural factors influence those experiences and behaviour (Parahoo, 2006). Such approaches adopt methods such as interviews, observations and diaries to interpret aspects of a certain phenomenon. The purpose is to provide a description and clarification of people's experiential life "*as it is lived, felt, undergone, made sense of and accomplished by human beings*" (Schwandt, 2001, p.84). Some studies used semi-structured interviews (Grewal et al, 2010; Karbani et al, 2011; Mooney et al, 2016), whilst others brief conversational styles to motivate and discuss SA patients' medication adherence challenges, to help them form realistic adherence goals (Osborn and Mulvaney, 2013). Using an in-depth technique encourages openness and elaboration to fully '*capture*' SA patient experiences (Nieswiadomy, 2002; Jepson, 2012; Wilkinson et al, 2012).

Alternatively, deductive methods adopt more structured quantitative methodologies such as surveys and questionnaires. Evidence indicates two types of measurement surveys, differential and summated scales have been used to measure and assess the use of text messaging interventions for the self-management of LTCs amongst SA participants (Shetty et al, 2011; Uzma et al, 2011; Osborn and Mulvaney, 2013; Patel et al, 2013; DeSouza et al, 2014; Vakili et al, 2015). The Patient Activation Measure (PAM) is an example of a summated scale used in the study (explained later), to assess participants level of confidence to independently self-manage LTCs.

Understanding patient experiences offers healthcare professionals new ways to interpret the nature of consciousness and of an individual's involvement in the world. Indeed, exposing

SA patient experiences of living with an LTC and using text messaging interventions to aid self-management, improves the understanding of how certain situations may present (Cohen and Crabtree, 2008). This can be achieved either using a single or combined methodological approach. This could include the use of both qualitative and quantitative data within a single analytical place to strengthen each method, maximising results that comprehensively answer research questions (Creswell et al, 2011).

### **Paradigms within a Mixed Methodology**

Both quantitative and qualitative approaches have been criticised for the inadequacy to integrate a broader array of information (Tashakkori and Teddlie, 2003;2010). Although, quantitative methods can help develop predictive models to explain human behaviour (Bauman, 2003), they do not account for evaluating complex and contextual experiences, behaviours, variables, characteristics and beliefs. Whilst qualitative methods address this, and provide richness of behaviour and experiences of illness, they have been criticised for using small samples with limited data reduction techniques and problems of generalising findings (Ritchie and Lewis, 2003). Therefore, research has mixed methods and combined the two approaches within different phases of the research process to overcome the limitations (Tashakkori and Teddlie, 2010).

Mixed methods research is a philosophically grounded methodology, intentionally combining both qualitative and quantitative approaches within a single study (Doyle et al, 2009), to provide a more detailed answer to the research questions, offering a broader and better understanding of the topic of interest (Creswell and Plano Clark, 2017). Connecting the two paradigms has been referred to as a 'pragmatism' paradigm (Morgan, 2014), which provides the rationale and underpinning of utilising a mixed methods approach, in terms of epistemology and ontology (Tashakkori and Teddlie, 2003; Bergman, 2008).

There was limited exploration of SA patient experiences and uses of mHealth technology due to the methods employed. Perhaps this was due to the differing philosophical perspective of the researchers. However, from the studies reviewed those combining both approaches were able to establish a deeper understanding of SA patient experiences of utilising a text messaging intervention for self-managing LTCs, along with discovering multiple variables affecting health behaviours in complex settings across this patient group. Furthermore, this approach has been fundamental in the construction of some quantitative instruments developed, from which the content has been derived primarily from qualitative methods

(Osborn and Mulvaney, 2013; DeSouza et al, 2014; Vakili et al, 2015). The challenge of using mixed methodologies is the inadequate reporting of qualitative evidence. Alongside the underrepresentation of quantitative data to explore macro and micro-level perspective concurrently whilst adding depth and explanation to research findings.

The evidence from the experiences of SA patients and their use of text messages and mHealth to enhance health outcomes and self-management is lacking particularly within the UK. Studies of similar topic area have predominantly been conducted amongst Caucasian samples within the UK, excluding ethnic minority groups (Fjeldose et al, 2009; Buntin et al, 2011; Marcolino et al, 2018). The premise of these studies is that ethnic minority groups (SA participants) will also share certain traits in terms of managing LTCs. They will have contextual components influencing their health behaviour, and will have key information and educational needs delivered through similar text messaging interventions at preferred times to aid the self-management of their condition. In order for this to be determined, a combined or mixed methodology consisting of both an inductive and deductive approach is considered most appropriate (Johnson and Onwuegbuzie, 2004).

### **Forms of Mixed Methods Designs**

There are four main types of mixed method designs: triangulation, embedded, explanatory and exploratory design. Table 16, outlines the advantages and disadvantages of different types of mixed methodologies.

The most important step in the research was to choose a methodology that would be best suited and most feasible to answer the research aims and objectives, within the expected time-frame. Careful consideration was paid to the selection of the design, along with the strengths and weaknesses. The study was to elicit the experiences and use or non-use of text messaging services by SA people, understand their challenges and barriers, and examine whether their readiness to self-manage influenced text messaging use. Therefore, the study was seeking explanations for observed behaviour, using both quantitative and qualitative data collection methods; and adopted a 'sequential exploratory design', using both (qualitative and quantitative) phases to explore and build evidence on certain behaviour that was observed.

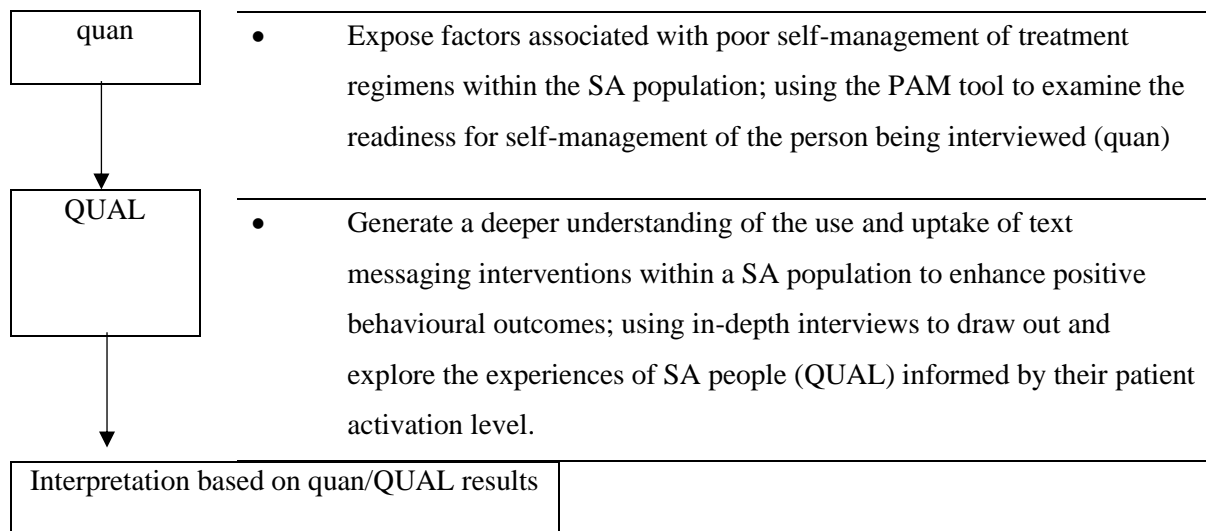
**Table 16.** *Types of Mixed Methods Design (Adapted from Tashakkori and Teddlie, 2003, p.11)*

	Triangulation (QUAN + QUAL)	Embedded (QUAN (qual) or QUAL (QUAN))	Explanatory QUAN → qual	Exploratory QUAL → quan
<b>Design</b>	Is a one-phased design used to obtain separate but complementary results within the same time-frame (i.e., during one visit to the field), to better understand the research problem.	Either data set in which quantitative and qualitative data is collected and analysed within either design.	Two-phased mixed methods design in which qualitative data can help inform or expand quantitative results (or vice versa).	A two-phase study design in which the results of the first method (for example, qualitative), can inform the second method (for example, quantitative) i.e., the results of the qualitative phase will help to make sense of the quantitative phase.
<b>Advantage</b>	Efficient- both types of data are collected during a single phase at the same time, saving time compared to other mixed methods.	Less time consuming and cheaper to implement.	Simple design to implement; can be conducted without a research team.	Includes separate phases which make the design straightforward to implement.
<b>Disadvantage</b>	Requires expertise and training; difficult to combine two sets of different data	Difficult to integrate results due to obtaining them during separate elements; training and expertise required; Likelihood of bias (for example social desirability bias).	Time consuming method to complete the data collection and analysis, given the two separate phases.	Time consuming; sometimes presents a challenge to decide which qualitative findings to use for the quantitative phase.

### Justification of Choosing an Exploratory Mixed Methodology

The main rationale for choosing the exploratory design (Diagram 8) was to provide a comprehensive view of the phenomenon under study (Tashakkori and Teddlie, 2010), and to gain completeness in the key areas of interest (Diagram 8). However, for this study it made sense to run the quan phase first, then the larger QUAL phase second and use the PAM scores to explore self-management in more detail during the in-depth interview. Creswell (2009), argues the two-phase approach to be time-consuming, which researchers need to recognize and build time into their planned study.

**Diagram 8.** *Overview of Exploratory Mixed Methods Design (Adapted from Creswell, 2009, p.76)*



This design was useful to assist in development and testing of the PAM instrument amongst SA ethnic minority groups (Creswell et al, 2011), and allowed for the in-depth exploration of the topic of enquiry (Morgan, 1998). An advantage of using this design is that the separate phases make it simple to describe, implement and report. Similar studies identified within the focused review (Chapter Three) opted for comparable study designs; for example, some objectively measuring adherence, whilst, exploring perceptions and insights of ethnic patients and their uptake of text messages (Dick et al, 2011; Lin et al, 2012; DeSouza et al, 2014; Prinjha et al, 2020).

Integrating, linking and contrasting the findings between the two constituents of the methods enabled (Tashakkori and Teddlie, 2010; Creswell et al 2011):

A richer and in-depth understanding of variables and their relationships, by drawing inferences between the strands of both methods to develop new knowledge with regards to



SA patient use of mHealth interventions (Tashakkori and Teddlie, 2003; Hoover and Krishnamurti, 2010). Whilst, undertaking research using mixed methodology can sometimes be time consuming, it can help to address broader questions, adding insight that could have otherwise been missed. Which in this case, would be exploring SA patient experiences, while measuring patient activation levels (Creswell and Plano Clark, 2017).

An increased confidence, rigour and quality of findings, through triangulation which allows for inconsistencies in findings between the two combined methods to be identified. This produces meaningful and valuable evidence in this study (Tashakkori and Teddlie 2010), while offsetting the shortcomings from using a single approach (Albert et al, 2009; Tashakkori and Teddlie, 2010; Caruth, 2013; Bryman, 2016). For example, activation levels reflect upon the degree of LTC self-management, and could offer insight as to the lack of text message uptake due to low self-management readiness; or increased uptake to improve self-management to overcome symptom burden from non-adherence exposed within the interview.

Most importantly, this methodology provided a combined framework for the complex evaluation of a text messaging intervention, integrating health and cultural beliefs to make sense of concepts pertinent to the SA ethnic minority population (Henderson et al, 2013; Polit and Beck, 2014). To comprehend the uptake of text messaging interventions by SA people, it was important to approach those from the same community or LTC modality who have chosen not to use or engage with the FLO text messaging system. This was to understand their preferences, and the subsequent impact on non-adherence, health behaviour and the self-management of their LTCs.

The study progressed in two phases, consisting of phase one (first phase), which is the quantitative patient activation questionnaire; which then led to phase two (second phase) the qualitative semi-structured interviews exploring the experiences of users and non-users of FLO text messaging, to promote self-management behaviour. Both phases took place on the same day during patient clinical visits.

### **Phase One - Quantitative Phase**

In phase one participants were asked to complete the Patient Activation Measure (PAM) to assess and determine an individual's level of knowledge, skills and confidence to assume responsibility for their own health and well-being (readiness to activate self-management).

PAM instruments were administered once eligible participants were selected and consented according to the inclusion criteria and eligibility checklist completed.

*Quantitative Tools/Measurements: Patient Activation Measure (PAM)*

Patient activation is a key concept concerned with patient-centred care as discussed in Chapter Two. The notion of ‘patient activation’ is supported by a quantifiable scale which is being used across the healthcare industry to determine the level at which individuals are activated and engaged in their own health (Heath et al, 2017).

The NHS emphasises the importance to effectively self-manage LTCs, ensuring individuals have the confidence to be able to independently do that. Although, there is a growing body of literature which supports the use of PAM (Hibbard et al, 2005; 2014; Gao et al, 2019), there is lacking evidence of it being applied to ethnic-minority groups, particularly SAs. In order to address the barriers related to self-management amongst SA, it was important to assess their level of knowledge, skills and confidence to be able to independently self-manage their condition. Therefore, the PAM survey would be utilised as an assessment for health and wellness behaviours amongst SA groups. Previous studies outline applications of the tool amongst the general population, and identify important patient characteristics that apply to the chosen study sample, and may influence their health and self-management outcomes (Hibbard et al, 2014). These include the:

- Ability to self-manage condition, illness or health problems
- Ability to engage in activities reducing health declines
- Ability and knowing the importance to intervene in treatment and diagnostic choices
- Ability to collaborate with health care providers and organizations
- Ability to navigate health care systems and providers based on performance and quality

The PAM a five-level Likert scale (disagree strongly, disagree, agree, agree strongly, N/A) made up of thirteen items which are answered according to the patient’s level of agreement or disagreement (Appendix 9). Although, it is described as a quantitative scale, it was used in this study to help frame and inform the interviews that took place after completing the survey. The tool helped provide more depth to patient responses when asked about their self-management behaviours, adherence to treatment regime, where they are up to with their health, how and whether text messages assisted them to self-manage their LTC.

The PAM is a validated and robust tool which has been extensively tested and reviewed by a number of studies outlined in Chapter Two (Maindal et al 2009; Hibbard et al 2010; Hibbard et al 2013; Gao et al, 2019), and translated in the common languages appropriate for the study (Urdu, Gujarati, Hindi, Bengali, Punjabi and Tamil). However, in this study there were issues raised on retrieving translated versions of the scale as there was an insufficient sample size (n=40) compared to what was required (n=200) to gain access to full translated questionnaires. To address this, all scales were translated by the researcher instead (discussed in more detail below).

Translated versions of the tool are shown in appendices 10, 11, 12, 13, 14, 15. All questionnaires were self-completed in a language of patient choice. Questions could also be dictated/read aloud in a preferred translated language where appropriate, depending on the preference of the research participant. In addition, an indication as to whether the individual was a user or non-user of FLO, was also provided at the start of the survey for the purpose of the study.

### **Phase Two - Qualitative Phase**

Phase two used semi-structured interviews to generate a deeper understanding of the SA participants' experiences of living with an LTC, and the use of a text messaging intervention to enhance healthy behaviours.

#### *Semi-Structured Interviews*

Interviews followed on from the completion of the PAM questionnaire during the same time slot. This method helped pursue in-depth information around the topic of interest, which was to uncover patient experiences of living with an LTC, and using the FLO text messaging system to support their self-management. Interviews explored the concepts of theories such as the CS-SRM and the HBM (outlined and discussed in Chapter Four) (Leventhal et al, 1997; 2016), to elicit illness-related beliefs and to make-sense of how SA individuals perceive and manage their illness.

An interview guide for both users and non-users of the FLO system was designed (Appendix 16 and 17) consisting of a set of pre-determined questions, to guide the researcher and to follow up on probes to uncover rich data that is individualised, credible and trustworthy (Nieswiadomy, 2002; Ellis, 2013). The guide was divided into five concepts and domains to help cover and address health threats, issues related to coping with symptoms, diagnosis,

health information and the use of technology. Each domain has been shown and outlined below.

*Domain 1:* Personal and socio-demographic characteristics where factors such as age, education level, employment status, gender roles, ethnicity and religion were collated along with its association to their adherence regime and their views and acceptance of the intervention.

*Domain 2:* Technology, and patient views on using/ not using the FLO system. Users were asked how long they had used the system for, how they found it (were the messages motivational and persuasive), the experiences and challenges faced when using it and what they would improve. On the other hand, non-users or those who had previously used the system were asked why they had stopped using the system, the challenges they faced and what they envisaged a text messaging intervention to entail.

*Domain 3:* Self-management and patient understanding of their disease and treatment regime. Whether their symptoms were controlled, self-efficacy, feelings and attitudes towards their condition (psychological impacts), whether they received sufficient information or support and whether they experienced any emotional consequences such as depression or anxiety.

*Domain 4:* Health beliefs and behavioural outcomes. Users were asked to reflect on whether the intervention had any benefit on their health, do text messages motivate participants to actively manage their condition, and whether it would be of any benefit for non-users showing poor health outcomes.

*Domain 5:* Religious and fatalistic factors, which focused on coping behaviours related to patient views on God and religion. Both users and non-users were asked if their religion helped them cope better, and whether cultural and traditional customs play a part in self-management. Both groups were asked whether they felt text messaging intervened with God and religion, their views and preferences of traditional remedies over western remedies and vice versa.

From the interviews, central themes were derived from the literature critically examined in Chapter Four (demographics; attitudes; subjective norms; health beliefs and perceptions; coping behaviour; psychological impact; persuasion and motivation; and self-efficacy), which were evident to effect SA illness-related behaviours. Furthermore, the application of the theories has been useful amongst SA samples, as the constructs allowed for probing cultural

and religious beliefs that influence decisions, activation levels and healthy behaviour related to the acceptance or non-acceptance of the FLO text messaging system. This helped to develop a better understanding of patient health beliefs, cultural norms, practices and behavioural patterns, which in turn predicts behaviours regarding the self-management of LTCs (Patel et al 2012; 2015).

### **Addressing Translation and Language Barriers**

A strategy from the outset of the study was to try to overcome literacy and language barriers for SA patients, preventing engagement with the study. Most users of the FLO system were able to speak, read and understand English. Therefore, translators were accessible for those who did not speak English. Of those, the majority of non-English speakers were present with a family member who they preferred to speak English on their behalf. All interviews were conducted using a language understood by each research participant, enabling the researcher to communicate effectively. Participants were welcome to ask a family member to sit through the interview whilst data was collected via questionnaires and interviews, to translate if they did not understand the English language. Twenty-Eight participants were present with an English-speaking relative who were able to translate the study material. For those who chose not to have a family member present, an alternative translator was provided through Language Line. A cost-effective and easily accessible service, offering interpreting and translation within healthcare over a simple telephone call. Participants using this system could speak to an individual translating the questions in the same preferred language. Only two participants utilised this system.

Interviews lasted between 45 to 60 minutes, were digitally-recorded and downloaded on a password protected computer with the participants consent. Then transcribed verbatim and erased from the recording device.

All study instruments such as the PAM tool, patient information sheets and consent forms were all translated (forward and backwards translating) into SA languages (Urdu, Gujarati, Hindi, Bengali, Punjabi and Tamil) with the help of existing SA interpreters to increase validity, reliability, and efficiency to aid in data collecting (Tsang et al 2017).

### **Research Personnel and Study Site**

The research process included myself, as the principal investigator carrying out all research procedures involved in collating data and the analysis. Study findings were paramount for creating best practice that would optimise the use of text messaging within SA populations to

promote self-management. Guidance was provided by my main supervisor and co-supervisor regarding methods and procedures that took place. The role of the clinician was to aid in the identification and access to appropriate SA patient groups from within his clinics.

Although, advice was sought on how best to conduct the study it was important to examine my own beliefs, judgements and practices, which could influence the research (Finlay, 2002). There were a few possibilities of imposing biases in the study. Firstly, by being an insider of the SA community and having my own assumptions about what I had already witnessed in SA people I knew. Secondly, my role as a researcher interviewing people sharing a similar cultural background, could also affect participants responses due to this, and some participants not openly sharing their true experiences. Therefore, the research process required openness and acceptance, in order for me to gain trust and establish a rapport. In hindsight, I kept a neutral attitude and remained sensitive to participants from a wider context, by interviewing and recruiting participants from varied characteristics to gain a broader awareness of participant experiences from different SA sub-cultures (generation groups, age groups, ethnicities, religious beliefs). This helped overcome biases and pre-existing assumptions about the broader SA community prior to the research.

Patient identification took place from NHS clinics held in West-Midlands. Participants were recruited from the renal diabetes clinic where patients with CKD and ESRD were found; and endocrine clinics consisting of patients with hyper or hypothyroidism, as well as diabetic patients from insulin pump clinics. Patients that were recruited included:

- Those who were already assigned to the FLO text messaging service by the consultant endocrinologist or diabetes specialist nurses (current users of FLO) offered to them to keep a routinely track of their condition;
- Those who had previously been assigned to the system for a set period of time for research purposes by the consultant (previous users of the FLO) but are no longer using it as the research study ended;
- Those who have never used or been introduced to the FLO, or have no interest to engage with it (non-users of FLO)

The number of users, non-users and previous-users were determined once the eligibility checklist (discussed below) was completed.

### **Inclusion and Exclusion Criteria**

An eligibility checklist (Appendix 18) was distributed to patients during their clinical appointments prior to obtaining consent. Subsequently, all checklists were checked prior to data collection, and research participants were selected accordingly dependent on eligibility criterion (Box 5). Key patient characteristics included: age, gender, ethnicity, whether patients have an LTC and whether they are a user or non-user of the FLO text messaging system. This helped ensure the diversity of subjects recruited for the study to meet the study aims.

#### **Box 5. Eligibility Inclusion Criteria**

- Aged 18 years and above
- Patients managing an LTC
- Patients belonging to a SA population (from countries such as Pakistan, India, Bangladesh, Sri-Lanka, Afghanistan, Nepal)
- Patients who could provide written informed consent
- Patients already using the 'FLO' system
- Patients who have used 'FLO', but may no longer be using it
- Patients who have decided not to use the 'FLO' system

Those who were under the age of 18, presenting with acute conditions, were Caucasian or from other ethnic minority groups were excluded.

### **Sample Selection and Access to Patients**

Services using FLO (agreement letter Appendix 19) included regions within Birmingham that had agreed to identify potential SA participants and administer the study information to each eligible person who were given the choice to contact the researcher to be involved in the study. Whilst, this was a common approach, it was not particularly good for accessing groups, where English may not be their first language or overcoming poor literacy skills making even reading translated study material a challenge. The lead clinician recommended recruiting participants face to face in clinics to allow information material to be given out during the clinic visit, and the researcher available at clinic to provide a verbal explanation and answer questions raised regarding study participation. Both approaches were combined to achieve maximum recruitment. However, the presence in the clinic and the identification of

the researcher as a member of the SA community was the more productive recruitment method.

For the study site, theoretical sampling was considered by reviewing case studies of those who had utilised the FLO text messaging service amongst similar samples, to inform the aims and develop a broader understanding of the area being investigated (Draukcker et al, 2007). This process included reviewing previous studies and contacting authors who have recruited SA samples using text messaging interventions for self-management, which in turn allowed for patient identification. The sampling process based on emerging theoretical concepts, allowed for a richer understanding of the concept dimension across a range of settings and conditions (Glaser and Strauss 1967). In this particular study it enabled the exploration of various themes across the samples in terms of genders, age, religion, cultures, and ethnicity, widening the sampling frame to more than just varied LTCs.

### **Sample Recruitment**

Once the eligibility checklists were completed by participants and screened by the researcher, consent was obtained from all eligible participants, to participate in phases one and two of the study. The recruitment strategy involved two steps:

- 1) The clinician collaborating within the study, agreed to distribute information packs to participants, which included the patient information sheet and eligibility criteria checklist, during patient clinical appointments. The clinician informed the patients of my presence within the clinic, and that they could ask me any questions or queries regarding their participation in the study;
- 2) Questions were answered and all the interested participants were asked to complete the eligibility checklist, to determine an appropriate sample selection, prior to consent being obtained. I was allocated a separate room within the clinical area, where participants freely approached me after their appointment for further information. Once consent was obtained many patients were happy to commence with the study immediately, but the option if preferred was to meet at a later clinic appointment. All study subjects were asked to complete the PAM tool followed by the interview within the clinic.

To fully understand the uptake with text messaging interventions by SA people, it was important to approach those who have chosen not to use or engage with the FLO text messaging system of the same community or LTC population. This would help develop an understanding of their preferences, views of using FLO to aid adherence, health behaviours



and self-management of LTCs. Once a SA participant was identified within the clinic, a purposive sampling technique was used to select a wide range of participants based on the characteristics selected within the eligibility checklist. Patients who did not meet the criteria were excluded. Majority of the SA patients selected, presented with LTCs such as diabetes, hypertension, CKD and ESRD.

## **Ethical Issues**

### *Ethical Approval*

Ethical approval was first granted by the University Ethics committee, a copy of the approval letter has been attached (Appendix 20). The next step involved seeking and gaining ethical approval from the NHS National Research Ethics Service, Health Research Authority, and local R&D office to gain access to patients (Appendix 21). Organisational and local service management approval was provided in writing prior to the start of the study, where permission was sought from the lead clinician (within Birmingham regions) to access patient data (from the FLO database if needed), already utilising FLO to provide healthcare services for the management of LTCs. A letter of confirmation from the clinician was sent back to the researcher (Appendix 19).

### *Informed Consent and Translation*

Participants were provided with English and translated patient information sheets, which explained what the research entailed, in languages the participants understood (Appendices 22, 23, 24, 25, 26, 27, 28). Preferred languages were garnered from the clinicians in the service, to ensure study information was presented and translated in a format participants could read independently. The researcher provided time for the study subjects recruited to ask questions also in a language they understood to clarify aspects of the research and what their participation would involve. Speaking to patients in their native language kept them engaged and interested due to a common cultural understanding. Therefore, for future studies translation would be considered again. The researcher had a command of the basic languages used within this population but had the language line translators available where appropriate (a service well known in the NHS). Participants were given the opportunity to ask the researcher any questions or raise concerns they had before providing informed consent, to ensure they fully understood the study. Once participants were satisfied, they were asked to sign an informed consent form in a preferred language (Appendix 29, 30, 31, 32, 33, 34, 35).

### *Confidentiality, Anonymity and Data Handling*

The Data Protection Act (2018), states that all confidential data should be protected and kept securely with authorised access. Therefore, all the gathered and transcribed data was kept in locked cabinets. All computers containing research data were also password protected and were accessible to members within the research. This included the data being accessed from the FLO Database (containing information regarding patient health outcomes via using the FLO). How patient data was accessed and how it would be used was explained on the consent form and permission was sought from patients, prior to data access.

Questionnaires remained anonymous, identifiers such as names were not included. Research codes were used to identify participants from the interviews and surveys, along with a master list of the participant names. Hard copies of study data were locked away in a filing cabinet, and uploaded digitally onto an encrypted computer accessed only by the research team. Furthermore, the quotes and information were used from the audio data collected from the interviews. The identity of participants was kept safe at all times so that information could not be traced back to them. In addition, patient data recorded within FLO and used in text within the thesis was anonymised and kept confidential at all times.

The study has been compliant with the Data Protection Act and the new General Data Protection Regulation (GDPR) which highlights that data should only be kept for as long as necessary. Hence, it was decided that anonymized research data will be kept for a period of three years on completion of the study, allowing time for post-peer reviewed publication of data to be challenged. All quotes used from the interviews within future publications will not be identifiable to any individual taking part within the study. However, any concerning information disclosed from the participants during interviews regarding self-harm, was to be reported to clinicians and participants to be sign-posted to the appropriate services, to prevent risk to patient safety or public protection (NMC, 2015). This disclosure was made explicit within the patient information sheet and reinforced during consent.

### **Data Analysis**

Different analysis techniques were employed to inform the qualitative and quantitative structures and manage the different approaches used to look at a phenomenon (Patton 2002). Data analysis was independently checked by the supervisor to minimise researcher bias. Triangulation, was used through cross data analysis of both the transcripts and the PAM tool, to compare and contrast data, and explore all aspects of emerging themes. This formulated a

relationship between the patient use of FLO text messages and their activation levels (interviews and PAM tool), enabling a deeper understanding of participants self-management behaviours and engagement with the mobile phone system. For example, health beliefs in relation to side-effects of taking prescribed medications, was a recurring theme explored and discussed throughout interviews. This helped explain why some patients were not adhering to their regime and reported having lower patient activation scores.

#### *Quantitative Analysis- PAM tool*

Quantitative analysis typically included descriptive and some inferential statistics; this was mainly due to obtaining a smaller sample than expected (n=40). In phase one data was coded and entered into an SPSS statistical package to perform the analysis for the quantitative element of the study. Descriptive statistics were used to scrutinise socio-demographic data, which were collated during data collection. Independent-samples t-test and one-way analysis of variance (ANOVA) analysed the association between using FLO and PAM levels; along with multiple variables influencing use or non-use of FLO (for example, age, gender, education levels, employability status, type of condition, ethnicity, religion etc). In addition, the Chi-square test was also used to determine correlations between demographics and patient activation levels. Statistical significance was set at  $p < 0.05$ .

With the PAM tool being a Likert-scale, ordinal data was collected in terms of performance of self-management behaviour, medication adherence, satisfaction with healthcare services quality of life and health outcomes. Hence, all items of the activation measure were ranked into four sequential stages listed below, and derived from the work of Hibbard et al (2005;2014), which were important in obtaining patient activation scores to help determine levels of activation.

Stage 1- Does not yet understand an active role is imperative

Stage 2- Deficit in knowledge to act on the problem

Stage 3- Starts to take action

Stage 4- Maintaining behaviour over time

#### *Qualitative Analysis- Exploring Patient Experiences of Text Messaging*

The search and identification of themes was an important element of qualitative data. Qualitative studies can either use a deductive or inductive method of analyses, this study employed an inductive approach to analyse interviews to enable themes to emerge (Maykut

and Morehouse, 1994). Qualitative interviews were digitally recorded and analysed using a thematic approach as most appropriate (Colaizzi,1978). Thematic analysis involved constantly moving backwards and forward between data to highlight similarities and differences across data sets (Braun and Clarke, 2006).

The analytical process adopted in phase two to explore the patient experiences of using text messages, delivered by the FLO system was guided by seven steps (Colaizzi,1978, p.644, Table 17):

**Table 17.** *Qualitative Thematic Stepped Approach*

<b>Analysis Step</b>	<b>Researcher Activity</b>
<i>Familiarise</i>	Thoroughly read the transcription of participant description twice to help confirm meanings grasped from the data. Supervisors read a random sample of interviews to confirm and corroborate trustworthy and credible thematic analysis following the same process.
<i>Identifying significant statements and themes</i>	Identified relevant statements, thoughts and perceptions of participants along with a transcription divided into sections relevant to the particular topic of study and concepts.
<i>Formulating meaning</i>	Meanings were identified, significant statements, words and phrases relevant to the phenomenon of study. Words of the researcher were used along with distillation to express participant's thoughts.
<i>Clustering and grouping themes</i>	Different emerging meanings created from the significant statements were compared and agreed with supervisors, and then clustered and grouped into themes.
<i>Constructing an exhaustive description</i>	Different experiences that had emerged from descriptions provided and the identification of common themes were also included through a final synthesis.
<i>Producing the fundamental structure (relevant experiences and meaning)</i>	From the data collected the researcher condensed the description of experiences to broad concepts that captured those aspects which were deemed to be essential or relevant to the structures of the study.

<i>Verification of fundamental structure</i>	Verified and asked all participants whether the broad concepts identified as the fundamental structures of the study, affected or influenced their experiences using the FLO text messaging, their activation levels and self-managing their LTC.
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Following such a systematic process of analysis enhanced rigour of findings and the quality of the research (Nowell et al, 2017). Thematic analysis enabled data to be analysed allowing themes to emerge dependent on the lived experiences, behaviour and practices in order to understand participants' perceptions and feelings. The interrogation of thematic patterns regarding social and personal meaning surrounding topics, provided a deeper understanding of the experiences of SA people with LTCs, their use of text messages to enhance healthy behaviours, alongside their health beliefs and levels of activation (Clarke and Braun, 2017).

### **Summary**

This extensive mixed methodology enabled a detailed exploration of the phenomena of SA patients living with a LTC, through the use of real-life, in-depth interviews. The study design allowed for a comparative analysis to be made between the two groups in terms of their differing views, perceptions, beliefs and experiences of using or not using the FLO text messaging system. Patient activation is a fairly recent phenomena in healthcare, the PAM tool was successfully executed for the first time amongst a SA sample, and proved to be a feasible tool that was able to assess and determine each individual's level of knowledge, skills and confidence to assume responsibility for their own health and well-being.

The study findings generated from the mixed methods research and the analytical processes were useful and helped to increase confidence in findings, for the complex evaluation of the FLO text messaging intervention. Incorporating behaviour change models such as the HBM and CS-SRM along with determinants identified in Chapter Four (demographics; attitudes; subjective norms; health beliefs and perceptions; coping behaviour; psychological impact; persuasion and motivation; and self-efficacy) provided a clear structure for interviews to be conducted, and integrated illness-related beliefs to make sense of concepts pertinent to the SA population. In addition, they explicated patient motivation and shift towards positive behavioural outcomes to managing their condition amongst users and non-users of FLO.

The data generated in this study have formulated results presented within two separate chapters (six and seven) demonstrating patient activation scores from PAM surveys, and key

themes that have emerged as a result, from the interview data; facilitating a deeper knowledge and understanding of SA patient uses and experiences of a text messaging system, and patient activation levels to self-manage their LTCs.

## Chapter Six

### Patient Activation and Text Message Use/Non-use

#### Introduction

An overarching aim of this research study was to assess whether patient activation measures provided a useful indicator of who would benefit or engage with a text messaging intervention. To achieve this, both users (including some previous users) and non-users of FLO were asked to complete the PAM. This chapter presents scores of the PAM scale that was used to measure the spectrum of skills, knowledge and confidence of each participant. From the data set collated, comparisons were made between scores of both users and non-users in relation to their level of self-management. Furthermore, a description of the demographic characteristics of the SA sample has been provided. Although, a small sample was obtained for in-depth statistical analyses to take place, variables such as age, gender, ethnicity, religion and socio-economic status were used to establish correlations between use or non-use of FLO and patient activation levels.

#### Sample Size and Characteristics for Both Study Phases

Examining previous studies, sample sizes and approaches (Shetty et al, 2011; Chen et al, 2018, Prinjha et al, 2020), it was anticipated that 40-50 participants would be a sufficient number of SA people to recruit for the study and obtain rich data. An equal spread of FLO users and non-users (including 5 previous users, 20 users, 15 non-users) had been recruited representing a range of different demographics (gender, age groups, ethnicity, religion, employment and education levels). At the same time clinic dates were reducing due to threat of COVID-19 and staff having other priorities, so a decision was taken to cease recruitment at 40 participants. Table 18, shows a summary of sample characteristics from which participants were recruited across.

Participants were asked about demographics during interviews. Demographical components such as: age, gender, employment status or socio-economic group, education levels, modality group and type of SA ethnic group, were found to reflect upon patient activation levels and experiences of adhering to their medication regime. Participants were predominantly from either Indian, Pakistani or Bengali backgrounds. None were found to be from regions including Sri-Lanka, Nepal or Afghanistan. The most popular modality groups were diabetes,

hypertension and kidney disease. Age was disclosed within the eligibility checklist, all participants were above the age of 18 years, ranging from 25-80 years.

**Table 18.** *Participant Characteristics of Users and Non-Users of FLO*

<b>Characteristics</b>	<b>Total Sample n= 40</b>	<b>User Group n= 20 (50%)</b>	<b>Non-User Group n= 20 (50%)</b>
<b>Gender</b>			
<b>Male</b>	19 (47.5%)	10 (50%)	9 (45%)
<b>Female</b>	21 (52.5%)	10 (50%)	11 (55%)
<b>Age</b>			
<b>&gt;18-40</b>	14 (35%)	11 (55%)	3 (15%)
<b>&gt;41-60</b>	13 (32.5%)	6 (30%)	7 (35%)
<b>&gt;61</b>	13 (32.5%)	3 (15%)	10 (50%)
<b>Religion/Faith</b>			
<b>Islam</b>	17 (42.5%)	8 (40%)	9 (45%)
<b>Hinduism</b>	5 (12.5%)	3 (15%)	2 (10%)
<b>Sikhism</b>	16 (40%)	7 (35%)	9 (45%)
<b>Christianity</b>	1 (2.5%)	1 (5%)	0
<b>No religion</b>	1 (2.5%)	1 (5%)	0
<b>Ethnic Group</b>			
<b>Indian</b>	23 (57.5%)	12 (60%)	11(55%)
<b>Pakistani</b>	15 (37.5%)	7 (35%)	8 (40%)
<b>Bengali</b>	2 (5%)	1 (5%)	1 (5%)
<b>Employment Status</b>			
<b>Employed</b>	24 (60%)	15 (75%)	9 (45%)
<b>Unemployed</b>	11 (27.5%)	4 (20%)	7 (35%)
<b>Retired</b>	5 (12.5%)	1 (5%)	4 (20%)
<b>Socio-economic Group</b>			
<b>Professional</b>	15 (37.5%)	10 (50%)	5 (25%)



<b>Admin/Secretarial</b>	5 (12.5%)	4 (20%)	1 (5%)
<b>Machine operatives</b>	4 (10%)	1 (5%)	3 (15%)
<b>Unemployed</b>	11 (27.5%)	4 (20%)	7 (35%)
<b>Retired</b>	5 (12.5%)	1 (5%)	4 (20%)
<b>Educational Level</b>			
<b>University level</b>	15 (37.5%)	11 (55%)	4 (20%)
<b>Secondary level- Highschool /College (GCSEs, O levels, A- levels)</b>	16 (40%)	7 (35%)	9 (45%)
<b>Primary level</b>	9 (22.5%)	2 (10%)	7 (35%)

### **Modality Groups**

All patients (n= 40) presented with LTCs such as diabetes, hypertension, CKD or ESRD and thyroid issues (hyper or hypo-thyroidism). Some were co-morbid where they had more than one LTC, 80% (n=32) of the sample presented with diabetes and hypertension combined; whilst, 52.5% (n=21) of participants had diabetes along with renal disease (CKD OR ESRD). Only 3 participants presented with thyroid issues.

### **Issues Regarding Quantitative Analysis**

A small sample resulted in difficulties to perform in-depth analyses and to appropriately assess for impact or significance. Some may argue that small sample sizes that are unequal or heterogenous lead to unambiguity, making it difficult to draw general conclusions (Ruscio and Roche, 2012). Nonetheless, the purpose of the analyses was not to draw conclusions or generalisations. The main purpose of using descriptive analysis for the PAM was to inform and enrich the qualitative analyses of the interviews. After seeking appropriate advice, certain inferential statistics were permitted to assist with the quantitative analyses. As categorical data was analysed, the ANOVA was deemed acceptable due to its familiarity, simplicity and robustness to withstand violations of key parametric assumptions, specifically with regards to analysing uneven or heterogenous sample characteristics as in this study (Stiger et al, 1996). According to the criteria a statistical test (F-test) is considered robust if Type 1 error rate is between 0.25 and 0.75 to achieve an alpha level of  $p = <0.05$  (Blanca et al, 2018). This is shown in Table 19, as some demographical characteristics appeared to correlate with use of

text messages. In addition to reducing type 1 error, the Bivariate Mahalanobis distance, was used to detect outliers between categorical variables to further assess for associations, which has been discussed below in more detail.

### **Demographics and Using FLO**

Experiences of users and non-users of FLO varied dependent on demographical factors. Therefore, ANOVA were performed to determine whether differences ( $p < 0.05$ ) existed between patients with respect to key variables such as: age, gender, ethnicity, religion, educational qualifications or levels, employment status, socio-economic status and the use of text-messaging (or use of mobile phones) to self-manage LTCs.

There was statistical significance found between system use (using or not using the FLO system) and variables such as age ( $p = 0.01$ ), education levels ( $p = 0.001$ ) and socio-economic group ( $p = 0.03$ ). Previous studies using larger samples also identify mobile phone use to be linked with both age, education and socio-economic status (Xiao et al, 2014; Müller et al, 2016). Age was seen to be a key determinant influencing behaviour change and acceptance of mobile phone usages. Younger participants between ages of 25 to 65 years were better adopters to the FLO system compared to older participants. This was due to being more up to date with modern technology and older individuals not owning or often using a mobile phone. Although, there was a retired participant ( $n = 1$ ) who used the FLO system. They demonstrated an understanding of the benefits provided, and were satisfied with the support offered to self-manage LTCs. Such participants appeared to be more activated, having a previous background of working within healthcare sectors.

From the study sample obtained differences were existent between education and literacy levels, which reflected on patient experiences of self-managing their LTCs, and the ability to use the FLO system. All users of the system had some level of education and were able to read messages and communicate their needs. Education appeared to be a major contributor to being able to self-manage, but was shown to vary considerably within the SA sub-groups (Bhopal et al, 2011; Choudhry et al, 2016). Ethnicity did not influence FLO use (User SD = 1.55, Non-user SD = 1.80,  $p = 0.17$ ), however, Indian participants generally had better education and higher activation levels than Pakistani and Bengali participants.

Cultural norms, such as gender and familial roles were also significant in self-management and health outcomes (Lucas et al, 2013; Kumar et al, 2018). However, there was no statistical significance noted in the mean difference between characteristics such as gender in terms of

users and non-users (User SD=1.40, Non-user SD=1.50,  $p=0.12$ ) (Table 19). On the other hand, employment status was significant in mobile phone use ( $p=0.00$ ). Most users were employed with a professional background, and were adherent to the text messages sent, compared to those who were machine operative or had secretarial roles with fewer users. Employability varied between genders. Majority of SA men were employed compared to SA women due to cultural gender roles that both play within the household (DeSouza et al, 2014). Older SA females were less likely to be employed compared to younger women, but were often dependent on the extended family to assist with medications, as a result of less confidence and understanding of taking medications independently. This was a recurring theme noted in other studies also, where family was often involved in self-management of older SA participants (Patel et al, 2012; Macaden and Clarke, 2015). In most cases, they were unable to read medication labels printed in the English language. Such subjects displayed lower activation levels.

Health beliefs and religion were prominent variables that were noted whilst conversing with participants regarding their LTC, self-management and using FLO. Though, literature has cited religion and fatalistic beliefs to be significant in managing illnesses, no statistical significance was detected between religion and using FLO or mobile phone devices ( $p=0.89$ ).

**Table 19.** Association Between Demographic Characteristics and Use or Non-use of FLO

Characteristics	Characteristics Associated with Use of Non-use of Flo	Mean scores (SD) FLO Users (n=20)	Mean scores (SD) FLO Non-users (n=20)	Mean scores (SD) Total Sample (n=40)	df (total sample)	F (Fisher's) value (total sample)	Statistical significance (P value)
Age	Use and Non-use of younger participants compared to older participants  >18-40 n=14 >40-60 n=13 >60 n=13	45.60 (15.80)	57.80 (13.20)	51.70 (15.67)	39	7.0	0.01*
Gender	Use and Non-use in males and females  Males n=19 Females n=21	1.65 (0.49)	1.40 (0.50)	1.50 (0.51)	39	2.54	0.12
Ethnicity	Use and Non-use in sub-ethnic groups (Indian,	1.55 (0.51)	1.80 (0.62)	1.50 (0.51)	39	1.96	0.17

	Pakistani and Bengali samples)  Indian n=23 Pakistani n=15 Bengali n=2						
Education level-	Use and Non-use in university or high school graduate compared to those not graduated  University graduate n= 15 Highschool/O levels n= 16 Primary level (no graduation) n=9	1.15 (0.37)	1.65 (0.49)	1.93 (0.83)	39	13.40	0.001**
Employment status	Use and non-use in those employed and those unemployed or retired  Employed n= 24	1.40 (0.50)	1.60 (0.50)	1.50 (0.51)	39	1.58	0.00**

	Non-employed n= 11 Retired n= 5						
Socio-economic status	Use and Non-use in those dependent on profession, education levels, finances compared to those who are unemployed and dependent  Professional n= 15 Admin/secretarial n= 5 Machine operative n= 4 Retired n=5 Unemployed n=11	2.85 (1.90)	3.20 (1.47)	3.03 (1.69)	39	0.42	0.03*
Religion	Use and non-use amongst those who are religious compared to those non-religious	2.15 (1.23)	2.10 (0.97)	2.13 (1.10)	39	0.20	0.89

	Islam n= 17 Hinduism n= 5 Sikhism n= 16 Christianity n= 1 No religion n= 1						
--	--	--	--	--	--	--	--

Notes:

SD=standard deviation

df= degree of freedom

\*  $p < 0.05$ , \*\*  $p < 0.01$ .

In addition, an analysis was also conducted between these characteristics with PAM scores to determine whether patient activation levels varied across different demographical components. A demographics capture sheet and PAM scores of each participant has been presented in Table 20, Appendix 36.

### **Administration of the PAM**

The first phase of the study involved the quantitative PAM survey that was distributed amongst SA participants. The PAM has been robustly used across the USA and other European countries. However, in order to use this tool within this study based in the UK, it was essential to request a license from Insignia health, which was obtained through NHS England.

All questionnaires were completed face-to-face with the participants in the clinics attended by the researcher, prior to the interviews. An advantage of this was that it was clarified that individual understood what each item of the instrument meant, how they should be answered or elaborated upon if needed.

In total, forty surveys were undertaken, in most cases the researcher assisted with the completion of the tool by reading out the items. Although, there were some participants who preferred to complete the surveys themselves. Having the researcher present during completion of the instrument was also an advantage, as it was ensured that no items were missed.

Surveys were also translated for those who could not read English, in a language of their choice to avoid language barriers. The original version of the PAM is available within Appendix 9, and the translated versions in Appendices 10, 11, 12, 13, 14, 15.

### **Translation and Adaption**

Validity of translated versions of the PAM surveys was achieved by translation (forward and backwards translating). It was vital to ensure the congruency between words and sentences, along with their true meaning in the particular languages in which the tool was translated in (Kalfoss, 2019). The instrument was translated by SA translators from English to a SA language (Urdu, Gujarati, Hindi, Bengali, Punjabi and Tamil), and back translated to English, by the researcher with assistance. The translated versions were pilot tested for face validity by SA interpreters known by the researcher, who had good command of both languages. This included three family members who could speak and understand Urdu, Hindi and Punjabi; along with four friends who could communicate in Bengali, Gujrati and Tamil. Urdu



questionnaires were read twice and translated by Pakistani relatives (n=3), who had suggested amendments to certain sentences. Hindi, Bengali, Gujrati and Tamil were read once, requiring no corrections according to the interpreters (one Bengali and three Indian friends) who offered translation support. The back translated version was compared with the original version of the scale, increasing validity, reliability and efficiency to aid in data collecting (Tsang et al, 2017). Initially questionnaires translated in Gujrati and Tamil were not needed as participants speaking those languages were not recruited. From the study sample, only five participants utilised translated versions including one in Urdu, one in Bengali, one in Hindi and two in Punjabi. Majority of individuals preferred their family member (if present) or the researcher to read out the questionnaire in English and then translate it to them in their native language. Ultimately the translated PAM versions were administered successfully amongst a SA study sample for the first time.

### **Items of the PAM Tool**

Hibbard et al (2005), proposed the 13-item PAM scale to enhance the feasibility of assessing and measuring activation in clinical settings. It included questions based around the four key patient activation themes (Appendix 9): 1- level of engagement; 2- level of awareness; 3- level of action; 4- level of maintenance of health behaviours. Some patients were asked to verbally elaborate these during interviews, examples of quotes are shown in Table 21. Pseudonyms have been used to distinguish between users as ‘U’ and non-users as ‘NU’.

The PAM was valuable in assessing SA patients’ ability to self-manage their condition at any given time. It identified what is needed to increase their level of knowledge, skills and confidence; and how interventions such as FLO can be tailored to individual needs, to increase the likelihood of SAs adopting behaviours contributing to better health.

SAs with high levels of activation understood their role in their self-management process and felt capable of fulfilling that role. These individuals were more likely to engage in positive health behaviours and able to manage their LTC more effectively. Conversely, SAs with low activation levels were less likely to play an active role in maintaining good health. These participants displayed poor health outcomes, were less likely to seek help from healthcare providers when needed or follow health advice that was given. Their lack of confidence and experiences of poorly self-managing their LTC, meant that they preferred not to think about it.

**Table 21.** *Patient Activation Characteristics by Level (Adapted by Insignia Health PAM Practice Manual, p.9)*

<b>Level 1</b>	<b>Level 2</b>	<b>Level 3</b>	<b>Level 4</b>
<i>Disengaged and overwhelmed</i>	<i>Becoming aware, but still struggling</i>	<i>Taking action</i>	<i>Maintaining behaviours and pushing further</i>
Individuals are passive and lack confidence. Display low levels of knowledge, weak goal-orientation and poor adherence.	Individuals have some knowledge, but large gaps remain. They believe their health outcome is largely unmanageable, but are able to set simple goals.	Individuals have key information/facts and are developing self-management skills. They are goal orientated strive for best practice behaviours.	Individuals have altered bad habits and adopted new behaviours, but may struggle in times of stress or change. Maintaining a healthy lifestyle
<i>“My doctor is normally the one in-charge of my health, so I don’t really need to do anything unless I am told to by him.” (NU 1)</i>	<i>“I could be doing more, but I am really struggling with my medication regime and maintaining a healthy lifestyle. I have decided to arrange an appointment with the nurse for more information on how I can improve my health.” (NU 2)</i>	<i>“The health care team play a big role in my health, without them I would not be able to manage my current health independently, without their support. I now know the consequences of poor adherence.” (U1)</i>	<i>“I am fully independent and responsible for maintaining good health, minimising my symptoms and taking my medications on time.” (U2)</i>



Increasing level of activation

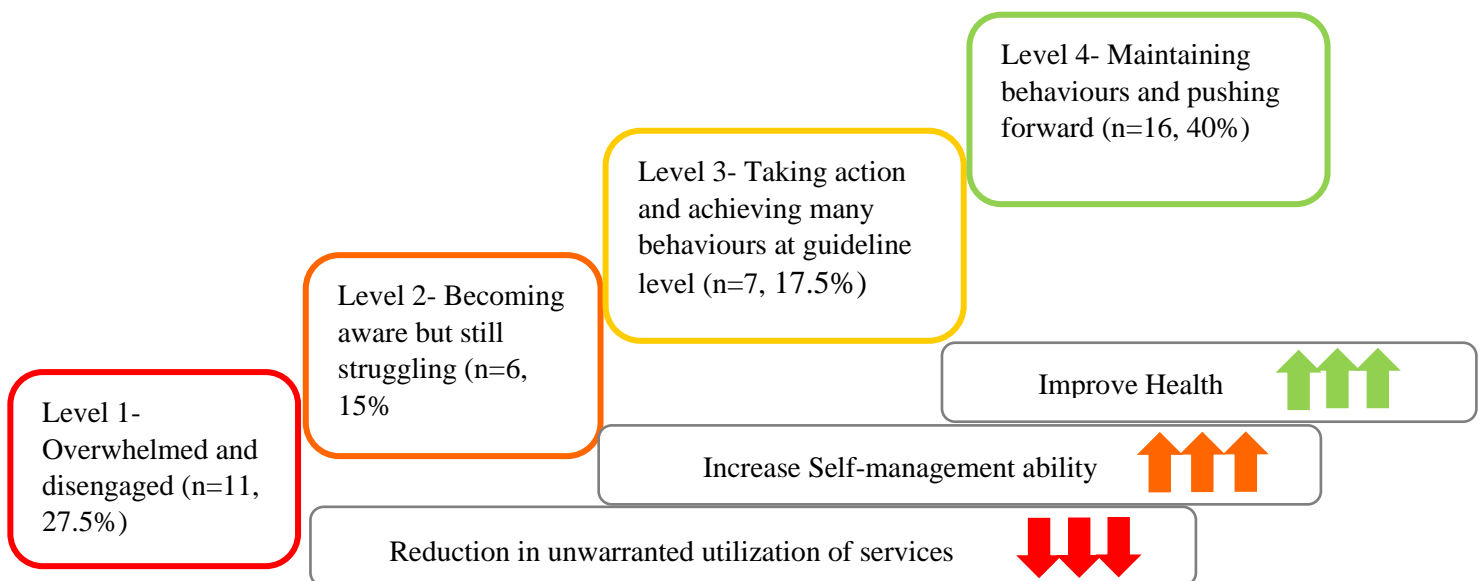
Patient activation levels ranged from 1-4, which have been mentioned in Chapter Five, levels 1 (Disengaged and Overwhelmed) and level 2 (Becoming aware but still struggling) are a result of low scores of activations; whereas, level 3 (Take action) and level 4 (Maintaining behaviours and pushing further) are obtained due to higher activation scores. Table 20, shows the distinct PAM levels, the expected behaviour within each level and examples of patient quotes whilst completing PAM surveys during the interviews.

The 4 four levels of activation assisted with the analyses of the PAM instrument; each stage has a cut-off point which has empirically been derived from the work of Hibbard et al (2005; 2014). Table 22, presents each activation level with a specific score range, whilst Diagram 9 represents the patient activation categories of the full study sample, and the number of participants categorised in each level.

**Table 22.** Patient Activation Levels and Cut-off Scores for Self-management (Adapted from Tabrizi et al, 2010, p.71)

Activation Level of Self-Management	One	≤47.0
	Two	47.1 to 55.2
	Three	55.2 to 67.0
	Four	≥ 67.1

**Diagram 9.** Patient Activation Levels of SA ample (Adapted from Hibbard et al, 2012 p.374)



## **Findings**

### **Obtaining PAM Scores**

For analyses of the PAM instrument to take place it was important to attain PAM scores. Assistance and advice were sought from Hibbard and Insignia regarding the scoring of the tool. Patient responses were converted into PAM scores and then stratified into one of four levels; scores are calibrated based on a scale of 0-100. To obtain activation scores, patients were required to rate the degree to which they agree or disagree to a statement. These answers were combined to provide a total score between 0 and 100, representing the individuals' concept of themselves being the active manager of their health care (Hibbard and Gilbert, 2014). Prior to obtaining scores, permission and a password was needed to access a password-protected software designed by Insignia, which automatically calculated PAM scores using a unique formula. To gain a password NHS England directed the researcher (myself), to the study site who then provided access.

Due to the exploratory nature of the study, there was only one PAM measurement taken as the tool was administered only once amongst those who were already using or not using FLO. Thus, it is unknown whether text messages activated individuals more or whether participants were engaging with messages due to having higher activation levels in the first place. Perhaps, further research could be considered using a pre and post interventional study design to assess activation levels more effectively and determine whether text messages activate participants or not.

### **Floor and Ceiling Effect**

The occurrences of a floor effect take place when study subjects score the lowest or near the bottom on a questionnaire; whereas, the ceiling effects occurs during the opposite, when subjects score the highest possible score range (McCabe et al, 2018). Floor and ceiling effects were considered to exist if more than 15% of patients achieved the lowest or highest possible scores. Scores ranged from 0-100. No individual scored 0, which was the lowest possible score. However, out of the 40 participants only two patients scored the highest score possible, which was 100. From the scores obtained, 27.5% (n=11) were placed into the lowest level (level 1), whilst, 40% (n=16) were allocated to the highest level (level 4) (see Table 22). The floor or ceiling effect was not present across scores; however, it could affect the reliability as participants scoring lowest or highest possible scores were not differentiated from one another (Terwee, 2007; Lim et al, 2015). Therefore, appropriate tests were used to analyse the study data to perceive statistical data (Fagerland et al, 2012).

### **Detecting Outliers**

The data presented a normal distribution, thus, to reduce outliers which may lead to a type 1 error, a parametric test was most suitable compared to non-parametric tests that depend mainly on occurrence, rather than observation and extremity of variables (Zimmerman, 1994).

The aim of the statistical process was to inform the qualitative data by understanding the relationship between PAM scores of users and non-users of FLO, and whether experiences of self-management and activation varied between the two groups. Therefore, careful attention was given to associations between the PAM and using FLO. Bivariate Mahalanobis distance for variable pairs, was used to assess whether any outliers existed, with p value recommended at 0.01 or less to allow for the relationship to become significant once outliers were removed (Tabachnick and Fidell, 2007). Consequently, no outliers were found, as significance was detected at  $p=0.00$ .

### **Association between using FLO and PAM Levels**

From the interviews it was evident that the FLO text-messaging system enhanced behaviours, which resulted in patients making healthier lifestyle choices and appropriately self-managing their LTC. An analysis of the quantitative phase was conducted to identify if there was a potential link between behaviour change and self-management readiness, rather than implying causality between the variables. At first a non-parametric test, Kruskal Wallis H test was considered as the sample was heterogenous; however, due to the sample size being small and equally distributed ( $n=20$  users,  $n=20$ ) the ANOVA was deemed most appropriate and robust to demonstrate a correlation between using FLO text messages across PAM scores and levels. Test results showed statistical significance between the two variables ( $df=39$ ,  $SD=0.51$ ,  $F=52.39$ ,  $p=0.00$ )

### **Responses to Items, Patient Activation Scores and Levels of Users and Non-users**

In terms of activation levels, users scored higher on the PAM than those not utilising text messages. They expressed an increase in confidence, skills and ability to independently manage their illness, and felt text messages were very useful and beneficial for appointment reminders, taking medications, positive lifestyle changes and measuring important parameters (for example, blood sugars and blood pressure). In comparison, previous users and non-users ( $n=12$ , 30%) disagreed on certain items based on their understanding of their health problems and their confidence to consult a healthcare professional when required.

Majority of non-users were either categorised in level 1 (disengaged and overwhelmed stage) or level 2 (becoming aware but still struggling). Of those, 35% not using the system were activated at level 1 with their self-management, leaving only two non-users (10%) who were at level 4. In comparison, most users (n=19), appeared to be taking action and maintaining healthy behaviours, 80% (n=16) of this group were at level 4 with their self-management regime. Patients that were at level 1 or 2, struggled to understand their regimen and how best to manage their LTC independently. Over half of participants (55%, n=22) desired more information regarding their condition to be able to self-manage independently, without being reliant on family and relatives. Many participants 36 (n=90%) stated information tailored to their needs (for example, a time they preferred to see doctors and translated text messages to be prompted) can help facilitate a better understanding of their treatment regime and create a greater sense of involvement (discussed in Chapter Seven).

Below items of the survey along with participant responses are presented in Table 23; whilst, Figures 1 and 2 display the comparisons between users and non-users to show how both groups differentiate with one another in terms of activation levels and scores.

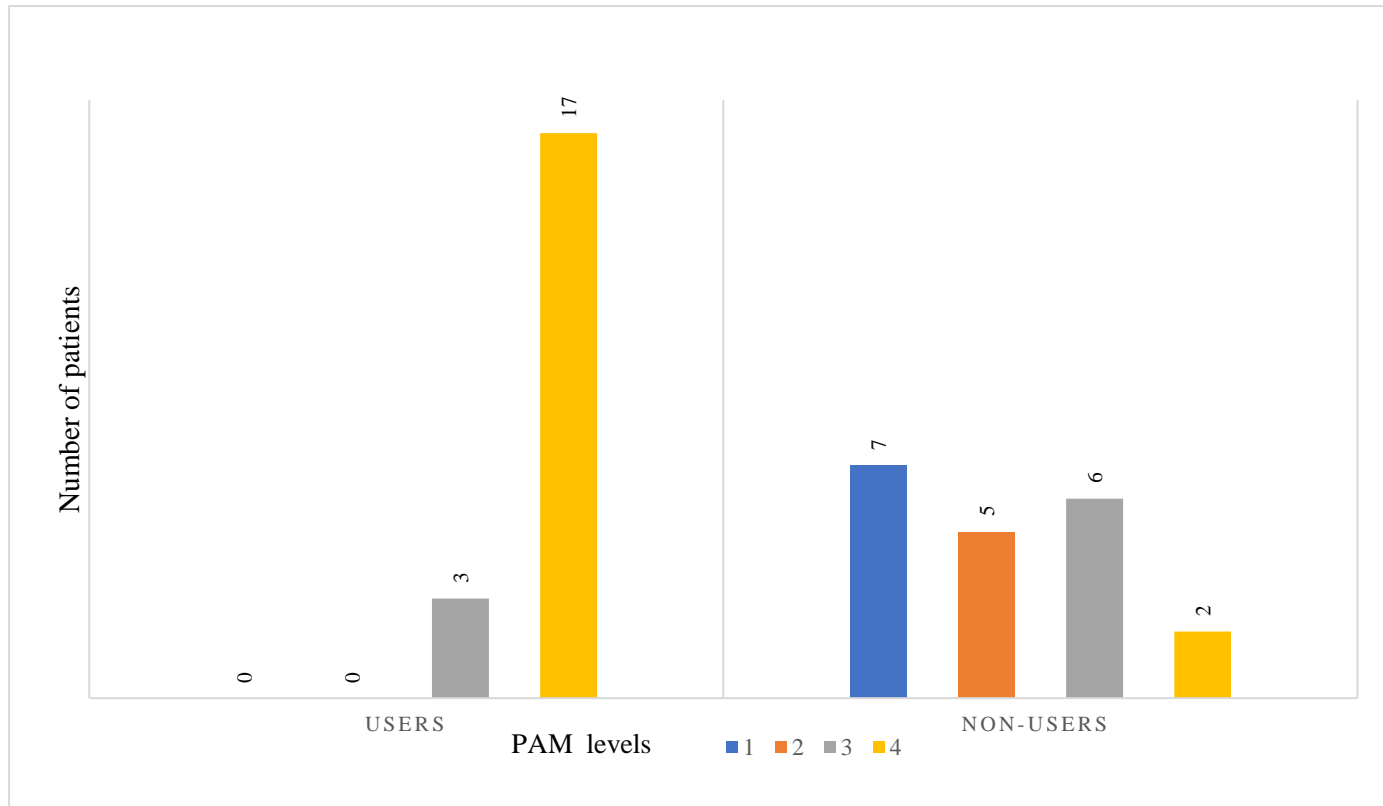
**Table 23. PAM Survey Items and Patient Responses**

Item	User and non-User	Level of Dis/Agreeability				
		Agree Strongly	Agree	Disagree Strongly	Disagree	Not applicable
1. When all is said and done, I am the person who is responsible for taking care of my health	User	20 (100%)	0	0	0	-
	Non-User	5 (25%)	10 (50%)	0	5 (25%)	-
2. Taking an active role in my own health care which is the most important thing that affects my health	User	15 (75%)	5 (25%)	0	0	-
	Non-User	8 (40%)	9 (45%)	0	3 (15%)	-
3. I am confident I can help prevent or reduce problems associated with my health	User	12 (60%)	7 (35%)	0	1 (5%)	-
	Non-User	6 (30%)	8 (40%)	6 (30%)	0	-
4. I know what each of my prescribed medications do	User	16 (80%)	4 (20%)	0	0	-
	Non-User	5 (25%)	8 (40%)	0	7 (35%)	-
5. I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself	User	10 (50%)	8 (40%)	0	2 (10%)	-
	Non-User	3 (15%)	7 (35%)	0	10 (50%)	-
6. I am confident that I can tell a doctor my concerns I have even when he or she does not ask	User	17 (85%)	2 (10%)	0	1 (5%)	-
	Non-User	6 (30%)	5 (25%)	0	9 (45%)	-
	User	12 (60%)	8 (40%)	0	0	-

7. I am confident that I can follow through on medical treatments I may need to do at home	Non-User	0	7 (35%)	11 (55%)	2 (10%)	-
8. I understand my health problems and what causes them	User	14 (70%)	6 (30%)	0	0	-
	Non-User	0	8 (40%)	0	12 (60%)	-
9. I know what treatments are available for my health problems	User	9 (45%)	11 (55%)	0	0	-
	Non-User	4 (20%)	9 (45%)	0	7 (35%)	-
10. I have been able to maintain (keep up with) lifestyle changes, like eating right or exercising	User	12 (60%)	8 (40%)	0	0	-
	Non-User	4 (20%)	8 (40%)	5 (25%)	3 (15%)	-
11. I know how to prevent problems with my health	User	6 (30%)	14 (70%)	0	0	-
	Non-User	0	10 (50%)	4 (20%)	6 (30%)	-
12. I am confident I can figure out solutions when new problems arise with my health	User	8 (40%)	11 (55%)	0	1 (5%)	-
	Non-User	0	6 (30%)	8 (40%)	6 (30%)	-
13. I am confident that I can maintain lifestyle changes, like eating right and exercising, even during times of stress	User	8 (40%)	12 (60%)	0	0	-
	Non-User	0	9 (45%)	0	11 (55%)	-



**Figure 1.** *Patient Activation Levels of Users and Non-users*



**Figure 2.** Comparing Patient Activation Scores of Users and Non-users

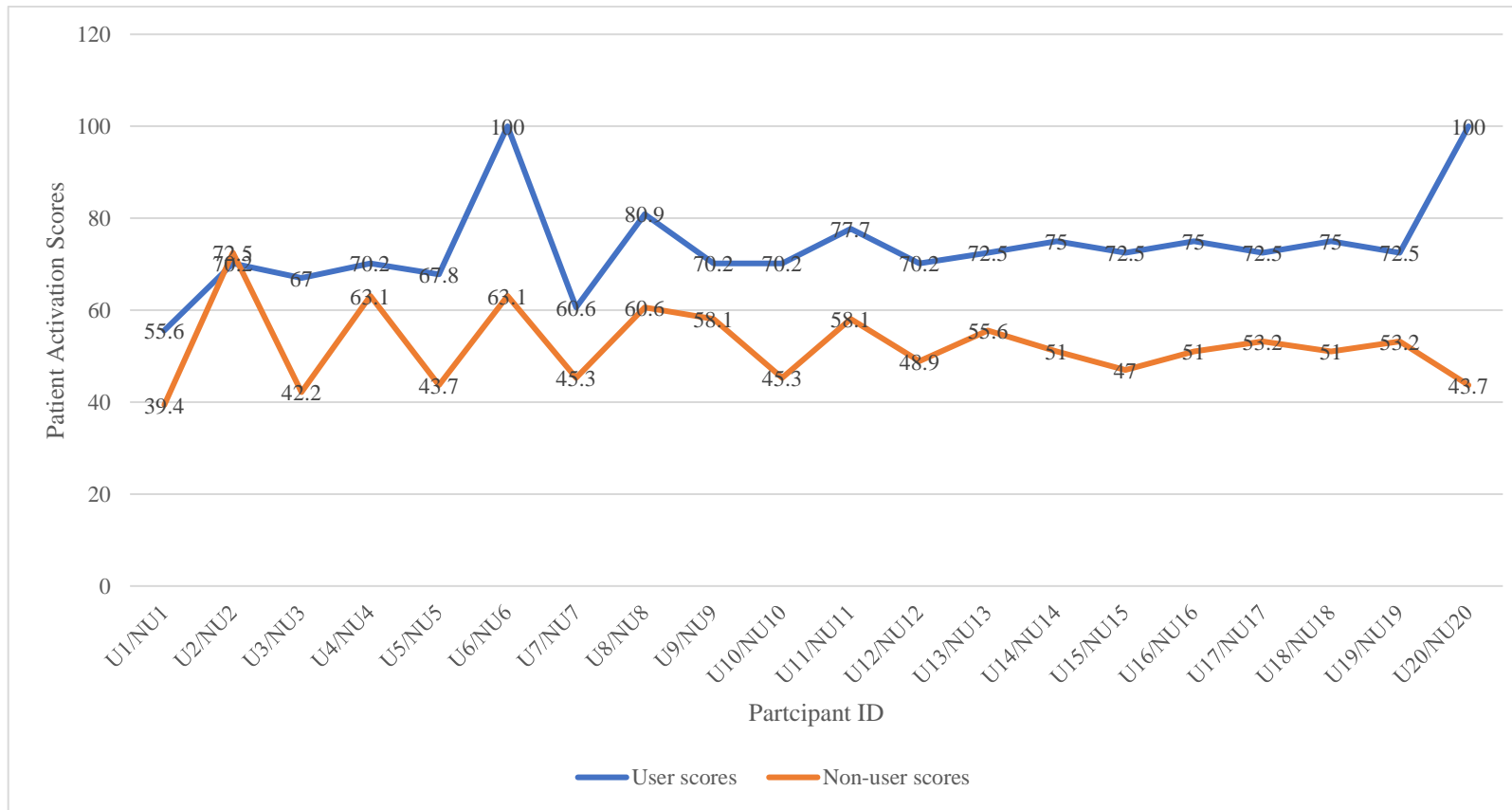


Figure 1 shows the number of users and non-users allocated to each activation level, whereas, Figure 2 presents a trend of activation scores achieved by each participant from both groups. Both figures show majority of users to be at level 3 or 4, with higher scores, whilst, non-users show the opposite by being in lower activation levels with lower scores.

### Demographics and Patient Activation Levels

Demographics appeared to reflect upon activation levels as it did on being a user or non-user of FLO. Thus, a demographical analysis was performed using the Chi-square test to assess for correlations and associations between the same variables (age, gender, religion, ethnicity, educational qualifications, employment and socio-economic status) and activation levels. Phi and Cramer's V was applied to get an effect size ( $p > 0.05$ ) showing the strength of association between variables of the small sample. Table 24, summarises the p values with respect to the variables listed below.

**Table 24.** *Chi-square and P-values for Sub-Group Characteristics*

Characteristics	Total Sample n= 40	Chi-Square	p-value
<b>Gender</b>			
Male	19	4.03	0.26
Female	21		
<b>Age</b>			
>18-40	14	98.33	0.000**
>40-60	13		
>60	13		
<b>Religion/Faith</b>			
Islam	17	59.00	0.93
Hinduism	5		
Sikhism	16		
Christianity	1		
No religion	1		
<b>Ethnic Group</b>			

<b>Indian</b>	23	56.36	0.03*
<b>Pakistani</b>	15		
<b>Bengali</b>	2		
<b>Employment Status</b>			
<b>Employed</b>	24	9.38	0.03*
<b>Unemployed</b>	11		
<b>Retired</b>	5		
<b>Socio-economic Group</b>			
<b>Professional</b>	15	32.70	0.001**
<b>Admin/Secretarial</b>	5		
<b>Machine operatives</b>	4		
<b>Unemployed</b>	11		
<b>Retired</b>	5		
<b>University level</b>	15	34.12	0.00**
<b>Highschool (GCSE or O level)</b>	16		
<b>Primary level</b>	9		

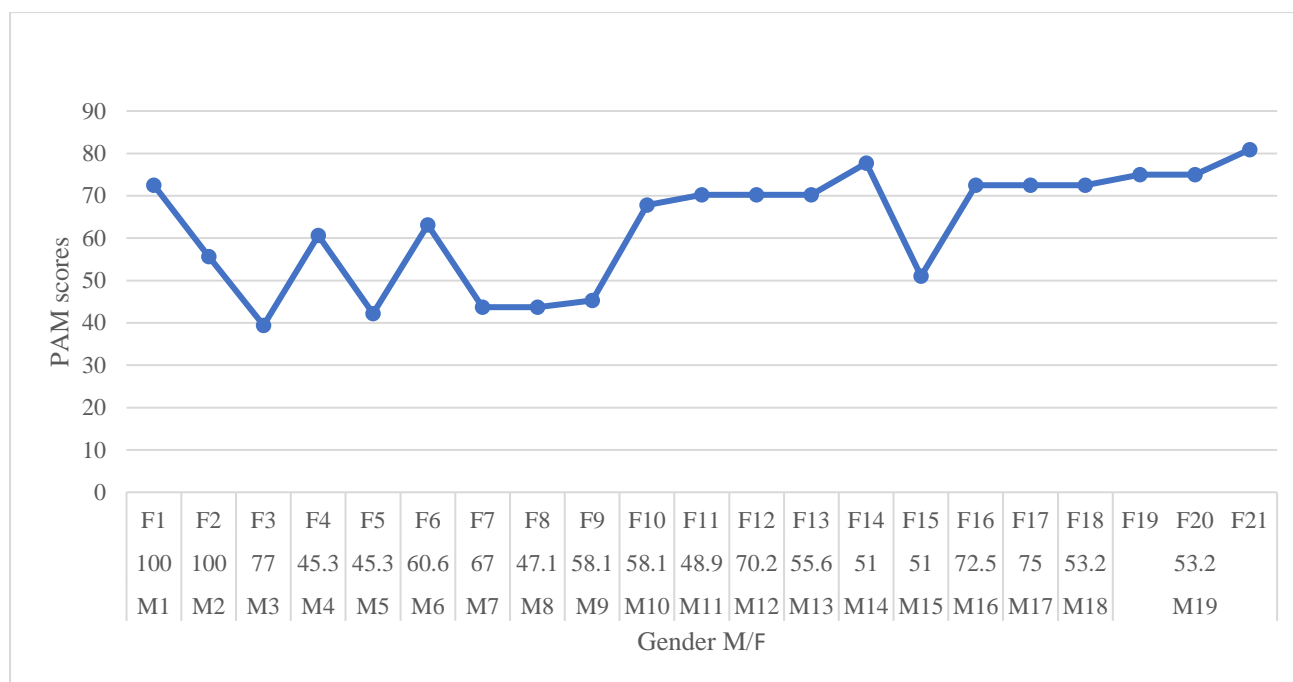
\*  $p < 0.05$ , \*\*  $p < 0.01$ .

### Gender

The PAM was distributed across an even spread of males ( $n=19$ , 47.5%) and females ( $n= 21$ , 52.5%), due to the assumption from previous literature which suggested women to be more actively involved and engaged in their self-management regime compared to men (DeSouza et al, 2014; Ahmed et al, 2018). Consequently, there were no differences noted between men and women or their activation levels ( $p= 0.259$ ). Although, no significant differences between genders were detected, findings from the female sample do align with those from DeSouza et al (2014). More women ( $n=12$ ) than men ( $n=9$ ) were activated at level 4; which meant 30% of females scored above 67.1, compared to 22.5% of men. However, there also appeared to be a greater number of females at level 1 compared to male subjects ( $n=3$ ). This reinforced that activation levels and scores were not associated with gender difference. Differences in patient activation scores between males and females are presented below in Figure 3, for

comparisons to show how the trend of both genders differentiate with one another in terms of activation scores and levels.

**Figure 3.** Patient Activation Scores of Males and Females

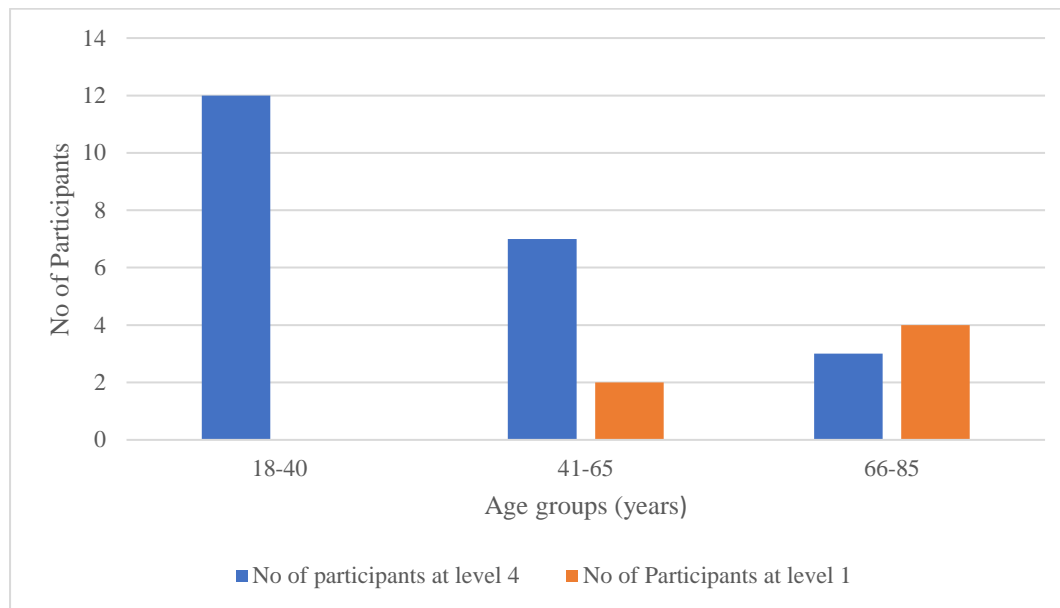


### Age

There were some notable significant differences ( $p=0.00$ ) between age groups and activation levels. This suggests an association between age, activation scores and levels. Younger patients (25-65 years) appeared to have a higher activation level than older subjects, with a greater awareness and understanding of their condition. This could be because of having increased education levels. Previous evidence supports this as similar findings reported younger subjects to be better engaged with their health, self-management and mobile phone use due to awareness and higher digital literacy skills (Shetty et al, 2011; Endebu et al, 2019; Prinjha et al, 2020). The Office for National Statistics (ONS, 2020) show that 100% of 16-24-year-olds have internet access via a smartphone, which can be useful when researching information regarding their condition, compared to only 40% of those aged 65 years and over. Older subjects (<65 years) were found to have lower activation levels, limited phone use and struggled to keep up with their treatment regime. It was important to note that majority of these older participants (25%) were from the first generation compared to younger patients between ages of 25-65 years (70%), from either second or third generation. Future research to study activation levels across different generations, in SA ethnic minority

groups, requires larger sample groups to increase reliability of differences in self-management behaviours. Figure 4 displays the differences across age groups and activation levels, including majority of younger individuals between ages 18-40 years (n=12, 30%) to be activated at level 4. No individuals from this age range were found to be activated at level 1, compared to those between ages 66-85 years (n=4, 10 %).

**Figure 4.** *Patient Activation Levels Across Different Age Groups*



### **Education Levels, Employment and Socioeconomic Status**

Demographics such as education levels, employment and socioeconomic status were noted at the start of the interviews (refer to interview guide Appendix 16 and 17). Patient activation levels were also compared against education levels and occupation. Employment status and activation were found to have a significant relationship ( $p=0.03$ ), suggesting that whether an individual was employed or not had relevance to their self-management and activation level. Similarly, socioeconomic status was also found to be significantly correlated with activation scores and levels ( $p=0.001$ ), alongside education levels ( $p=0.01$ ); 60% ( $n=23$ ) of the sample reported to have some level of schooling and were activated at either level 3 or 4. Education contributed to an individual's ability to self-manage independently with adequate knowledge, skills and confidence. Most subjects that were educated up to university level were likely to be employed with higher activation levels (Figure 5) and those with low levels of education, and unemployed with lower activation levels (42.5%). Individuals with low education and literacy skills were categorised in levels 1 or 2, unable to communicate with health care

providers regarding problems that affected their health, and their inability to understand, follow their treatment regime, and potentially their ability to engage with technology.

**Figure 5.** *Level of Education and Impact on Patient Activation Levels*

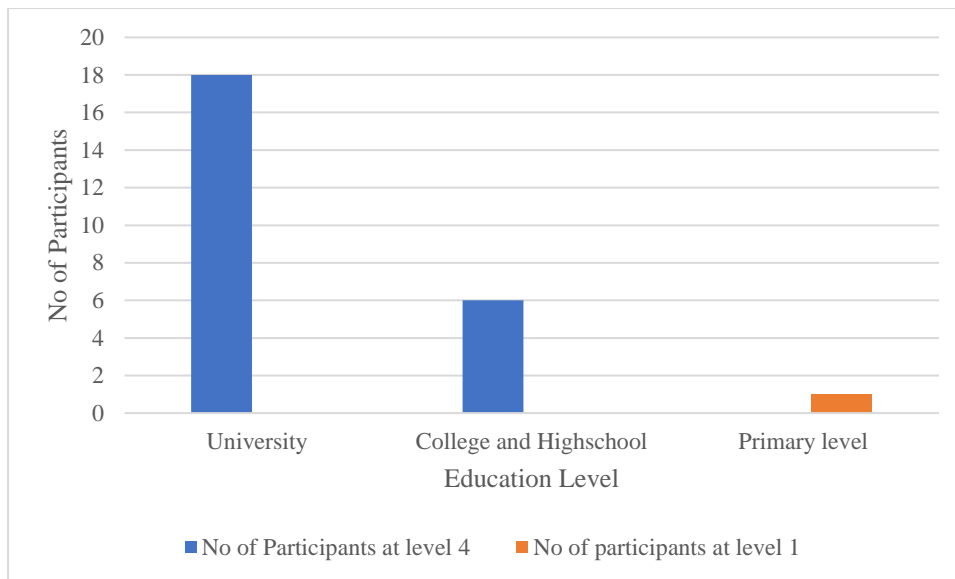
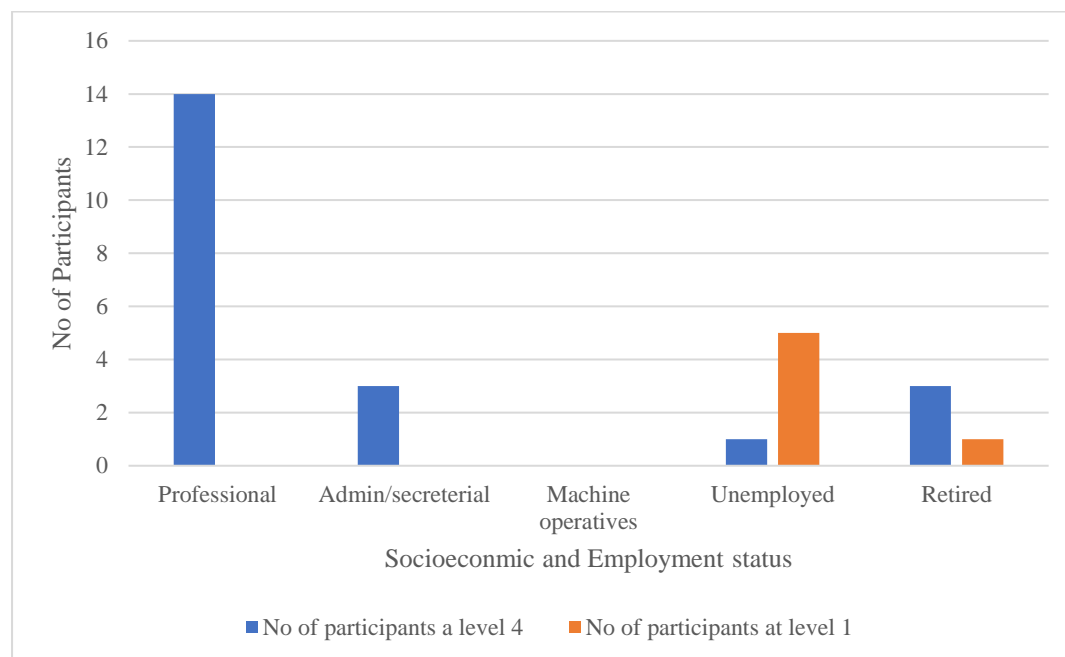


Figure 6 depicts activation levels associated with socioeconomic and employment status. Majority of those with a professional background were activated at level 4 (n=14, 35%), this includes some participants that were retired (n=3, 7.5%). No participants that were unemployed or machine operatives were found to be at level 4, most unemployed individuals were at level 1. This could be due to having lower education levels, as those activated at level 4 had higher levels of education (as shown in Figure 5) and a professional background.

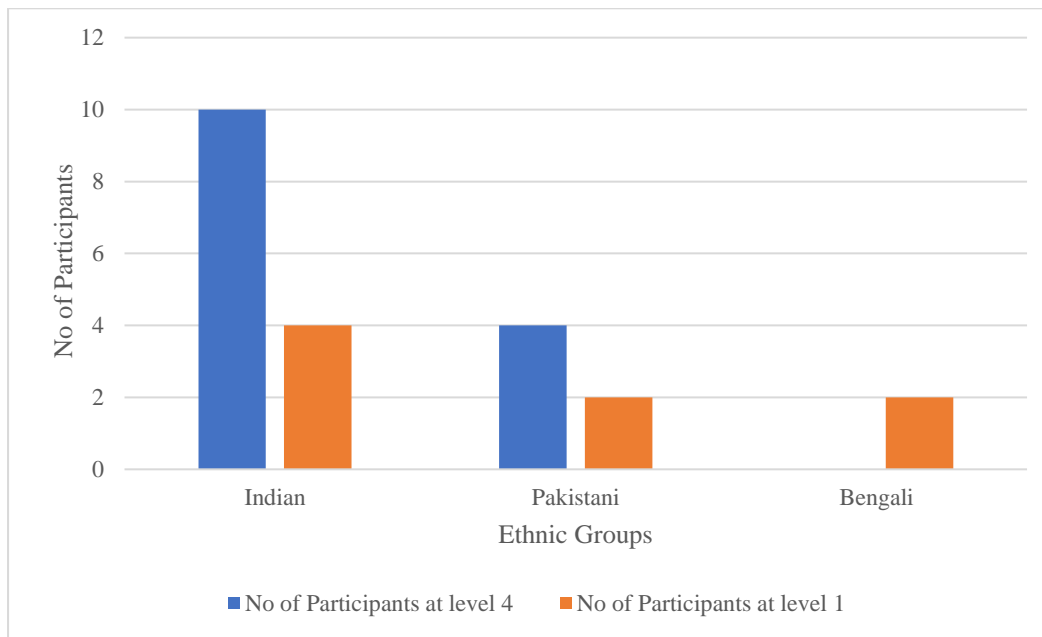
**Figure 6.** Comparison Across Socioeconomic Groups, Employment Status and Patient Activation Levels



### Ethnicity and Religion

Findings were gathered from SA subgroups in regards to ethnicity (Pakistani, Indian and Bengali) and religion. Ethnicity was found to be significantly associated with activation levels at  $p=0.03$ , which advocated those differences in health outcomes and activation levels existent amongst SA sub-ethnic groups. The study sample comprised of 23 Indian, 15 Pakistani and two Bengali participants. Education appeared to be a determinant influencing self-management and activation levels (shown in Figure 5) across the different ethnic sub-groups. In general, Indian participants had better health outcomes and activation scores, in contrast to Bengali and Pakistani participants. Fifteen Indians (37.5% of sample) were activated at level 3 or 4, whilst, 22.5% ( $n=9$ ) of Pakistani patients in comparison. The remaining six Pakistani participants scored between 47 and 55, hence, were grouped at activation level 1 or 2. Bengali individuals appeared to have the lowest activation levels compared to other ethnic groups as both subjects scored low and were also put into either level 1 or 2 regarding their self-management. These patients stressed the complexities of their regime, being on multiple medications they had limited knowledge about, and little confidence to consult health issues with their healthcare providers (see chapter 7). Figure 7 shows a breakdown of individuals from the different sub-ethnic groups at level 4 and those at level 1.



**Figure 7.** *Patient Activation Levels in Ethnic Groups*

The differences in groups were associated with education levels, where Indian people were found to acquire higher education compared to both Pakistani and Bengali groups. Other studies support these findings, that education levels differ considerably between the three groups, with Indians being more educationally qualified and having better health outcomes over all (Patel et al, 2015; Bhurji et al, 2016). Therefore, this contributed to majority of the FLO users being Indian than any other ethnic group. They reported making positive lifestyle changes by engaging with text messages, improving their diet and increasing physical activity; whereas, Pakistani and Bengali groups had less motivation and knowledge to make these changes.

The notion of religion was found to be significant for most SA participants (n=39, 97.5%), who expressed the importance of faith in God to help cope and manage their illness, within the interviews (discussed in Chapter 7). However, there was no statistical significance in this study found between religion, activation levels or scores (p=0.93).

### Summary

Given that the fundamental study focus was on use of text messages to enhance positive behavioural outcomes. It was necessary to explore and examine the self-management levels, or levels of activation of SA patients living with a LTC. This was achieved using the PAM tool, adding to the reliability and validity of its use and the existing evidence base.

SA participants were found to have a varied spectrum of confidence, knowledge and skills to be able to independently self-manage their LTC. Multiple demographical characteristics and influencing variables were found to reflect on patient activation and self-management. Main findings from phase 1 of the study, have been summarised in Box 6. Although, the study instrument (PAM) was distributed across a small sample of patients, it was a feasible tool to assess activation scores and levels across SAs, and can be recommended across larger ethnic minority groups. Chapter Seven presents the findings from the qualitative phase (phase two), which will elucidate patient experiences of using the FLO text messaging system and self-management behaviours.

**Box 6.** *Key Findings from Phase 1 (Whole Sample)*

- The ANOVA demonstrated statistical significance between use of FLO text messages and patient activation levels ( $p < 0.05$ ).
- Majority of participants with high activation levels were found to be users of the FLO, indicating that text messaging interventions such as FLO could support or activate self-management behaviours. However, further research is needed to confirm this via interventional study designs.
- Demographic factors such as gender and religion do not influence patient self-management, activation level or using FLO; whereas, characteristics such as age, education levels, socioeconomic and employment status and ethnicity were associated with the use of FLO, activation levels and scores.
- Differences were found to exist between younger and older samples, particularly regarding generations. Older samples of first generation (above age of 66 years) appeared to have lower literacy skills affecting activation levels. Younger participants (age of 25-65 years) of second or third generation had a higher education and activation levels.
- Differences were also observed across sub-ethnic groups of the SA participants. Indians (37.5%) were more qualified and highly activated. In comparison, Pakistani and Bengali participants had the lowest activation levels.
- High activation levels were present amongst those who had higher levels of self-efficacy and control. These individuals ( $n=20$ , 50%) reported FLO text messages to assist their self-management journey.

- Low activation was seen across subjects (n=13, 32.5%) who required assistance from family members, could not read or communicate in English and desired more information.
- 30% of the sample (n=12) scored lowest on items which asked whether they took an active role in their health, having control over their symptoms, knowledge about prescribed medications, causes of condition and ability to confidently discuss health issues with the doctor or health care provider.
- Education seeking behaviours were evident in those who were better educated. Patients who had lower education and literacy levels requested translated information or education.

## Chapter Seven

### Patient Experiences of Text Messages and Positive Behavioural Outcomes

#### Introduction

Exploring SA patient experiences of text messages to enhance health was central to the aims of this research study. Key themes were identified through the use of semi-structured interviews and then compared and contrasted against existing evidence. These were obtained from patient views, opinions and preferences of using the FLO text messaging system and the self-management of their LTC. This second findings chapter presents the analysed data from phase two patient interviews.

Interviews were undertaken with SA participants (n=40) with varied characteristics, conditions, experiences and adherence behaviours (sample characteristics Table 16, Chapter Six). An equal spread of FLO users and non-users had been recruited representing a range of different demographics (gender, age groups, ethnicity, religion socioeconomic status, employment and education levels).

The analysis from the interview data drew upon relevant factors identified within the literature review, as well as key theoretical constructs pulled together in Chapter Four, which have demonstrated to influence SA people's self-management behaviour and acceptance to text messages in this study. An analytical framework was formed on the basis of key information and was progressive in nature; it consisted of eleven categories. The confirmation and verification of themes presented mirror the analytical process. These core themes uncovered new knowledge which add to behaviour change theories and were used to inform and reflect upon patient activation levels.

#### Overview of Analytical Framework

The qualitative data was inductively analysed, using a thematic analytical process (Colaizzi, 1978), described earlier (Table 16, Chapter Five). All interviews (40) were transcribed verbatim and checked for accuracy against audio recording. To identify key themes interviews were read and listened to. Significant words and phrases used by participants, to identify varied themes and meanings were noted in relation to using or not using text messages and how it influenced behaviour, and coded alongside a description. Different

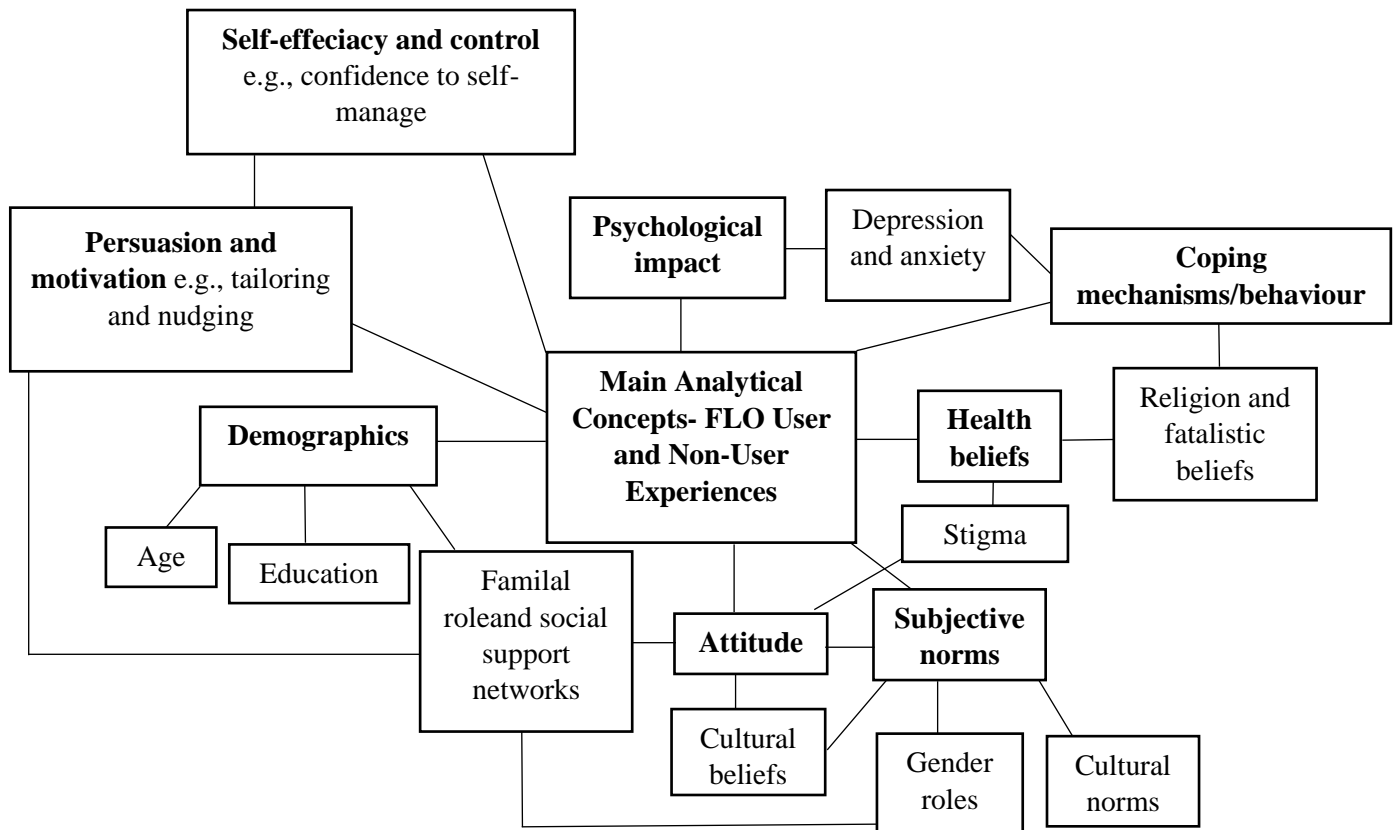
meanings in the data were discussed, compared and agreed between the researcher and supervisors.

After 13 interviews eleven broad themes were identified. At this point, data appeared saturated as no new themes were emerging. Qualitative researchers may argue that at this stage it is time to stop collecting information to begin the analyses (Grady 1998; Saunders et al, 2017). However, the researcher decided to cease data collection from different groups when made empirically confident by ‘theoretical saturation’, where similar instances were repeated, and the category or construct that make up the theory are fully represented rather than the data (Glaser and Strauss (1967). Although, data reached saturation at 13 interviews, a further 27 interviews were conducted to look for varied groups that stretch diversity of data to ensure that saturation is based on the widest possible range of data on a particular group or criterion (Starks and Trinidad, 2007). This allowed to search for new meanings amongst SA subgroups (different age groups, education levels, religiosity, employability etc.), from which 58 sub-themes emerged; adding depth and confirmation to existing themes.

Where there was uncertainty or ambiguity with phrases as to which category they belonged, they were collected in a ‘miscellaneous’ category, then reviewed, recoded or dismissed if not relevant to the final categories or the study focus. The final 11-themed analytical framework (Table 25, Appendix 37) was applied to the transcripts and included determinants drawn from appropriate theories including HBM and the CS-SRM, to examine behaviour change amongst SA participants. Data in the form of phrases, sentences, or complete paragraphs were coded and organised under broad theme headings, some were further divided into the sub-themes. These themes were found to reflect on patient behaviours to treatment adherence, experiences of living with a LTC and SA use of text messages.

### **Clarifying Main Analytical Concepts**

As the thematic analysis progressed certain concepts and issues became prominent in relation to patient adherence, engaging with text messaging systems to self-manage LTC, behavioural change processes and patient activation levels. The key concepts drawn from the critical synthesis of the current literature regarding behaviour change theory (Box 3, Chapter 4) assisted in theorizing and understanding self-management behaviours in regards to LTCs, and use of FLO text messages in a SA sample. These are presented below in a thematical map (Diagram 10), discussed in detail and further clarified through different patient scenarios, along with descriptor statements.

**Diagram 10. Main Analytical Concepts**

Participant scenarios discussed, present examples of patient perceptions from different socio-demographic characteristics and contexts, to demonstrate and allow data comparisons to highlight findings that confirm and extend current knowledge. Furthermore, whilst completing the PAM with participants they expanded and qualified their selection choices. This data was recorded on their questionnaires and with the patient consent used to elaborate on their responses. Some responses were relevant to the themes presented; hence, they have been included for discussion in this chapter.

### **Demographic Factors Affecting Experiences of User Experience**

Patients were interviewed across varied sub-groups, and certain demographic components were found to affect participant experiences of using and accepting the FLO system, as well as their activation levels. These particularly included age, employment status, gender roles and education levels (explored later, after age groups).

Age was explored to influence using text messaging systems, younger individuals expressed positive experiences compared to older patients. Quotes from patients of both age groups are presented below.

*U1: "I really love using the system for managing my diabetes, however, I do wonder how such a system can be used by someone like my mum, who is in her seventies now, and doesn't have a clue of how to text." (33-year-old Indian male User, with Diabetes and Hypertension)*

*U2: "FLO has been amazing I don't know how I ever managed without it. It has really optimised my self-management and really motivates me. I think an advantage is that it is very simple to use. I haven't had any issues with it." (44-year-old Pakistani male User, with Diabetes and Hypertension)*

*U3: "First generation people struggle more with such systems, for example my mum has had a falling out with the GP due to the self-check in system as she can't use it." (38-year-old Indian female User, with Diabetes and Hypertension)*

*NU1: "In our day there was no such thing as mobile phones... this is just something that has become recent now... and something the children are more engaged with." (67-year-old Indian female Non-user, with Diabetes and Hypertension)*

*NU2: "I do think the system is helpful as it would display blood results etc. But I don't feel interested in using technology, maybe it's an age factor. I am too old to take interest in these things now. It is for younger people." (77-year-old Pakistani male Non-user, with Diabetes, Hypertension and CKD)*

Similarly, education, literacy levels and employment status were also found to influence patient experiences and use of FLO.

*U1: "Education definitely makes a difference to the way you self-manage your illness, having that advantage enables me to interact and engage with my healthcare providers through FLO and technology"*

*U4: "I do think most people who have a busy schedule like myself due to work, will find that the system is quite convenient. I definitely think employment and education are linked, and are quite relevant to be able to use a system like FLO." (37-year-old Indian male User, Employed, with Diabetes and Hypertension)*

*U5: “Being a doctor for so many years, and being diagnosed with diabetes I finally understand what my patients go through and can understand the barriers that exist within our SA community. I think our community would benefit from such an intervention.... It can really help with monitoring their health and reporting any issues they may face.” (75-year-old Indian male User, Retired, with Diabetes and Hypertension)*

*NU3: “I really struggle with taking medications... I do not really understand what it is for, I sometimes ask my son or daughter in-law to help with identifying each medicine... I did not attend high school back home [referring to India], so I cannot speak or read English messages; I sometimes ask my grandchildren when my daughter in-law is busy with cooking.” (70-year-old Indian female Non-users, Unemployed, with Diabetes, Hypertension and CKD)*

With regards to gender roles in previous studies, men were less likely to visit health care professionals due to being busy with work, compared to women who were more likely to communicate their health issues with clinicians when needed. However, contrasting findings from this study revealed that men who were employed were more likely to be educated. Hence, they knew the consequences of poor adherence and not attending appointments when needed. Many took out the time to attend their appointments to discuss their self-management progress of conditions such as hypertension and diabetes. During interviews such individuals also stressed a greater importance of being educated to understand their condition and the appropriate self-management regime to follow. Having that knowledge and information resulted in patients feeling satisfied and confident to actively control their symptoms and engage with text messages sent.

Gender roles differed between SA participants, which are explored alongside attitudes and subjective norms in greater detail with regards to acceptance of FLO by SA male and female.

**Box 7. Key Findings- Demographic Factors Affecting User Experience**

- All patients had varied views and attitudes dependent on socio-demographics such as age, gender, type of generation (first, second or third generations) and employment and education levels.
- Younger age groups were more likely to accept and use the FLO compared to those from older age groups.



- Certain participants expressed an association between employability, education and being able to use and accept FLO text messages (U5).
- Education was a key contributor to being able to use and read text messages, as well as having an understanding and knowledge of the individual's LTC and self-management regime.
- Gender roles have been found to correlate with familial attitudes and social norms which in turn influenced acceptance and use of FLO (discussed below).

## Overview of Attitudes and Subjective Norms

### *Familial and Gender Roles*

SA men and women socialized to possess varied roles and values which were found to form differences in attitudes and behaviour. Majority of men were accustomed to being the bread winners and women traditionally the house wife, concerned with taking care of the home, children and the wider extended family. NU4 is a non-user who presented with low literacy skills and unable to communicate her health needs. Hence, she attended clinics with her husband who interpreted for her. She reported having limited time to engage with the texts sent, and stated having house chores to do, and mobile phones to be a waste of time. Table 25 presents exemplar of female participants with differing familial contexts and their experiences of engaging (or not engaging) with FLO.

Participants who had a similar context to NU4, support these statements (Table 25) and indicate the male spouse to be considered as the head of the household, hence, they are the main decision-makers. Such females expressed being accompanied by their partners, the importance of having their husband's involvement during decisions to be made regarding their health outcomes, treatment regimens, their self-management and whether or not it was acceptable for them to use mobile phones or text messaging systems (NU5). Therefore, most non-users were found to be SA female participants who were housewives with multiple commitments irrelevant to their health.

*NU5: "My husband normally runs the household, and accompanies me during my appointments. I don't think he would approve of me signing up to a mobile phone system. I doubt I would even check my phone I am normally quite occupied with household chores." (46-year-old Pakistani Female Non-user, with Diabetes and Hypertension)*

On the other hand, another female participant (U6) who was more qualified and employed, was better engaged with her health. In comparison to NU4, she was able to attend clinics alone, communicate health concerns, engage with texts messages, demonstrated a good understanding of her condition and felt more confident about the prescribed treatment and self-management regime. U6 also speaks about gender equality in the SA family system, the importance of being educated and employed; as well as the benefits to look after health with the aid of FLO. These factors resulted in her to have higher activation levels than NU4. Table 25, shows a comparison of both familial contexts of NU4 and U6.

NU4 Explained the duties and responsibilities of house chores and looking after the family, to be “*more important than her own health*” and engagement with FLO; whilst, U6 elaborated how her Husband and children support her through her self-management journey, and help out around the house. Similarly, a few other SA females (U7) and males (U8) also touched on changes in the traditional SA family system and gender equality within the household, where their spouses took responsibility for their own household tasks and assisted with the cooking and cleaning. They emphasised how small changes in the norms of SA family system can aid women to focus closer on their health needs and self-management regime. These findings suggested a shift towards “advancements”, “modernizations” and greater acceptance to gender equality to exist amongst the younger SA generation (Bandari et al, 2017, p.1).

*U7: “I’ve always made sure we share the house chores equally, as me and my husband both work. I think it’s only fair. Since my diagnosis he has been more supportive and helpful around the house especially.” (33-year-old Indian female User, with Diabetes, Hypertension and CKD).*

*U8: “I look after my wife; I like to make sure she’s not over-doing it with the household chores. So, I do the cooking and cleaning most days. She has had a lot of health issues recently, and has had to stay in hospital since she was diagnosed with cancer, which has now resolved with treatment.” (32-year-old Indian male User, with Diabetes and Hypertension)*

The welfare of the wider family also appeared to hold great importance in SA traditions, this included, grandparents, uncles, aunts and cousins (Patel et al, 2015; George et al, 2016). The notion of living within a nuclear or extended family was common within the study. It was noted during interviews and triangulation, that those living under such circumstances were busy looking after the family and house hold than themselves (NU5)

*NU5: "I am usually so busy at home; I don't really get time to monitor my blood sugars or my health... I have to look after the family, and also my in-laws who live with us too."*

The causes of non-adherence were clarified by participants such as NU5 and NU6, expressing that extended household tended to be dominated by the senior or elder parents or grandparents. Dietary decisions were therefore, made by the mother-in-law, mother or the grandmother. Hence, individuals were expected to sacrifice their personal desires to ensure the well-being or desires of other family members (Astin et al, 2008), which led to diabetic and hypertensive participants experiencing difficulties in switching to a healthier diet plan.

*NU6: "We are very traditional with what we do. So, my in-laws rule my house [laughs] with my children etc. they have a say in pretty much everything and are well-involved in our child care and the dietary choices, which may not always be the healthiest. (53-year-old- Indian female Non-user, with Diabetes and Hypertension)"*

**Table 26.** Exemplar of Varied Familial Roles Influencing Acceptance and Use of Text Messages in SA Females (Housewife and Employed Female)

<p><b>NU4 Context-</b> Female (37), Indian, attended secondary school in India, unemployed, newly diagnosed with diabetes. Hindi speaker, does not speak English very well.</p>	<p><b>U6 Context-</b> Female (42), Indian, attended college, employed. Type 1 diabetes for 24 years and hypertension developed recently. She expresses her views of education being an important factor when learning to self-manage a LTC, and FLO assisting her to do better.</p>
<p><b>FLO Non-user</b></p>	<p><b>FLO User</b></p>
<p>[General views of FLO]: <i>“I don’t find the system interesting to use, My English is not great I don’t think I will be able to adhere to messages very well.”</i></p> <p>[Familial roles and adoption to FLO]: <i>“I don’t really use my phone much... I have too much to do around the house... I am not really interested in texting...I only really use my phone to make important phone calls. Otherwise, I am very busy with household chores and cooking for my husband and family.”</i></p>	<p>[General views of FLO]: <i>“I think systems such as FLO are brilliant, especially to help remind me to check my parameters at the right times. The messages are educational with advice of controlling my blood sugars.”</i></p> <p>[Familial roles and adoption to FLO]: <i>“I am able to engage with text messages, and run my household. I get a lot of help from my husband and kids. Since I have signed up to it and started changing my lifestyle, they have joined me.”</i></p>
<p>Low activation level (level 1) and less concerned with taking responsibility for self-management.</p>	<p>High Patient activation levels (level 4) and better engagement with FLO text messages.</p>
<p><i>“I don’t really make my own decisions, my husband has supported me since I have come from India, he attends my appointments and helps me make the best choice for us.”</i></p> <p><i>“I don’t think he would be too happy for me to engage with a system I am not too familiar with, plus I have many responsibilities at home.”</i></p>	<p><i>“You have to make time for your appointments, and just your well-being as a whole. Education is very important especially when trying to understand your illness or condition. I have the knowledge to self-manage my condition well.”</i></p> <p><i>“Ever since FLO I am always learning something new, and my family are very supportive and want to learn with me so that they can help in case of a hypo, or anything else that can go wrong.”</i></p>

Marital status was not a variable measured but appeared important in terms of gender roles and self-management, gathered from SA male and female perceptions (NU4 and NU5). The male spouse was seen to have a role in decision making for SA females; whilst married (NU7) and unmarried men (U9) elaborated how their wife, mother, sisters or relatives assisted them to adopt a healthier lifestyle.

Women appeared to play a major role in the self-management of the males of the household. However, they themselves seemed to be more reluctant to change their diet as they did not want to affect the rest of the family who did not have hypertension or diabetes, especially for their husbands. This reflects upon the concept of male-dominance described by Patel et al (2012) in the SA household, where men have the right to exert influences over dietary recommendations, compared to women who are expected to accommodate her husband's needs than their own health requirements.

*NU6: "I would like to make changes to my diet, but then that would mean having to change for everyone... I don't think my husband would like to change the traditional food we normally have at home."*

NU7 a previous user of FLO, explains the benefits of the system, but also expressed how his wife played a significant role in altering his dietary intake to assist with his diabetes. He described that if an individual in the family has a condition and illness, one must alter their lifestyle to suit their needs, as family is expected to be *"there for one another"* as seen in the SA community in general. In contrast, U9 a user of the FLO system, also revealed receiving support with dietary requirements at home from other females in the family, such as the mother, sisters and cousins. He signifies the importance of female members of the family in the SA culture. Although, NU7 is a previous user of the FLO and is no longer using it, he reports the system as a *"big support"* and aiding the management of multiple conditions, which parameters to record and monitor, and specifics of dietary intake. Similarly, U9 a current user of FLO expresses how FLO improved symptom control and lifestyle changes, along with receiving support from the females at home such as his mother and sisters.

Table 26, shows a comparison of both cases along with example quotes, and highlights that regardless of being a previous user or a current user, support from female family members is vital when dealing with a LTC.

**Table 27.** Exemplar of Varied Familial Roles Influencing Acceptance and Use of Text Messages in SA Males (Married and Unmarried Males)

<p><b>U7 Context-</b> Male (42), Indian, completed Masters in UK after arriving from India, married, employed. Diabetes, hypertension and CKD. He discusses the difficulties of managing multiple LTCs and maintaining a healthy lifestyle.</p>	<p><b>U9 Context-</b> Male (28), Pakistani, attended university, unmarried. Borderline diabetes, controlled by diet and lifestyle. Proficient with technology and IT. Patient signed up to FLO following his diagnosis in 2018.</p>
<p><b>FLO Previous user</b></p>	<p><b>FLO User</b></p>
<p>[General views of FLO]: <i>“For me the FLO has done wonders, I signed up to a study a few years ago, I really loved it, it has helped me so much in terms of my self-management. I am no longer using it since the study stopped, but I think it has really helped me adopt a better lifestyle.”</i></p> <p>[Familial roles and adoption to FLO]: <i>“Family support is very important along with FLO...we are there for one another. They really help me get through it... Since using the system, I began eating a lot better, and after I stopped, I continued. My wife has helped me throughout with my diet and cooks healthier food so I can maintain a healthy life...”</i></p>	<p>[General views of FLO]: <i>“FLO has helped me get back on track, the messages were very informative for me especially after being newly diagnosed. It sent me good reminders for my follow-up appointments and also good advice to keep my blood sugars under controlled.”</i></p> <p>[Familial roles and adoption to FLO]: <i>“Although the messages are good enough to support me with lifestyle changes, I do rely on my mother or sister when it comes to cooking at home, they normally do it so I leave it to them. Recently, they have been helping me eat better by cooking healthier meals”</i></p>
<p>Increased support with self-management and improved activation, level 3</p>	<p>Increased support with self-management and improved activation, level 4 (p=0.00).</p>
<p><i>“The FLO has had a very positive impact in my life although I am no longer using it, I would have suggested it to my close relatives and the wider community who are dealing with similar issues to me.”</i></p>	<p><i>“I really like the FLO system but I feel without my mom and sisters support, I would not be able to get back on track with my health. I appreciate the messages but I think I needed the extra support from my family to bring my sugar level back to normal.”</i></p> <p><i>“Mothers are very nurturing in the SA culture, for them the children remain precious no matter how old we get. Our health and well-being will always be the most important thing for them.”</i></p>

*Adherence to Medications and Healthier Lifestyle: Family and Social Support Networks*

Social cohesion, connectedness and co-operation were fundamental in the study for SA communities (Jibeen et al 2016). This included family involvement, an important aspect in medication adherence, maintaining healthy lifestyles and using text messages to achieve optimal health outcomes.

The qualitative phase of this study identified the important roles of family members and friends in providing information about their condition, accompanying the patient to appointments, helping them use the FLO system, read text messages and also reminding them to take their medications. Relatives accompanied some individuals, such as U10 and U11 who attended clinic and the interview. Such participants were interdependent on relatives, friends and religious networks as the major source of identity and protection against the hardships of life, such as living with an LTC.

Table 27 shows the contrasting views expressed by U10 and U11 regarding support from family members with their adherence and assistance with translating messages.

**Table 28.** Exemplar of SA Participants Requiring Support with Adherence and Assistance with Translation from Family Members

<p><b>U10 Context</b>-Female (76), Indian, unemployed, obtained primary level education, low literacy levels, unable to communicate in English, speaks Hindi and Punjabi. Attends clinics with husband. Has diabetes, hypertension and CKD.</p>	<p><b>U11 Context</b>-Female (73), Bengali, unemployed, obtained primary level education, low literacy levels, Bengali speaker. Has diabetes, hypothyroidism and hypertension. Is a user of FLO, who is needing daily assistance with administration of Insulin.</p>
<p><b>FLO User</b></p>	<p><b>FLO User</b></p>
<p>[General views and perception of FLO]: <i>“The system is very good it has helped my family assist me to manage my diabetes.”</i></p> <p>[Familial roles and adoption to FLO]: <i>“My grand-daughter normally helps me read text messages, as I cannot speak or read English. Only then I am able to follow the advice provided to improve my health and condition. She also showed me how to check my blood sugars with the glucometer.”</i></p>	<p>[General views and perception of FLO]: <i>“The system is very handy and helpful, especially in our situation, we know when mum has an appointment, and when her blood sugars or Insulin are due.”</i></p> <p>[Familial roles and adoption to FLO] (Daughter of U11): <i>“My sister and myself were shown by the nurse of how to administer it for my mum, but then I trained and showed my sister in-laws how to do it in case I or my sister are not there, so they know what they are doing now. It’s the same with the text messages, we normally read the messages out to her in Bengali to update her on her health.”</i></p>
<p>Increased support with self-management, but low activation levels due to not being able to self-manage independently (level 2)</p>	<p>Increased support with self-management, but low activation levels due to not being able to self-manage independently (level 1)</p>
<p><i>“My husband is very helpful he assists with the house work, he helps me do the laundry, especially over the last few years since I have developed multiple health problems such as diabetes and blood pressure. He also helps with medications and checking my blood sugars.”</i></p> <p><i>“I do get lots of support from my children, as I live two or three minutes away. They all come according to their convenience; everyone is close by to me all my children, daughter in-laws, and grandchildren.”</i></p> <p><i>“My son is also a nurse so we get a lot of help with medication updates and translation with text messages. All the family support me and my health including</i></p>	<p><i>“The messages are great, but she can only adhere to them if one of us is at home with her... an advantage is that I just live next door to her, So I can pop in and check on her, and check the updates via FLO.”</i></p> <p><i>“She has made some improvements via FLO, but she is not 100% with her health and self-management. She is not as motivated; she says it’s because she has had diabetes for a long time now, and it’s never going to get better. Also, she relies on us to help out, she hates needles so me or my sister have to help her with insulin injections”</i></p>



<i>my sons, daughters, daughter in-laws, cousin brothers and sisters. They keep me going.”</i>	
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Participants such as NU4, NU5 and NU6 described living with immediate family or the extended family, and being reliant on relatives and family members to assist with their treatment regime. Language barriers were witnessed amongst NU5 and similar subjects, but particularly more commonly in first-generation family members. These individuals could not communicate in English but still owned a mobile phone, they relied on other individuals from the wider or extended family to translate (for example, U10). This was often a son, daughter, daughter-in-law or grandchild that would read out or translate text messages regarding their health outcomes, accompany them during their appointments to avoid language barriers or meeting “random” interpreters, as well as receiving assistance with medications and monitoring of parameters such as blood pressure or blood sugars. Such participants (U10) also reported receiving support from family and relatives that lived nearby when it came to taking medications, checking blood sugars, blood pressure, cooking and preparing meals.

U10 a user of the system was unable to act upon messages sent to them by FLO. As a result, she is reliant on English speaking family members. Alongside this, she described opposing views to NU5, that she has multiple health issues, is dependent on her husband and received help with domestic chores such as cooking and cleaning, assistance with taking medications, taking blood sugar readings and attending clinic appointments. Furthermore, she also received emotional and practical support from children and daughter in-laws (example quotes presented in Table 27). U11 described a very similar context to U10, she attended follow-up clinics with her daughter who was her next-of-kin and translator. The participant is assigned to FLO but is reliant on her daughter and wider family to support her to translate messages and her self-management. The interview was conducted with herself and her daughter present to translate. The daughter translated back to the researcher (myself), that the system has helped them monitor and track their mother’s (U11) condition and progress. They keep a daily record of her blood sugars and blood pressure.

Many felt a sense of comfort by sharing their health problems and information about conditions such as diabetes, CKD and hypertension with other individuals who experienced similar illnesses (for example NU8 and NU9).

*NU8: “Family support is very important...we are there for one another. They really help me get through it. We share everything with one another, including those from the wider community to try help and support one another” (48-year-old Pakistani female, Previous FLO user, with Diabetes and Hypothyroidism)*

*NU9: "I learnt from other people from the same community facing similar issues, and family have supported me throughout my illness" (67-year-old Indian male, Previous FLO user, with Diabetes, Hypertension and ESRD)*

This contests previous reports on the stigma and being labelled with conditions such as diabetes (Chaudhry et al, 2016; Kumar et al, 2016; Syal et al, 2019). Instead, participants with diabetes such as NU7, expressed that it was useful knowing others from the family and the wider community who also had diabetes, as it gave them opportunities to exchange information about the condition, lifestyle adjustments, alternative remedies, and the benefits of using the FLO system amongst other users.

*NU7: "I was a previous user of the FLO system; I think it was a great system so I informed my relatives who had similar problems with their diabetes to sign up to it. We also try to offer one another health advice... Especially myself, as I have had it a very long time now, so I try help as much as I can."*

The findings from the qualitative element reports that participants felt most comfortable surrounded by those who shared common cultural traits and languages to communicate, avoiding any barriers. This included consulting healthcare providers who were also SA. Thus, stigma was not an issue for some; whereas, others feared being labelled by the wider community, felt ashamed and tried to hide their condition. Hence, many refused sitting with interpreters.

#### *Issues Using Interpreters*

The Midlands has a large multicultural population, patients were found to speak diverse SA languages for which professional interpreters were available, to reduce language barriers. Instead of utilising the translational services provided in the study, majority of the participants preferred to use a family member or relative as a non-professional interpreter with a knowledge of the language (Hadziabdic and Hjelm, 2013). Participants refused to have an interpreter they did not know personally due to ethical reasons, specifically trust, confidentiality and anonymity, a response reported in other studies (Patel et al, 2012). They felt uncomfortable at the thought of having a "random" person listening to their personal matters regarding their LTC, especially if it was to be someone drawn from the outer SA community (NU10 and U12). This supported the view of SAs being more comfortable and relaxed during appointments with a family member, as such participants relied heavily on

them for emotional and instrumental support in remaining adherent to their medication regimen.

*NU10: "I am happy to begin the interview with my son present. I feel more comfortable as he knows my issues. I don't trust an outsider, what if they tell someone from the community?" (65-year-old Pakistani male, Non-user, with Diabetes and Hypertension)*

*U12: "I can't imagine the thought of being stuck in this room with a random person I do not know, disclosing personal issues related to my health. I would rather like to keep my illness and health private." (39-year-old Pakistani male User, with Diabetes and Hypertension)*

Prior to the study, it was anticipated that having a family member as a translator may influence participant responses. However, an advantage was that common languages were understood by the researcher so they could verify and monitor the conversation between family members and participant. Attention was given to participants' body language to identify signs of distress when giving responses to questions asked. Establishing a rapport between the three parties: researcher, participant and participant's relative was important for the credibility and trustworthiness of the data gathered.

**Box 8. Key Findings- Attitudes and Subjective Norms**

- All patients had varied views and attitudes dependent on socio-demographics such as age, gender, type of generation (first, second or third generations) and employment.
- Gender roles played a significant role in self-management of LTC and acceptance of text messages. For example, housewives were dependent on their husbands to make important decisions regarding their health, and whether or not it was appropriate to take up text messages.
- For most male participants, varied female roles (wives, mothers, sisters) played an important part in their self-management journey, even whilst using FLO, to help adopt healthier behaviours.
- Familial roles within extended families also contributed to self-management, where it was important to look after the wider family first before your own health needs.

Participants spoke about the influences the wider community and family had on behaviour changes and acceptance to FLO (NU4, NU5, NU6).

- Participants preferred attending clinics with a member of their family than having an unknown interpreter sitting with them during their appointments.
- Social support from family and wider communities appeared to be paramount in most SA participants' self-management journey, positive behaviour changes and acceptance to FLO.

### Overview of Health Beliefs and Perceptions

Health and cultural beliefs were a major theme explored throughout the interviews that strongly correlated with SA adherence behaviours and patient experiences of self-managing LTCs, influencing engagement with technology (FLO) and activation levels. Certain subthemes emerged which coincided with evidence uncovered from previous studies on similar SA samples (preference of traditional remedies, toxicity of medication, cultural norms and stigma) (Lucas et al, 2013; Kumar et al, 2016). Most participant health beliefs resulted due to demographic variables such as religion, ethnicity, education and age groups.

Non-adherence and lower patient activation levels were associated with certain health beliefs that prevented SA participants from adhering to their regime, such as: taking alternative or herbal remedies, believing prescribed medications to have more side-effects than benefits, fear of toxicity and stigma. In regards to PAM items concerned with patient understanding of their prescribed medications, certain participants mentioned their fear of side-effects (NU13), resulting in taking reduced or incorrect dosages. Others such as NU7 and U11, scored low due to lacking confidence to administer therapies such as insulin, or consulting with the doctor or nurse about associated health problems.

*NU7: "I don't have the confidence to self-administer the insulin, especially in public. I feel even worse to tell the doctors and nurses, what will they think of me? I do get help from my wife sometimes."*

*U11: "My mum hates needles, she won't take the insulin unless me or my siblings assist her, she also thinks it doesn't work, so there's no point in her taking it."*  
(Daughter of U11 translating Participants views on regime)

Majority non-users such as NU11 and NU12, elaborated trying herbal remedies in addition to their prescribed medications, or only taking alternative therapies instead of the advised treatment regime. Such participants informed the researcher, that such remedies acquired natural benefits and were bound to ‘cure’ their LTC compared to ‘western medication’ recommended by their healthcare provider.

*NU11: “I prefer taking medicines that are natural or from the earth than English medications [referring to prescribed regime], things like raw vegetables and Karela (bitter melon) helps reduce Diabetes. I think if I continue to take it, it may cure the illness.” (55-year-old Indian male Non-user, with Diabetes and Hypertension)*

*NU12: “I feel safe when taking herbal remedies as they are natural, there are many that I think can eventually cure my Diabetes such as Karela [referring to Bitter melon].” (40-year-old Pakistani male Previous FLO user, with Diabetes)*

Some patients (NU12, NU13 and U13) experienced more than one LTC, hence, they were advised to take increased number of medications to manage their conditions effectively. Regardless of symptoms improving, these participants were doubtful of whether taking multiple medications was actually safe or not. Such individuals appeared to have lower education and activation levels. NU13 describes her views of taking multiple medications to control her symptoms for hypertension and diabetes. She claims that “*whether or not you are using FLO, the number of medications taken will not change*”. Furthermore, she has expressed that she is not interested in FLO, instead recommends messages to be tailored to understand individual’s health beliefs (Further examples of quotes and patient context shown in Table 28)

Cultural beliefs about traditional and alternative remedies also appeared to play a prominent role in the way people made decisions about medicines across the SA sample. SAs who shared such beliefs often turned to alternative remedies and felt they were ‘natural’ and safer. Examples included bitter melon, referred to as “Karela” in some SA languages, and other vegetables which are a common remedy believed to “cure” diabetes amongst SA subjects, also explored across other studies (Patel et al, 2012; Kumar et al, 2016). These remedies were most commonly used amongst patients from the first generation. Use of mobile phones and text messages was not observed amongst this group of participants, due to negative attitudes of them “*not working effectively*” or not having the time or interest to learn how to use a mobile phone.

NU14 describes using alternative therapies such as bitter melon. He states that FLO cannot cure him, and is reliant on paper-based system rather than technology, for example, preference of receiving appointment letters through the post than on text (example of quotes in Table 28). A few Pakistani females from similar age groups, such as U13 reported seeing an herbalist (known as 'Hakim' in Hindi and Urdu) to try out herbal medications to replace or add to prescribed medications, with the hopes of being cured or to reduce symptoms quicker (see Table 28). The participant expressed having a good understanding of her condition, and is self-managing well. However, she was keen to try herbal remedies.

Younger age groups with higher education levels from the second or third generation, were strictly adherent to their medications and argued there to be limited evidence to suggest the safety or effect of taking traditional remedies. Instead, they expressed the best way to reduce symptom severity was to adhere to the medications prescribed on time (U14). U14 describes her experiences of trying herbal medications alongside her prescribed regimen. She reported them to have no effect and no evidence to support their benefits. Also, she expresses FLO to assist with adherence to a healthier lifestyle.

Cultural norms, stigma and family or community's views majorly influenced participant views and perceptions of their illness and self-management regime. Asian sweets or 'mithai' were one of the main staple foods distributed during celebrations such as weddings and birthdays amongst SA communities. Younger groups appeared to be more careful about their consumption of sweets compared to older participants, mainly to hide their illness. Groups from the second and third generation (U15) articulated older participants from the first generation were more reluctant to disclose information about their condition. This was noted amongst those with diabetes, who felt more secretive to use insulin during public events or gatherings due to their fear of being labelled.

U15 newly diagnosed with diabetes, discusses the stigmas associated with insulin administration in her family. Regardless of this, has been adapting to a healthier lifestyle by using FLO alongside 'Patient Knows'. The individual was asked to compare and contrast systems, and reported FLO to be more useful as it provided updates on her treatment options and good reminders. Messages were also friendly and motivating (See quotes in Table 28).

Some participants (NU7, U15) also articulated feeling embarrassed to discuss issues they experienced due to their LTC, for example erectile dysfunction, cancer, and injecting insulin. SAs believed such topics very taboo and unacceptable to discuss or display in the open,

which further led to inadequate confidence, knowledge and skills to adequately self-manage, resulting in poor activation levels across this SA group.

*NU7: “Like you said before about cultural issues and taboo to discuss confidential things can be a problem sometimes. For example, erectile dysfunction is something I am experiencing, and studies show it is to do with diabetes, but I find it difficult to discuss it with others.”*

*U15: “There is a stigma of injection and insulin in SA communities, but we just get on with it, it has to be done, it is fine. I am quite strong in terms of my health care management.” (33-year-old Indian female User, with Diabetes and Hypertension)*

Culture, customs and norms appeared to mediate the different ways participants understand and view their illness, as these individuals expressed those illnesses such as diabetes were not considered acceptable in the wider SA society.



**Table 29.** Exemplar of Varied SA Participants' Contexts Regarding Health Beliefs, Perceptions and Acceptance to Text Messages

<p><b>NU13 Context- Fear of Side-effects: 1<sup>st</sup> generation</b></p> <p>Female (69), Indian, has obtained primary education in India, unemployed. Has diabetes, hypertension and CKD. Reported feeling quite anxious and scared for taking multiple medications to treat her symptoms, which may increase risk of side-effects.</p>	<p><b>NU14 Context - Trial and use of herbal/ alternative remedies:1<sup>st</sup> generation</b></p> <p>Male (70), Indian, educated up to secondary school in India, retired. Living with diabetes and hypertension. Discusses his experiences of trying herbal remedies as an alternative to prescribed medications. Mentions the benefits of them being natural and “good for you”.</p>	<p><b>U13 Context - Trial and use of herbal/alternative remedies: 1<sup>st</sup> generation</b></p> <p>Female (58), Pakistani, attended university in Pakistan. Has diabetes, hypertension and CKD. Reported FLO to have a positive outcome on her health, sometimes receives support from her daughters with messages as not great with technology. Patient can communicate and read in English. Made a trip to Pakistan where she explained visiting a “<i>Hakim</i>” (herbalist/ or allopathic practitioner) who informed her that diabetes could be cured through herbal medications he gave to her.</p>	<p><b>U14 Context - Trial and use of herbal/alternative remedies: 2<sup>nd</sup> generation</b></p> <p>Female (44), Indian, obtained secondary level (college) education, employed. Attending clinics due to her type 2 diabetes (also has developed hypertension). Has reported improved symptom control and positive outlook after using FLO. However, speaks about her experiences of going to India to visit relatives who advised her to try herbal remedies as a cure to diabetes.</p>	<p><b>U15 Context - Experiences of stigma attached to condition; 3<sup>rd</sup> generation</b></p> <p>Female (33), Indian, obtained secondary level (college) education, employed. Attending follow-up clinic for her diabetes (also has developed hypertension). Prefers the FLO system in comparison to ‘Patient Knows’. Outlines the differences of both systems below. Discusses the stigmas that exist in her family in regards to diabetes treatments such as insulin administration.</p>
<b>FLO Non-user</b>	<b>FLO Non-user</b>	<b>FLO User</b>	<b>FLO User</b>	<b>FLO User</b>
[General views and perception of FLO]: “Generally, from the information you have provided about the system, it	[General views and perception of FLO]: “I am not really a technology user; throughout my life I have not found it important to use it. I	[General views and perception of FLO]: “FLO has helped me; the texts are very good. I manage with the system but sometimes when I need to send	[General views and perception of FLO]: “If it was not for FLO, I think I would be forgetting to take my medications on time and	[General views and perception of FLO]:” I really love FLO I have been using ‘Patient Knows’ but that only shows me my blood test

<p><i>sounds pretty good, especially for those needing reminding to check blood sugars and blood pressure daily.”</i></p> <p>[Health beliefs and adoption to FLO]: <i>“I am not saying that the system is not good, it’s just that I don’t think using it will reduce the number of tablets I am taking it will only remind me to take all of them, which is what I am trying to avoid. I believe taking too many medications are bad for my health, however, doctors have told me the opposite that they are there to help me. If they want me to use the system [referring to FLO], they need to understand my beliefs.”</i></p>	<p><i>am quite old-fashioned and much rather prefer to receive information and updates via the post.”</i></p> <p>[Health beliefs and adoption to FLO]: <i>“I don’t think I could keep up with FLO. It wouldn’t help me; I am not used to the mobile phone as I have never been interested in learning how to use it. I also don’t believe that texts will cure my disease. I am happy with the remedies I am trying such as Karela (Bitter melon) juice, which I think are more effective than English [referring to prescribed medications] medicine.”</i></p>	<p><i>my readings for blood sugars or blood pressure, I ask my daughter to help me. I think translated messages would be better.”</i></p> <p>[Health beliefs and adoption to FLO]: <i>“I think my views regarding FLO and my illnesses are separate. I do believe the system to have helped me personally with my conditions. However, I also feel bad for wasting my money and believing that the remedy given to me by the herbalist can cure me. I have learnt that there is no cure to the diabetes...The system has improved my self-management. Therefore, I will continue to use it.”</i></p>	<p><i>have difficulties to remember to monitor my blood sugars. I have a busy schedule so having FLO is convenient.”</i></p> <p>[Health beliefs and adoption to FLO]: <i>“I have tired herbal remedies when I went to India...I will never go back to using them again. I think the most beneficial thing is my routine, which is to take the medications my health care provider has told me to. Ever since my doctor has signed me up to FLO, I have gained more confidence in managing my diabetes.”</i></p>	<p><i>results. On the other hand, there’s FLO which has really helped me keep on track with my diabetes care. I love receiving reminder texts regarding my blood sugars and updates on my treatment options. “</i></p> <p><i>“FLO is quicker and easier to use and messages are quick to access; whereas, when using ‘Patient Knows’ I normally have to login and wait for it to upload, and it can sometimes take a while.”</i></p> <p>[Health beliefs and adoption to FLO]: <i>“There are certain health beliefs in the SA culture, especially a stigma for things like cancer and diabetes. There are a few people with diabetes in my family and they all tend to keep insulin administration a secret, I think it’s because they find it embarrassing and wouldn’t want the wider SA community finding out.”</i></p>
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				<p><i>“Although, there are health beliefs in our culture regarding illnesses such as diabetes, I never let it get in the way of my regime or even my use of FLO. It’s quite irrelevant to me, I only care about my health and that’s it.”</i></p>
<p>Poor self-management and low activation levels (level 1) as reluctant to take medications, due to health beliefs regarding side-effects.</p>	<p>Poor self-management and low activation levels (level 1) due to health beliefs regarding alternative therapies. Does not fully understand the full benefits of taking prescribed medications.</p>	<p>Good self-management regime, following prescribed regime. Stopped the herbal remedies and adherent to messages sent. High activation level (level 3), has a good understanding of her treatment regime.</p>	<p>Good self-management, following prescribed regime. Finds messages useful, increased confidence and activation levels (level 4)</p>	<p>Good self-management, following prescribed regime. Finds messages useful, increased confidence and activation levels (level 4).</p>
<p><i>“I take eight tablets in the morning and nine in the afternoon, I asked him [referring to doctor] to reduce the number of tablets due to the side-effects associated with them, but the doctors said no.”</i></p> <p><i>“Even my GP was very surprised too. I was beginning to think I will develop a lot of side effects. I</i></p>	<p><i>“I do take a lot of bitter melon, my wife always tells me to buy Karela because it is meant to be good for this, some also say to eat pepper especially green pepper, but to eat these vegetables raw.</i></p> <p><i>“I don’t think a mobile phone system would be satisfying for me because I think it will just be sending me instructions rather than</i></p>	<p><i>“I went to Faisalabad (city in Pakistan) to see a hakim and they told me that they could cure my diabetes.”</i></p> <p><i>“I really should not have been so naive; I am going to continue to stick to what my doctor and the FLO system advise me to do.”</i></p>	<p><i>“I have eaten bitter melon as well, I have also drunk water of that, I have had people from our community show me videos that if you dip your feet in crushed karela that it will work, I was like that’s not going to work... it’s got to get into your blood. I guess it can help thin the blood, as it is very healthy, it is my favourite</i></p>	<p><i>“I am not sure what the big issue is, especially with injecting insulin in public. The grown-ups in my family [referring to first generation family members] need to be better educated in regards to their illness. There needs to be a less stigmatised view and better self-management. I think a system like FLO can</i></p>

<p><i>stopped them all because of that, I now only take metformin.”</i></p>	<p><i>have an understanding of my needs. I think these remedies are working for me because they go through my blood stream, it may even cure me.”</i></p>		<p><i>vegetables but that does not mean it will cure my diabetes, it won't replace my insulin, I wish it would but it's just another alternative to you know...but in reality, it won't control your blood sugars.”</i></p> <p><i>“It's a proven fact, for example, If I stopped taking my insulin I would have fallen and I'd be admitted. The herbal medications are not proven to be scientifically effective, they're not real medications. If they were proven to be good for you, I would take them.”</i></p>	<p><i>really help people like my mum.”</i></p>
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**Box 9. Key Findings- Health Beliefs and Perceptions**

- Health beliefs were integral (or influential) in terms of self-management of LTCs and using FLO text messages to self-manage illnesses.
- The phenomenon of alternative or herbal remedies was most common amongst first generation individuals. These participants also rejected the use of the FLO text messaging system because of their health perceptions; whilst, second and third generations were more adherent, knew the benefits of taking prescribed medications and the consequences of not. Text messages were also more likely accepted by these groups.
- Some patients did not have an understanding of what an LTC is, and how best to manage it. Many of these individuals were hopeful that herbal remedies would “cure” them.
- Stigma and taboo were concepts hindering optimal self-management.

Overall, younger groups had better activation levels and better engagement with FLO text messages in comparison to older groups who required more education and knowledge about their condition and interventions such as FLO, to be able to self-manage optimally in public.

**Overview of Coping Mechanism, Behaviours and Psychological Impacts**

Interviews explored coping methods used by SA participants from which the concept of religion and fatalistic beliefs came about. Some Indian subjects (for example, NU15, U16) reported feelings of denial and anger, and claimed that the condition was a punishment for not looking after their health.

*NU15: “This is all my doing. It is because of my eating habits I developed diabetes. It’s all my fault, sometimes I hate myself for this.” (80-year-old Indian Male Non-user, with Diabetes and Hypertension)*

*U16: “I have a negative attitude towards my diabetes and didn’t take it seriously, it’s with all sorts of illnesses. Even with asthma, when the doctors diagnosed me with asthma, my dad said I don’t have it. He was in denial. He said you don’t need an inhaler so I managed without it.” (38-year-old Indian female User, with Diabetes, Hypertension and CKD)*

Those (for example, U1, U4) who were at level 3 or 4, also reported feeling depressed or anxious due to their condition, but felt like they must go on for their family. This included views from male and female participants from varied age groups and modalities.

*U1: "I want to fight this and get better. Many people in our community tend to get very upset but I try not to get upset about my health. I need to be strong for my children, so I try control it."*

*U4: "Obviously, I am not happy, but I am beginning to come into terms with it, I know diabetes affects certain parts of the body, the doctors have kind of explained that to me"*

Subsequently, participants were asked what supported their coping. Family was the main source of support for all; whilst a vast majority were also reliant on God, religion and fate (n=37, 93%) to help them "get through it" (NU16). Although, there was no significance between religion and patient activation levels, religion played an important role for SA self-management and coping behaviours, especially for older age groups (over 65 years). Commonalities were existent amongst Muslim, Hindu and Sikh participants, with regards to having faith in God, which cultivated positive behaviours, improved their well-being and gave them hope of getting better. Some (NU16, NU17, U17) identified that they would also turn to scriptures, prayer, and counsel with religious clerics to deal with mental distress. All individuals were asked about their views of religion and coping, perceptions of God and self-managing their illness, in relation to using FLO. Examples of participant context and views from varied religious backgrounds are shown below in Table 29. NU16, a practising Sikh discloses that God and religious scriptures helps cope with her health issues and dealing with a LTC.

Predestination was another view expressed, particularly by Muslim participants (for example NU17, U17), who believed that everything had already been predetermined or decided by God. Majority of Muslim subjects were from Pakistan, a country which is heavily influenced by the Islamic way of living. These individuals felt that their illness was either a punishment or a test of their faith in God, some even viewed it as a gift that brings them closer to God. For this reason, participants felt it was acceptable not to take medications as they had more confidence in God than themselves, resulting in them showing little interest, knowledge and lower activation levels (NU17). NU17 states the significance of predestination in Islam and

self-management not being important as God has already predetermined everything. For that reason, FLO is not being used by him (example quotes presented in Table 29).

Majority of the subjects from varied religious groups reported mobile phones and text messages to not intervene with their religiosity and faith in God. Although, Muslim participants found the FLO system beneficial they felt that God was most “powerful”, “merciful” and “benevolent” (U13), believing only he can help control symptoms and cure their illnesses (U13, NU16). This view was also expressed by Sikh participants who felt God is omniscient and omnipresent, and that technology could not be compared to God because of this. For this reason, some participants rejected the use of FLO.

*NU17: “Every second, every minute God is with me. I feel technology and God are separate. For example, I can use my mobile phone to make a phone call to India, but God is everywhere I don’t need to use technology to reach him, he is everywhere. The person who designed the mobile phone, was designed by God himself. Nothing is greater than God.” (58-year-old Pakistani male, Non- user, with Diabetes, Hypertension and CKD)*

Even though FLO text messages were educational and informative in regards to patient conditions, many SA FLO users still felt religion and God helped them cope better and make sense of their condition (U17). U17 speaks about her faith in Allah (God), although she is a user, God helps her cope better (example quotes in Table 29).

Coping strategies varied across the sample. Older age groups were reliant on religion and spirituality to deal with emotional consequences, where many patients spoke about feeling isolated, depressed or anxious, and felt that God helped to restore faith (NU18).

*NU18: “I do believe whatever happens is for a reason. I am religious and believe in God. I am a firm believer and I look for guidance in God. God can do anything; he can cure me if he wanted to. I try not to get depressed about my illness because of my beliefs in God.” (70-year-old Pakistani male Non-user, with Diabetes and Hypertension)*

Some younger participants often discussed depressive feelings to be associated with the onset of their illness at an early age, as they believed it to be common only amongst the elderly (U18). U18 describes feeling depressed due to being diagnosed with diabetes at a young age. She describes herself as religious and believes in God. However, religion does not intervene

with her self-management. She also reported FLO helping to optimise her self-management and view her condition more positively.

U18 defined depression to be linked with ease and acceptance, and that God does not make one suffer more than what they could tolerate and will always help when a problem occurs. However, certain participants that were younger and educated had greater belief in medication and scientific evidence in relation to the causation of an illness, rather than God and religion (NU19). Such individuals felt more supported through engaging with counsellors or health care clinicians when support was needed. NU19 also describes feeling depressed with her LTC, she is a non-user who felt that such a system can help with her negative emotions and self-management (example quotes on Table 29).



**Table 30.** Exemplar of SA Participants View on Coping with their LTC (Experiences of Participants Coping Strategies, Depressive symptoms, Religion, Spirituality and Text Messages)

<p><b>NU16 Context - Female Muslim</b></p> <p>Female (60), Pakistani Muslim, attended primary school in Pakistan, unemployed. Has diabetes and hypertension. Discussed views of her religion, she is a practising Muslim. Reported God and religion to give her hope and think positively about her illness. She is a non-user, who expresses that even if she was using FLO, it would not give her hope the same way God and religion does.</p>	<p><b>NU17 Context - Male Muslim</b></p> <p>Male (58), Pakistani Muslim, attended college, employed. Has diabetes and hypertension, developed CKD secondary to those, a year ago. Patient states his belief in predestination and that the onset of his LTC was meant to be; and if God wills, He is the only one that can make him better. For these reasons he has not been adhering too well with his medications, and was not interested in using FLO to optimise self-management.</p>	<p><b>NU19 Context - Female Hindu</b></p> <p>Female (38), Indian Hindu, attended university, employed. Diagnosed with diabetes less than a year ago. Has been experiencing depression, is Hindu but does not practice religion. Patient discusses relying on friends for emotional support, seeing a counsellor or a healthcare provider when feeling anxious, uncertain or depressed about her condition. Has expressed a system like FLO would help with her self-management especially taking medications on time.</p>	<p><b>U17 Context - Female Muslim</b></p> <p>Female (55) Pakistani Muslim, obtained secondary level (college) in Pakistan, unemployed. Diagnosed with diabetes and hypertension two years ago. Patient said that she finds FLO very helpful in regards to her self-management, but her faith in God, mainly helps to cope since her diagnosis.</p>	<p><b>U18 Context - Female Hindu</b></p> <p>Female (35), Indian Hindu, attended university, employed. Diagnosed with diabetes a few months ago. Has described depressive symptoms, said prayer and going to the temple make her feel happier. Also discloses that since using FLO, she has gained a more positive outlook on her self-management. She outlines demographical factors such as having an education to play a key role in self-management.</p>
<p><b>FLO Non-user</b></p>	<p><b>FLO Non-User</b></p>	<p><b>FLO Non-User</b></p>	<p><b>FLO User</b></p>	<p><b>FLO User</b></p>
<p>[General views and perception of FLO]: <i>“I am not a FLO user but I</i></p>	<p>[General views and perception of FLO]: <i>“I am not too keen to use FLO, I</i></p>	<p>[General views and perception of FLO]: <i>“I think a system like FLO</i></p>	<p>[General views and perception of FLO]: <i>“FLO is a good system; the messages</i></p>	<p>[General views and perception of FLO]: <i>“FLO messages have been just</i></p>

<p><i>think it can assist and improve self-management for those struggling. I am doing fine for now so I don't think I need to use it."</i></p> <p>[Coping, Religious views and adoption to FLO]: <i>"God is enough for me, He helps me get through it. I don't need to use FLO. If I have God, I don't need anything else."</i></p>	<p><i>don't have interest in mobile phones or texting. I barely use my phone I am busy with work."</i></p> <p>[Coping, Religious views and adoption to FLO]: <i>"If God has predetermined my illness, then only he will make it better, I don't believe in using a text messaging system to try improve my health. Only God can make me improve."</i></p>	<p><i>would really help me remember to take my medications on time and check my blood sugars when needed."</i></p> <p>[Coping, Religious views and adoption to FLO]: <i>"I don't really think religion or God has any relevance to my condition. Although, I think FLO would help me improve my adherence, I really struggle with taking my tablets on time... I take multiple medications due to uncontrolled blood sugars and it becomes quite depressive."</i></p>	<p><i>are informative and educational. I also find the reminders convenient. However, my English is just okay, it's not the best I'm lucky I can read the messages, but I think there should be translated content instead, to help others who don't read English at all."</i></p> <p>[Coping, Religious views and adoption to FLO]: <i>"The disease is from Allah, we have all trust in Allah, only He can cure us, even advances in technology (mobile phones or text messages) don't have that power."</i></p>	<p><i>great. I think it is very quick and easy to use. They keep me well informed with new updates and encourage me to keep a record of my self-management progress."</i></p> <p>[Coping, Religious views and adoption to FLO]: <i>"I have been very depressed since the diagnosis. My religion and faith in God have helped me feel more normal. FLO has also helped me bounce back with my life."</i></p>
<p>Following and understanding prescribed regime, has a positive outlook on her Diabetes. Good activation levels (level 3)</p>	<p>Poor self-management, non-adherent to medications. Low activation level (level 1).</p>	<p>Non-adherent sometimes due to forgetfulness. Lower activation level (level 2).</p>	<p>Adherent with some messages and self-management tasks. Low patient activation levels (level 1)</p>	<p>Adherent with messages and self-management regime. High patient activation levels (level 4)</p>
<p><i>"Well, scriptures do say, God can do anything, he can cure you if he wants, I do my prayers every day,</i></p>	<p><i>"They tried to persuade me, they kept telling me the complications, but I didn't care at that point, I</i></p>	<p><i>"I am Hindu, but I don't really follow my religion. I don't think God or religion has anything to do with my</i></p>	<p><i>"Faith and self-management are two sperate factors.</i></p>	<p><i>"I attend the temple daily, praying to God and seeing people from the community</i></p>

<p><i>so God gives me a reason to cope.”</i></p>	<p><i>thought if it is meant to be it will be. It is all in God’s hands. It’s the same with FLO, I don’t think it’s any good.”</i></p> <p><i>“I do believe whatever happens is for a reason. I am religious and believe in God. I am a firm believer and I look for guidance in God. God can do anything; he can cure me if he wanted to.”</i></p>	<p><i>condition. My condition is to do with my own doing. diabetes is due to biological reasons not because of religion. I do think science and technology are quite common and important these days.”</i></p> <p><i>“I am not really that religious, I do believe in God... But in terms of my health, I am more reliant on scientific evidence and treatments that can treat my symptoms.”</i></p>	<p><i>Using FLO does not intervene with my religion.”</i></p> <p><i>“Although, technology is good and the texts are educating me, it doesn’t matter how much you are suffering, only God can restore happiness and health.”</i></p>	<p><i>has provided a lot of emotional support for me.”</i></p> <p><i>“When I first heard the diagnosis of diabetes, I was really down, and when I was on the ward it was all old people, I was like where are all the young people gone, is this a disease that only old people get? I just wanted to hide myself, what is happening to me? My healthcare providers have really supported me and introduced me to FLO which has helped me even more.”</i></p> <p><i>“I think the first most important thing is to be educated, only then you can understand your illness properly. I think second to that would be to have the motivation and courage to want to change. “</i></p>
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As a whole, coping strategies varied and were dependent on individual religious backgrounds. Majority of the sample expressed turning to God and religion whilst dealing with their illness or LTC. This included both users and non-users. Variables such as gender, age, education levels appeared significant to religiosity and coping. Females expressed feeling depressed and anxious (U18 and NU19) more than males who spoke about staying “*strong*” for their family (U1). Older age groups were more spiritual and religious compared to some from younger groups with higher education levels (NU16, NU17 and NU18). In general, FLO was viewed positively and did not intervene with religion, in fact it helped most users cope better and view their LTC positively (U17 and U18). However, non-users claimed religion and faith in God to restore hope instead of engaging with a text messaging system (NU16, NU17 and NU18).

During interviews it was revealed that factors such as persuasion, motivation and self-efficacy interlinked with use of the FLO system. These theoretical constructs were seen to influence SA patient self-management behaviours, acceptance and adoption to text messages (Jensen et al, 2012; Ershad-Sarabi et al, 2016; Kumar et al, 2016). Patient views in regards to these concepts have been explicated in greater detail below.

**Box 10. Key Findings- Coping Mechanism/Behaviours and Psychological Impacts**

- God, religion and spirituality appeared to be the main elements to help certain participants cope.
- Although, FLO was being used by SA patients, God and religion held greater importance than technology-based systems.
- Concepts such as predestination and having faith in God’s plans was linked to patients rejecting FLO text messages.
- Psychological impacts such as depression and anxiety were evident in certain patients (U18, NU19). Older participants were reliant on God to help them cope with depressive symptoms, whilst, younger individuals would turn to counselling therapies and scientific evidence based on their treatment regime.

**Patient Perspective and Experiences of Users and Non-Users**

Exploring patient experiences of using or not using FLO was fundamental. Initially, the FLO was used to determine whether negative behaviours were altered to promote positive health and effective self-management. Findings revealed FLO users to have better activation levels,

scores and general health outcomes compared to non-users. Text messages focused on self-management elements such as those in the PAM, by reminding participants to independently monitor and record parameters (for example, blood pressure or blood sugar), increase physical activity, take medication on time and consult a health care provider when needed to. Majority of the people in level 3 and 4 were found to be users and some previous users of the FLO who reported text messages to be persuasive and motivational (NU7, NU8, U7, U8, U9), which enhanced their self-efficacy and self-management behaviours to manage their condition. Views from different individuals in terms of key demographics such as age, gender, ethnicity and education levels were included. Information from patients with varied illness modalities were also collated, to reflect on their self-management with FLO (for example, monitoring parameters such as blood pressure).

*U7: “The system was quite good. My blood pressure is well controlled now, I am not even on any medications now it is all diet control, I am also exercising a lot more as I understand the benefits, and I can speak to my healthcare provider when needed.”*

*U8: “The feedback from messages is always positive and motivates me to carry on with my self-management in the best way. It gives me hope.”*

*U9: “For me the FLO has done wonders, I signed up to a study a few years ago, I really loved it, it has help me so much in terms of my self-management. I am no longer using it since the study stopped, but I think it has really helped me adopt a better lifestyle.”*

*NU8: “FLO is a very good system, in all the time I used it I never had any issues. Messages really helped me keep on top of my health goals.”*

### **Influencing Persuasion and Motivation via Text Messages**

Chapter Four discusses persuasion and motivation to be interconnected concepts to allow for behaviour changes to take place and be effective. Previous evidence suggested motivation and persuasion to best take place through goal-directed behaviours using informative tools (Sandler et al, 2011). Majority of FLO users, expressed messages to be motivational which persuaded them to make better lifestyle choices and improve adherence to their prescribed treatment regime (U12, U14, U15). U8 also defines positive experiences of using the system for over a year, and describes messages to be motivating and persuasive (example quotes in Table 30).

On the other hand, the non-users (NU3, NU14) explained their lack of motivation to be due to not being prompted to look after themselves. A lot of them were from older age groups (over 65 years), and unable to engage with the system due to experiencing language barriers as FLO only delivers messages in the English language.

*NU3: “She wouldn’t be able to read English, secondly, the complexity of the phone, she even has difficulty of trying to make telephone calls, so we have to ring her. So, it’s just the confidence and the complexity to use it.” [Son Translating for his mother, NU3]*

*NU14: “I cannot text, so I don’t use the FLO system, also my English is not great, and I feel I am too old now to be up to date with new technologies.”*

NU10 mentioned that he would like to receive messages from FLO, but would not understand them as they are in English. He elaborated such messages to aid him and others just like him who struggle to keep up with their regime. Table 30, shows a comparison between user and non-user views of FLO (U8 and NU10).

**Table 31.** Exemplar of SA Participants View of Text Messages (Experiences of Receiving Persuasive and Motivating Messages)

<p><b>U8 Context-</b> Male (32), Indian, attended University, employed. Has diabetes and hypertension. Expressed messages to be persuasive and motivated him to adopt a healthier lifestyle.</p>	<p><b>NU10 Context-</b> Male (65), Pakistani, attended literacy and numeracy courses (secondary level), retired. Has diabetes and hypertension. Struggles with reading and speaking English. A non-user, expresses his thoughts on the benefits of translated messages delivered by FLO. Suggests such messages would constantly motivate him to do better, in a language understood by him.</p>
<p><b>FLO User</b></p>	<p><b>FLO Non-User</b></p>
<p>[General views and perception of FLO]: <i>“Messages are easy to follow, very educational and provide good tips on improving my health.”</i></p> <p>[Motivation and adoption to FLO]: <i>“Text messages from FLO, have helped encourage me to adopt a healthier life style. I exercise, eat healthy, attend appointments and never miss out in taking my medications. The messages are very motivational which persuade me to do the best I possibly can.”</i></p>	<p>[General views and perception of FLO]: <i>“I think if messages were translated in Urdu, I would be very keen to receive them. I don’t understand English for that reason the system wouldn’t be effective for me.”</i></p> <p>[Motivation and adoption to FLO]: <i>“Text messages in Urdu can really motivate me, as I would have a better understanding of what I need to be doing. Right now, I struggle with my regime, sometimes I even forget to take my medications on time or even check my blood sugars daily.”</i></p>
<p>Adherent with messages and self-management regime. High patient activation levels (p=0.00) (level 4)</p>	<p>Non-adherent to regime due to forgetfulness and language barriers. Low activation levels (level 1)</p>
<p><i>“My experience with FLO has been very positive so far, it offers good support and continuously motivates me to eat better and make healthier lifestyle choices for myself.”</i></p>	<p><i>“I don’t really have a very good understanding of my condition; I don’t always know when to take my medications. Language barriers don’t always help either. I think there needs to be better translating services, or maybe FLO can offer that.”</i></p> <p><i>“I am not really good at doing my blood sugars, exercising or eating healthy, so something like FLO would be quite useful for me as a reminder, perhaps text messages can help encourage me.”</i></p>

Important concepts relative to persuasion and motivation was the delivery of tailored content and personalised care, which was elucidated in the evidence from the focused review (Chen et al, 2019; Endebu et al, 2019; Prinjha et al, 2020), and also proven in this research study.

### **Acceptance of Tailored Text Messages**

Participants explained messages to be adapted to their health needs and the LTC they were presenting with. Furthermore, users expanded on the content to be more goal-directed, persuasive and meaningful to them. Examples of text messages are shown below which were sent by FLO to certain users (Box 7).

#### **Box 11. Examples of Tailored Text Messages sent by FLO**

*“Hi Raj, could you please check your blood glucose and text in your reading.”*

*“Hello Simran, just A quick reminder that your SATs reading is due, e.g., “OX 95”.  
Thanks FLO.”*

*“Hi Rani, please ring your COPD nurse for advice ASAP, your score means that you may need a change to your current treatment. Take Care FLO”*

*“Well done, Mr Singh, your blood pressure reading was better than yesterday. Keep up the good work.”*

Messages were signed by FLO or a healthcare provider, and used participant names making them more personalised. This reportedly made users (U13, U15) feel cared for and increased adherence, improved health behaviours and acceptance to FLO, as the texts appeared to reinforce personalised care compared to a non-tailored reminder.

*U13: “The messages are tailored to mum’s condition and would ask for blood pressure readings, so it would prompt us... I would check her blood pressure and send it off, if the blood pressure was high or the reading was not as good, it would provide some good advice through messages.” [Daughter of U13 speaks about the benefits of messages prompting her to assist her mother with her blood pressure monitoring]*

*U15: “Translated messages would be very, very useful for those who speak other languages other than English, and those that do not understand English so well.”*



Although, tailored information and/or messages are beneficial in enhancing positive behaviour changes, not all participants experienced the benefits, especially those facing language barriers. Messages were personalised in terms of name and illness of participants; however, they were not available in a language that could be understood by those who did not speak or read English. Such patients (NU6 and NU11) stressed the importance and advantages of having messages translated, as that would mean that they would also be able to optimise their self-management regime by following messages they can understand. Non-users (NU6, NU11, NU16) state the usefulness to have messages delivered in a language of their choice, which could increase the uptake of the FLO system across those experiencing language barriers and willing to take part (example quotes, Table 31).

Individuals such as U10 and U11 were reliant on getting assistance from family members to translate messages in order to act, resulting in some not using the system altogether (NU11, NU15, NU16). For this reason, content of messages was considered important and relative for the delivery of tailored, personalised care (example quotes, Table 31).

### **Content of Messages**

The content of information, satisfaction of content, and timing of the delivery of messages reportedly impacted behaviour of patients and influenced their engagement with FLO (For example, U3, U9, U13, U17).

*U3: "I think it would be good if the messages were sent earlier on in the day, to prompt, like I received this message regarding the appointment only yesterday."*

*U9: "It would be good if text messaging systems such as FLO would send messages at a time preferred by myself, preferably out of work hours, it is less disruptive."*

*U13: "I have been using the system for some time now, information provided is great but could be better if it was in Urdu. At least, then I will be able to read and understand it quicker."*

*U17: "I am unable to use this system independently sometimes as I am not great with English, I cannot communicate with the texts I receive. If texts were in Urdu, they would be good to prompt me to take medications and monitor my blood sugars regularly. Currently, I rely on family members to translate the content sent."*

In comparison, there were some users happy with the messages and found them "useful", "motivational", "persuasive", "educational" and "informative" (for example, U1 and U19).

*U19: “The information provided in the messages is useful as they make you aware of your own blood sugar levels or blood pressure, and what you should be aiming for when self-managing at home.” (25-year-old Pakistani female User, with Diabetes)*

U1 indicates texts have increased his level of awareness regarding his illness and how best to manage the condition (Table 31).

Participants appreciated the personalised feedback received if they were on track with their health, expressing that it helped them develop strategies through which their health goals could be tailored and achieved (U2 and U16).

*U2: “The personalised feedback helps keep me on track with my progress and allows me to set goals to help me optimise my health and reduce symptoms.”*

*U16: “I really like the feedback sent back, along with the praises when I have done well with managing my symptoms, it is really motivating when my efforts are recognised.”*

These were expressed to be a persuasive mechanism, as discussed in the ELM in Chapter Four, where participants suggested that messages that include personal features increased their motivation, ability and enhanced their involvement with FLO. This resulted in positive lifestyle changes, decreased symptoms and also resulted in high activation levels. Persuasive features included the use of a friendly tone, addressing patients directly by their names, praises and statistical evidence to persuade users to make changes to their daily lives. Examples of texts sent include:

*“Well done for keeping up the good work Mohammed, you are doing really well with keeping your glucose levels well-controlled”*

*“Hi Preeti, did you know that 1 in 4 people will suffer from a common mental health problem when faced with a long-term illness – you are not alone”*

However, a few users also complained about the time messages were delivered (U12 Table 31). U12 stated that he did not have time to respond to messages that asked for recent readings to be sent of their blood sugars or blood pressure, as they were at work. Such participants suggested preferences that the system be adapted, to send messages at a time suited by them, for example, before or after work. Some older or retired subjects described the frustration of reminders being sent repeatedly (NU20), whilst, others felt that content of

some messages could be improved to include more detailed information about appointments for example, the location and the name of the specialist they were seeing on the day (U13).

*U13: “The thing is she is seen by different people for her kidneys, and for her ears too as she has tinnitus so the text didn’t say what the appointment was for and who it was with. It would be beneficial to receive location on messages too” [Daughter of U13 who discusses mother’s co-morbidities for which she has multiple appointments, expresses messages for each appointment would be useful]*

A few individuals also preferred systems such as Google OK, or ALEXA alternatively to text messages, this was due to not wanting to receive messages or not being able to read English texts (NU20). NU20 speaks about his previous experiences and frustration with text messages from FLO, and how he prefers to use ALEXA instead to monitor his self-management (example quotes, Table 31).

### **Communication Differences and Language Barriers**

Language was the main element in regards to the content of messages, their acceptance and understanding. From the studies reviewed messages were translated into the local or regional languages dependent on the location of the study, to overcome language barriers (Mbuagbaw et al, 2012; DeSouza et al, 2014; Bobrow et al, 2014; Xiao et al, 2014; Vakili et al, 2015; Bartlett et al, 2019). However, this was not the case with the FLO system. SA participants argued messages were of no use due to not being able to read or respond to them (NU1, NU2, NU3). Majority non-users were amongst those who did not speak or understand the English language well (NU3, NU15, NU18). These individuals further elaborated that having a choice of languages in which the content of message can be sent would be most appropriate, as such translated interventions can help overcome the burdens of living with an LTC (For example NU1). NU1 also explains her stresses of poor management of her diabetes, and the advantages of having a translated text messaging system to support her better (Table 31).

**Table 32.** Exemplar of SA Participants View of Text Messages with Regards to Persuasion and Motivation (Views on Tailored messages and Content)

<p><b>U1 Context- Views on content of messages</b></p> <p>Male (33) Indian, attended university, employed. Has diabetes and hypertension. Began using FLO in 2019, has found messages very informative and educational, which in turn, motivated him to improve lifestyle.</p>	<p><b>U12 Context- Views on content of messages</b></p> <p>Male (39) Pakistani, attended university, employed. Has diabetes and hypertension. States messages to be disruptive during work hours, and sometimes difficultly faced with adherence, due to inconvenience in replying to messages. Has recommended being given a choice to receive and respond to messages.</p>	<p><b>U17 Context-Views on content of messages</b></p> <p>Female (55), Pakistani, Educated in Pakistan (secondary level). Has diabetes and hypertension, reports getting by with her prescribed regime. Would prefer information sent in Urdu to respond more effectively to the messages.</p>	<p><b>NU1 Context- View on tailored messages in terms of persuasion and motivation (preference of translated texts)</b></p> <p>Female (67), Indian, educated in India up to primary level, unemployed. Has diabetes and hypertension, reports having issues with her self-management regime. Complains about forgetting to take medications and sometimes needing assistance from family members to help administer medication as cannot read English.</p>	<p><b>NU3 Context- Views on content of messages (preference of translated texts)</b></p> <p>Female (70) Indian, primary education obtained in India, unemployed. Has diabetes, hypertension and CKD. Poorly managing her diabetes due to forgetfulness and lack of understanding with regimen. Expressed the need for translated services to assist with adherence.</p>	<p><b>NU20 Context-Preference of another system</b></p> <p>Male (73), Bengali, attended university in Bangladesh, retired. Although, has high level of education, has expressed feeling demotivated to self-manage his multiple LTCs (hypertension, diabetes and CKD), and his frustration for FLO. He said since he stopped using FLO his progress with his self-management has gone “downhill”. However, expresses that he finds text messages frustrating and prefers using ALEXA.</p>
<p><b>FLO User</b></p>	<p><b>FLO User</b></p>	<p><b>FLO User</b></p>	<p><b>FLO Non-User</b></p>	<p><b>FLO Non-user</b></p>	<p><b>Previous FLO User</b></p>
<p>[General views and perception of FLO]: “Generally, the system is okay, it is easy to use,</p>	<p>[General views and perception of FLO]: “The system offers good support for self-</p>	<p>[General views and perception of FLO]: “I think so far FLO has been okay in</p>	<p>[General views and perception of FLO]: “I think FLO would really help me with my regime.</p>	<p>[General views and perception of FLO]: “I think a system like FLO can help me. I have</p>	<p>[General views and perception of FLO]: “The system has its benefits of providing useful messages,</p>

<p><i>provides support for those who may have difficulty remembering or adhering to their regime. I think the system could be even better if messages were translated for those people experiencing problems with English.”</i></p> <p><i>[Content and adoption to FLO]: “The FLO messages are really good, they are really educational and informative, whilst, motivating at the same time. They always prompt me to check my blood sugars on time, and recommend the best ways to control my symptoms. I definitely believe that such systems could really help alter negative behaviours and mindset.”</i></p>	<p><i>management but can be improved to suit patient needs better in terms of timing of delivery. “</i></p> <p><i>[Content and adoption to FLO]: “The system is great, but it can be frustrating when prompts are sent constantly, that require immediate responses... For example, sending a blood sugar at a certain time. Sometimes that is not always possible as I am busy at work etc.”</i></p>	<p><i>helping me to remember my regime and checking my blood sugars. “</i></p> <p><i>[Content and adoption to FLO]: “I think I could take back more from the messages if they were sent to me in Urdu.”</i></p>	<p><i>I have heard about other people I know, that use the system to also manage their regime. However, I won’t be able to follow the prompts or messages as they are English.”</i></p> <p><i>[Content and adoption to FLO]: “I would really like to use FLO; however, I can’t read English. It would be beneficial to design systems that would be more tailored to suit our needs, such as better translated content and services.”</i></p>	<p><i>heard the messages provide good reminders to check blood sugars on time etc. But English messages cannot help me.”</i></p> <p><i>[Content and adoption to FLO]: “I have had diabetes for many years now, sometimes my symptoms are okay, sometimes they are not. I don’t always remember to take my medications, or follow a healthier diet. I think FLO text messages can help me, but language is an issue. Reminders could help me, but only in a language I understand.”</i></p>	<p><i>but I realised I am not really following messages well, as I am not a mobile phone person. I prefer ALEXA and systems like Google OK. FLO is annoying, I don’t like receiving repetitive messages all the time.”</i></p> <p><i>[Content and adoption to FLO]: “I really hate receiving texts, I don’t like reading them. ALEXA is better, I just talk to the system and it responds to whatever I ask for. I sometimes set alarms and ask ALEXA to remind me in regards to my medications and checking blood sugars. I think for me this is fine.”</i></p>
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<p>Adherent to messages, satisfied with content of messages. High activation levels (level 4)</p>	<p>Adherent to messages, satisfied with content of messages. Good activation levels (level 3)</p>	<p>Adherent to some messages, would prefer to read content in Urdu. Low activation levels (level 1)</p>	<p>Non-adherent to regime due to forgetfulness and language barriers. Low activation levels (level 1).</p>	<p>Non-adherent to regime, no understanding of English, cannot follow messages, prefers receiving translated messages if assigned to system. Low activation levels (level 1)</p>	<p>Stopped using FLO, non-adherent to regime. Low activation levels (level 2)</p>
<p><i>“Messages are very easy to follow, the information provided has helped me adopt a healthier lifestyle. “</i></p> <p><i>“I think the content is great, messages are very informative and educational which motivates me to do better as it educates me about my illness and how to adapt my lifestyle.”</i></p>	<p><i>“Educational messages sent are most beneficial and really help with self-management of diabetes.”</i></p> <p><i>“Messages sent to me outside of working hours would be beneficial as I can respond more promptly without rushing or missing key information”</i></p>	<p><i>“I think my self-management level can be even better if reminder messages were in Urdu, it would help me respond effectively to the advice given.”</i></p> <p><i>“Otherwise, the texts have helped me do well with my health. I haven’t faced any problems with the system”</i></p>	<p><i>“I sometimes need to get assistance from my daughter in-law when having my medications, I sometimes forget which medication is for what, and I can’t always read the labels.”</i></p> <p><i>“Messages in Hindi would be really useful for me as I won’t need to be reliant on anyone. I will get reminders that I could follow and adhere to. Right now, my self-management is all over the place, it is not as good as it can be.”</i></p>	<p><i>“Currently my Diabetes is out of control. Messages in Punjabi will help me, I will be able to get a better understanding of my treatment regime as I will be receiving updates I can read. Maybe then my sugars will be controlled.”</i></p>	<p><i>“Messages have some good information, but I feel like I have adapted to my ALEXA, I can speak to it directly when I want, I also think it is more advanced than texts, so for that reason I like it more. Either way I cannot say that I have improved my self-management by using either system my health has gone downhill, I just can’t be bothered now. I am getting old it is natural.”</i></p>

Participants facing communication barriers were not able to communicate effectively and lacked expression of their needs and desires, leading to inappropriate disease management. Knowledge on the individual's part was central for them to be able to self-manage effectively (NICE, 2016). Some SA participants had an inadequate understanding of their long-term illness, the role of pharmacological treatment, the benefits of taking medications and the availability of other therapeutic options. This resulted in patients not adhering to their regime. A few of the non-English speaking patients expressed a lack of involvement with doctors and nurses and did not understand their care plan. Some individuals also felt uncomfortable communicating their health needs with UK or British clinicians due to lack of confidence resulting from cultural and language barriers, instead individuals preferred to sought advice from SA doctors and nurses who they felt could understand them better (NU1, NU2, NU9).

*NU1: "I do prefer to consult an Indian doctor who speaks the same language as me, I feel like I can express my needs better." (67-year-old Indian female Non-user, with Diabetes and Hypertension)*

*NU2: "The doctor speaks Punjabi so I can communicate my needs effectively without barriers." (77-year-old Pakistani male Non-user, with Diabetes, Hypertension, CKD)*

*NU9: "My main doctor is Indian, but I sometimes don't always get the chance to see him as they send patients to be seen by trainees, who are not always Indian nor can communicate with me in my language." (67-year-old Indian male Non-user, with Diabetes, Hypertension, CKD)*

Furthermore, despite messages being delivered in English, some participants viewed them positively and felt that their promptness could help overcome poor adherence, if they were more tailored to suit their needs, for example, in a language they could read and understand (NU3).

*NU3: "I feel excluded as I can't understand the messages sent, which is unfair. There should be translations to messages available for people like me, for whom English is not the first language. I think only then the system can be good and effective, if they are delivering information, we can actually read and follow." (70-year-old, Indian female Non-user, with Diabetes, Hypertension, CKD)*

Interestingly, those who spoke English had positive views regarding the use of FLO compared to those speaking in Urdu and Punjabi. Language differences were also found to

impact patient perceptions about their condition, self-management and FLO. For example, the belief that one's disease was due to fatalistic causes such as God or destiny, and viewed prescribed or 'western' remedies negatively, was a view portrayed by those who communicated in SA languages (NU8 and NU15). FLO was rejected by such participants

*NU8: "Although technology is good and the texts may be educational, it doesn't matter how much you are suffering, only God can restore happiness and health." (48-year-old Pakistani female, Urdu speaker and Previous-user, with Diabetes)*

*NU15: "I don't believe in these texts, it's all rubbish, I only have strong belief in God, only He will make it better." (80-year-old Indian male, Punjabi speaker and non-user, with diabetes)*

English speaking participants were better engaged with FLO and also believed the occurrence of their illness to be due to biological causes than their fate.

**Box 12. Key Findings- Persuasion and Motivation Influenced via Text Messages**

- Patients reported text messages being persuasive and motivational- allowing adoption of healthier lifestyles, improved adherence to medication and recording important parameters
- Views of users and non-users differed in terms of demographics-Users were more highly educated, able to understand messages sent, whilst some non-users struggled due to language barriers.
- Tailoring text messages, content and timing of receiving messages were important to ensure individuals were motivated enough to act upon the advice provided.
- From SA patient experiences of using FLO, majority of users and non-user suggested the need for translated content to better motivate the wider SA community in terms of self-management.

**Enhanced Self-Efficacy Using Text Messages**

The Self-efficacy theory discussed in Chapter Four, proposes that the confidence in an individual's ability to perform a certain behaviour (i.e., self-efficacy) influence the intensity, direction and perseverance of a behaviour. Similarly, activation levels determined whether individuals were persistent enough to maintain healthy behaviours, lifestyle changes and adhere to their medical regime. Users at level 4 report FLO to have increase their self-



efficacy and their ability to self-manage appropriately (U14). U14 expressed having better control over her condition as she felt motivated to make the changes required to reduce symptoms and improve her health outcomes.

*U14: “FLO has really helped me understand the importance of being able to manage my condition independently. It makes me feel I am in control of my health. That includes what I eat, when I exercise and taking my medications the right way. I would definitely recommend it to others struggling.” (44-year-old, Indian female User, with Diabetes and Hypertension)*

U20 claims the system to be a “life saver” which has helped him view his situation more positively (Table 32). He elaborated that FLO enables him to interact and connect with healthcare providers when needed, as well as receiving updates about his care plan and treatment options. In addition to the FLO system, he has mentioned the support from family and friends to be another major factor contributing to increase self-efficacy. U20 has also mentioned depression and hopelessness being associated with the diagnosis of a LTC, which affected his self-management. Although, FLO text messages changed his negative attitude to positive, to ensure this constant positive change family support was most important.

Users at level 3 (U13) also appeared to take relevant action, by keeping a track record of their progress, attending follow-up appointments and asking for further information on how they could reach optimal self-management targets.

*U13: “FLO has some very good reminders in regards to checking my blood sugars in the morning, and also it notifies me of any upcoming appointments that I may forget to attend. It has really helped me keep my health in check and track the progress I have been making from my last appointment.” (33-year-old, Indian female User, with Diabetes and Hypertension)*

Participants at levels 1 and 2, (NU1 and NU15) showed lower self-efficacy, motivation and desire to make positive changes to their life. These patients elaborated on certain PAM items regarding the maintenance of healthy behaviours, and the confidence to make lifestyle changes. Instead, they voiced their concerns of feeling “hopeless” (NU1), having less control, and low assurance, as some behaviours were difficult to maintain, leading them to make little effort and under-perform.

*NU1:” I feel hopeless with my condition sometimes, especially when I don’t have anyone at home with me to help administer the medications. I normally have trouble*

*then when I can't read the English labels on the medicine boxes, so I don't bother sometimes."*

*NU15: "I have had my diabetes for nearly 20 years, and it has only gotten worse. I have now also developed blood pressure problems [referring to his Hypertension]. I don't feel motivated anymore to take medications. I think they have done more harm than good." (80-year-old, Indian male Non-user, with Diabetes and Hypertension)*

Low activation scores could be a result of asking individuals who are the least activated to perform complex behaviours, which will discourage them from wanting to do better (Hibbard et al, 2012). Understandably an individual will not make lifestyle changes to advance their health, unless they understand what to do. Therefore, some individuals (NU19) claimed the need for further education and information to assist them to adopt behaviours that are feasible to take on, and increases their opportunity to experience success in their self-management journey.

*NU19: "I haven't had Diabetes too long, I would really benefit from more information and education regarding the illness, I think then I may understand the importance to take my medications. I don't give them too much importance and usually forget." (38year-old, Indian female Non-user, with Diabetes)*

### **Positive Behavioural Changes**

Findings from a report published in 2020, suggested FLO to have positive health outcomes, which resulted in significant improvements in the quality of life of patients living with LTCs. Although, many users of the system reported the system to be a solution to enable convenient interactions between clinicians and patients, portable monitoring of vital parameters and reminder messages (Collins, 2020), there was limited evidence collated regarding behaviour changes that took place within users of the FLO system. Subsequently, this study demonstrates FLO to have led to improvements in glucose monitoring, adherence to medications and adoption to healthier life styles across participants seen during endocrine clinics, within the Midlands (U6, U9, U13, U19, U20).

The situation of U20 shows self-efficacy to be closely interlinked to positive behaviour changes. This was also supported from previous literature, that text messaging interventions can produce behavioural changes in relation to health (Armanasco et al, 2017). Participants reported that ever since they began using the system, they have wanted to shift behaviours towards a healthier way of living with their LTC (for example U4, U16, U17). This included

taking medications on time, strictly adhering to their prescribed treatment regimen, adopting a healthier diet and exercising regularly.

Educational and informative messages aided in lifestyle modifications as many participants (U3, U9, U15) realised the benefits a healthier life had on their LTC. Such individuals found it easier to make changes as they felt messages guided them and allowed them to gain more awareness of what they should or should not be doing. Some also had their families involved, particularly male participants who were reliant on their families to help them change certain behaviours, for example, developing healthier eating habits and altering dietary intake by avoiding certain foods (U1, U9, NU7).

Participants also felt keen to receive messages that prompted them to check parameters as it assisted them to make certain changes to improve them. For example, reducing sugar intake to keep the blood sugars within normal range, which led to increased patient activation levels and improved self-management.

Those who chose not to engage with the FLO system found it difficult to change their habits due to cultural norms and practices. This was noted amongst older participants who preferred to eat traditional SA foods (NU11). After speaking to such patients and reviewing SA recipes from various literature, it was notable that most their food types and cuisine involved the use of Ghee (clarified butter) and a lot of frying as a method to prepare certain meals (Abdool et al, 2018). During interviews some non-users were asked whether they would like to receive information or texts regarding the benefits of healthier eating which could positively impact hypertension and diabetes. Many patients refused as they did not want to change their way of life as they preferred the “*taste of their own food*” compared to alternative healthier options (NU20). Such participants explained that they were advised by the diabetes specialist nurse to avoid foods such as fried rice, onion bhajis, samosas and oily masala curries. However, such foods were the main staple of the SA culture, hence, some participants felt that they were being asked to change their identity which was the greater challenge to adopt. NU11 spoke about the importance of traditions and heritage of SA culture. He mentions these factors identify who he is, and the resistance to change negative health behaviours and accept interventions such as FLO text messaging. This resulted in low self-efficacy and patient activation levels (Table 32).

**Table 33.** Exemplar of Self-Efficacy of SA Users and Non-Users (Example of Enhanced and Low Self-Efficacy)

<p><b>U20 Context - Enhanced self-efficacy</b></p> <p>Male (48), Pakistani, educated up to college and is employed. He is diabetic and hypertensive, was diagnosed with CKD stage three last year. He reported feeling depressed and hopeless. Introduced to the FLO system by the Endocrinologist he is seeing for his diabetes. No issues with technology or IT, so decided to sign up to FLO and is receiving daily messages to support self-management.</p>	<p><b>NU11 Context - Low self-efficacy</b></p> <p>Male (55), Indian educated in India up till secondary school, employed. Living with diabetes and hypertension. Is a Punjabi speaker, does not speak English too well. Expressed the importance of food in the Indian culture and difficulty to change this, even to improve self-management and using the FLO.</p>
<p><b>FLO User</b></p>	<p><b>FLO Non-User</b></p>
<p>[General views and perception of FLO] <i>“Messages are very useful and helpful. Has helped me connect with my care providers when I need support. The information provided in texts helps me do better.”</i></p> <p>[Self-efficacy and adoption to FLO]: <i>“FLO has given me hope, and has made me want to do better for myself and my family. I don’t think I can manage as effectively without it. Since I have started using it, I have developed a better routine. I make sure I am checking my vitals, exercising often and eating right.”</i></p>	<p>[General views and perception of FLO]: <i>“I don’t really think I would follow the messages as I am not good with technology... I can speak to the doctor face to face when I need to.”</i></p> <p>[Self-efficacy and adoption to FLO]: <i>“I do not want to change my lifestyle. Therefore, I don’t want to start using the system now. I cannot change what I have been doing my whole life” [referring to lifestyle].</i></p>
<p>Increase in self-efficacy, and high activation levels (level 4) (p=0.00)</p>	<p>Low self-efficacy, and low activation levels (p=0.00) (level 1)</p>
<p><i>“When I was faced with a diagnosis of a long-term illness such as diabetes and CKD, it came as a shock to me. I did not know what to do, I mean... the help was there but I thought ‘what’s the point’. I did not feel like trying anymore. But once I was introduced to FLO, my life changed.”</i></p> <p><i>“I am always improving now according to my annual appointments and that is the way forward, all thanks to FLO.”</i></p>	<p><i>“I like my current lifestyle, to eat things like curry and samosas, pakoras, biryani is our food. It is our identity. I don’t think me or my family will ever change that. We don’t eat fried food as often anyway so it is okay.”</i></p> <p><i>“I don’t think a text messaging system will make me change my ways. I guess they can offer good advice but for me that won’t work, I don’t think I will follow it. For that reason, I never signed up.”</i></p>

<p><i>“Although I have FLO, my family have been my main supporters without them, this journey would be impossible.”</i></p>	
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**Box 13. Key Findings- Enhancing Self-Efficacy Using Text Messages**

- There was improved self-efficacy, motivation and activation levels amongst educated individuals who were able to use the system.
- Increased self-efficacy was seen in participants who were using the system and also receiving family support (U20).
- Text messages sent by FLO impacted positive behavioural outcomes and enhanced self-management.
- Certain lifestyles of some SA participants were seen as part of their identity (for example dietary choices, staple dishes etc). These participants were reluctant to change unhealthy choices, presented with lower self-efficacy and patient activation levels (NU11).

**Summary**

This chapter addresses the gaps identified in the literature by exploring the experiences of SA participants using text messages, and generated a deeper understanding of them living with a LTC, their adherence behaviours and behavioural change processes involved in optimising their self-management. Interviews were an appropriate and useful method to extract data that highlighted and described contextual factors in relation to SA health beliefs and perceptions that reflected upon their mobile phone usage and self-management.

Valuable findings helped achieve the aims of this study by examining how factors such as age, gender, religion, health, ethnicity and education levels influence the adoption of text messaging within a SA population. Differences were found amongst the selected sample in terms of these factors. Furthermore, new knowledge was generated through applying behaviour change theories such as HBM and CS-SRM, which provided a useful theoretical framework to explore how SA individuals make sense of their illness, their present behavioural patterns and the steps involved in altering bad behaviours to improve their self-management. Key themes relative to certain theoretical constructs, emerged and also became pertinent to participants' acceptance of FLO (Demographics; Attitudes and Subjective Norms; Health Beliefs and Perceptions; Coping Mechanism/Behaviours and Psychological Impacts; Persuasion and Motivation; Enhanced Self-Efficacy), which could be taken forward to understand the steps involved in the acceptance of text messages or digital health interventions.

In addition, the diverse experiences collated from users and non-users of the FLO offered a unique perspective from SA participants with regards to living with an LTC, their attitudes towards their self-management journey, and their views on the FLO system (likes or dislikes about the systems, their preferences of message content, the language in which messages should be delivered and positive behavioural changes the system offered) which before this study had not been explored.

## Chapter Eight

### Discussion

#### Introduction

The original basis of this study was that the use of text messages and digital health-based interventions would influence positive behaviours amongst SAs, and optimise the self-management of their LTC. The findings support this viewpoint but more significantly provide new depths of knowledge that creates a clearer understanding of the complex barriers faced by SA ethnic minority groups within the UK in regards to their health care needs and outcomes. This chapter draws together a summary of findings of this mixed methods study, to be discussed alongside previous literature and the implications for the findings regarding the use of text messages to enhance health behaviours. The main purpose of this research was: to address the existing gaps and generate new knowledge by investigating contextual factors influencing adherence behaviours and adoption of mHealth interventions; embedding systems such as FLO within clinical practice, to complement a range of approaches promoting self-management amongst similar ethnic-minority groups; and to provide an evidence base to guide clinicians and healthcare workers on PAM, so that ‘tailored’ interventions focused on the health needs of ethnic-minority groups (for example, South-Asians) can be facilitated to effectively self-manage their health.

There are five conceptual factors that become pertinent from the study findings that were warranted for discussion:

- Understanding contextual factors affecting use and acceptability of text messages
- Using text messages as a behaviour change agent amongst SA participants
- The definition of a tailored intervention for a SA sample
- Patient activation levels of SA participants
- Information provision and educational needs of SA ethnic minority groups

This chapter also concludes with a critique of the strengths and limitations of the study.

#### **Understanding Contextual Factors Affecting Use and Acceptability of Text-messages**



Although, multiple studies support the use of text-messaging or mobile phone based-interventions for self-management (Whitehead et al, 2016; Dobson et al, 2017; Marcolino et al, 2018), there were multiple barriers participants exposed during interviews, which hindered them from using FLO. These included demographic variables, content, and timing of messages (U12 and U13).

Demographics such as age, education levels, ethnicity, religion, employment and socio-economic status, interplayed with mobile-phone use and acceptance of text messages. Individuals who were younger, employed, had some level of education and were literate in English, were able to use the system effectively, in comparison to older, uneducated individuals who could not participate with FLO. Previous literature also cites mobile phone use and text messaging interventions to be increasingly employed amongst younger and more educated adults (Joe et al, 2013; Xiao et al, 2013). Participants with lower levels of education experienced language barriers with limited digital literacy. These individuals perceived the intervention positively but felt left out due to messages not being available in a language of their choice, which could otherwise support their self-management. For this reason, content of messages was criticised by some patients (NU10), whilst, others recommended messages to be more detailed and informative in regards to appointments, or messages to be sent at a more convenient or suitable time (U12 and U13).

Other factors such as cultural and religious beliefs were also associated with lack of acceptance to use FLO. Such individuals were found to intervene with fatalistic beliefs of God curing them than to be reliant on a mobile phone system. This concept was held by older participants who were found to be more rooted with their cultural beliefs (NU16 and NU17), as society and culture were more important than reconciling health advice or using technology as an aid (Patel et al, 2012). It became evident that many variables were linked to one another with respect to acceptance of text messages and adherence to treatment regimen (discussed above). These findings suggest the recommendation on how systems such as FLO can be improved, and made suitable for the involvement of individuals from other vulnerable populations similar to SA ethnic minorities, and offers advice for the implementation of further interventions tailored to meet the needs of each individual.

#### *Language Barriers*

Evidence suggests doctors or other healthcare professionals who share the same language or ethnicity results in improved patient satisfaction, and quality of health care outcomes (Ahmed et al, 2015). Similarly, it was noted that delivering a digital health intervention (for example,

FLO), to SA ethnic minority groups would be most beneficial if messages were sent in a language understood by them. Many gained trust for the researcher maybe due to sharing the same language, and being an insider of the SA culture. They were able to empathise and informed that the researcher understood their needs. Some individuals spoke to me in a SA language, explaining they did not understand English text messages or their regime due to the language differences, which led them to ignore messages, reject the system and also take their medication in an improper manner. This was common amongst those from the first generation who were non-English speakers and found mobile phones complex (for example, NU3, NU14, NU15).

*NU3: “She wouldn’t be able to read English, secondly, the complexity of the phone, she even has difficulty of trying to make telephone calls, so we have to ring her.”  
[Son Translating for his mother, NU3]*

There was also the notion of some feeling excluded due to not being able to interact with the system due to the language barriers encountered (NU1 and NU3).

*NU1: “I would really like to use FLO; however, I can’t read English. It would be beneficial to design systems that would be more tailored to suit our needs, such as better translated content and services.” (67-year-old, Indian female Non-user, Diabetes and Hypertension)*

*NU3: “I feel excluded as I can’t understand the messages sent, which is unfair. There should be translations to messages available for people like me, for whom English is not the first language. I think only then the system can be good and effective, if they are delivering information, we can actually read and follow.” (70-year-old, Indian female Non-user, with Diabetes, Hypertension and CKD)*

Language plays an important role in communication. Consequently, it is important to consider having the availability of a mutual language to allow for better communication and greater understanding through the exchange of thoughts and ideas (Hadziabdic and Hjelm, 2013). Furthermore, findings from the study suggest translated content to be associated with ease of using text messages, increase in uptake, improved disease awareness and self-management. Therefore, there is a need to integrate translated services into healthcare to meet patient needs (Pardhan et al, 2017; Vandan et al, 2018).

### *Age and Adherence*

Resembling the evidence collated from the focused review (Xiao et al, 2014; Vakili et al, 2015), the current study findings also revealed a higher acceptance of FLO and better adherence, amongst younger participants from the second or third generation, compared to older participants from the first generation. This was due to better digital literacy skills, acceptance and being able to use mobile phone devices and engagement with text messages.

### *Cultural Norms, Traditions and Roles*

Patient health outcomes were greatly influenced and embedded within their culture, which for most participants was their identity. This included their behaviours of engaging with text messages encouraging health behaviours such as exercise, altering food and eating practices. Social and cultural norms were paramount for most SA participants interviewed; however, these individuals reported feeling anxious and struggling to transform their behaviours (for example NU11). Perhaps there is a need to consider the delivery of ‘family-centred’ education, rather than just patient-centred, as family is a key element of support within the SA culture. It is also a necessity to consider the nature of social support networks, essential for promoting health and behaviour changes, amongst extended families and family members who can help encourage mobile phone use for adherence to healthier eating and physical activity (Davis et al, 2020).

The distinct and traditional gender roles between men and women (Ghose et al, 2017; Davis et al, 2020), was another aspect noted to influence certain health behaviours. In order to adhere to text messages, some male participants were reliant on their wives to prepare meals to adopt a healthy lifestyle; whilst, some females would adhere to what their husbands would say rather than the health advice to follow text messages to promote their self-management (NU4 and NU5). Proper engagement with one’s health and the healthcare system are only possible if there is an understanding of the information given to make decisions to improve health (Vandan et al, 2018). Some women felt rapport to be lacking and found the advice given to be culturally sensitive, hence, experienced challenges to adhere. As general findings suggested, some participants preferred to consult with same-gender clinicians, which was evident amongst Muslim SA females. These individuals cited restrictions in Islam, and feeling more comfortable discussing sensitive issues or exposing their bodies to another female (Attum et al, 2020) (NU16).

*NU16: “I feel a bit embarrassed when I come for check-ups and find that it is a male healthcare provider. I feel more comfortable with female doctors and nurses, preferably those who can speak my language.” (60-year-old, Pakistani female Non-user, with Diabetes and Hypertension)*

These findings support evidence to suggest that awareness is needed for health professionals and governmental policies to be made culturally appropriate to enable individuals to put the information given into practice (Lucas et al, 2013). A 2019 petition was put forward to give people the option to see a same-sex healthcare provider, however, this was rejected due to being broad and not clear enough of what it asked of the government to do. To address this, a similar petition has been suggested by the government, which can aid in highlighting the implications of poor health outcomes seen in ethnic-minority groups, and identifying training needs to improve knowledge and skills in engaging with and supporting SA samples (Kumar et al, 2019).

The cultural practices outlined are noted to be important in the self-management of SA participants. Certain patients (NU5, NU11, NU16) struggled and requested culturally adapted care and text messages in a way that was compatible in terms of language, culture, and context (Castro et al, 2010). However, these structures are not synonymous, and intersecting issues can easily be missed in ethnic minority groups (for example, SA in the UK), including socio-economic status and acculturation (Terrangi et al, 2018). It is important to consider and acknowledge wider social contexts and multiplicity of identities and resources among individuals with the same ethnic origin. Therefore, self-management and use of FLO in SAs was explored alongside multiple factors such as age, gender, socioeconomic status, education levels, ethnicity and religion.

#### *Health and Illness-Related Beliefs*

Interviews consisted of open-ended questions framed using elements of the CS-SRM and HBM, which provoked health and illness-related beliefs particularly in relation to adherence and acceptance to text messaging technology. Factors that became prominent during the qualitative phase of the study included: fear of side effects, turning to alternative therapies, stigma and fatalism. The concept of taking alternative therapies was consistent throughout the literature explored (Darr et al, 2008; Lucas et al, 2013; Amin et al, 2015; Patel et al, 2015). This supports the findings of this study, as participants reported fearing side-effects or taking multiple medications to control symptoms. Instead, many participants tried herbal therapies

such as ‘karela’ (bitter melon) or herbs advised by a herbalist or ‘hakim’, to avoid western or prescribed remedies. This was mostly seen in older participants from the first-generation, who expressed mobile phones and text messages to be a “*waste of their time*” (NU15).

Stigma was another major factor contributing to non-adherence, particularly amongst diabetic participants who felt it was not important to take insulin to control symptoms. Literature advocates that SA participants fear disclosure to others due to feeling shameful and embarrassed, affecting their ability to seek appropriate support (Patel et al, 2012; Vandan et al, 2018). Studies also suggest SA ethnic groups to associate life events such as disease and illness with a greater power, being God, and religion (Saffari et al, 2013; Patel et al, 2015; Davis et al, 2020). Many participants attributed the cause of their condition being due to fatalistic beliefs, including their ‘fate’ or ‘destiny’. This was another reason why participants rejected FLO and text messages, particularly Muslim and Sikh subjects (NU11, NU12, NU16). Such individuals lacked motivation, viewed their self-management negatively, and perceived health and illness as a supernatural phenomenon, as they seemed more reliant on God to ‘cure’ their problems instead of taking medications or using FLO.

*NU16: “God is enough for me; He helps me get through it. I don’t need to use FLO. If I have God, I don’t need anything else.” (60-year-old, female Non-user, with Diabetes and Hypertension)*

From the results collated and the empirical evidence reviewed it is clear that gaps remain in understanding and investigating health beliefs, perceptions, attitudes and behaviours of ethnic minority groups in the UK. These findings establish an understanding of the cultural factors responsible for poor adherence to treatment regimen and acceptance of text messages; highlighting the need of a ‘culturally-sensitive’ approach to facilitate such interventions to enhance health behaviours, modify negative beliefs (for example, stigma), educate and support self-management of SA populations.

### **Using Text Messages as a Behaviour Change Agent amongst SA Patients**

Overall, the findings from the qualitative phase explicate the FLO text messaging system to optimise positive behaviours, alter negative ones and act as an aid for health promotion. This viewpoint coincides with previous studies extracted during the literature search based on SA groups from within their own regional area, as well as the UK (Shetty et al, 2011; Uzma et al, 2011; Rodrigues et al, 2012; Vakili et al, 2015; Prinjha et al, 2020). Interviews unveiled positive responses from users in relation to their experiences of engaging with the FLO

system. All patients reported text messages based on their condition or illness to support their self-management for LTCs such as diabetes, hypertension and CKD. Users (including previous-users) with diabetes also explain how the intervention had positively changed their lives leading to significant improvements in their weight, dietary regime and glycaemic control (NU7, U9, U20). Messages were reported to be good reminders for taking medications, symptom control, appointment attendance and monitoring important parameters (for example, blood pressure or blood sugars).

The platform has proven to show a high level of acceptability amongst this ethnic-minority sample, as individuals mentioned its usefulness and willingness to recommend it to friends and family with similar health issues (for example NU7, U14). On the other hand, FLO was also criticised in terms of language, content and preferences of other alternative systems (NU1, NU3, NU10, NU20).

In general, the study contributes to the growing body of evidence surrounding the use of SMS to support LTCs, and particularly research regarding the FLO text messaging platform (Cottrell et al, 2015; Cund et al, 2015; De et al 2016). However, contextual factors related to those not using the system were missed in these previous studies (Cottrell et al, 2015; Cund et al, 2015, Poole et al, 2016), hence, were addressed in this study and summarised below.

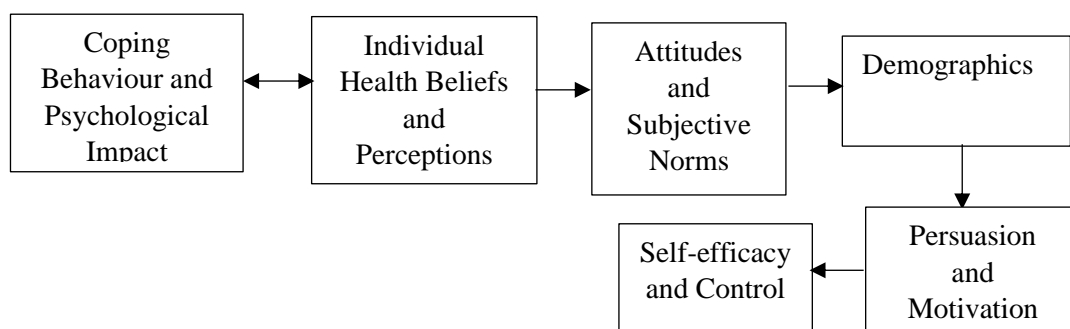
### **Understanding Behaviours of SA patients: A Theoretical Approach**

This was the first study attempting to theoretically explore and understand behaviours of a SA sample with LTCs in the UK, along with their use and acceptance of text messages. Interviews were useful to collate information and reflect upon behaviours surrounding the self-management regimen, levels of adherence and participant views of the FLO system. Interesting findings were obtained relative to concepts of behaviour change theories such as CS-SRM and HBM (Janz and Becker, 1984; Leventhal et al, 1997; 2016) which are outlined in Chapter Four. The rationale for applying these theories to the interview guide, was to generate a clearer understanding of why SA patients may not engage in behaviours to prevent illness or disease; why they may accept or reject mobile phones or text messages; what they expect from a text messaging system; their interpretation of illness, self-management, the healthcare system, and their coping behavioural outcomes. Evidence suggests cultural barriers, attitudes, norms and beliefs to contribute to lack of uptake of technology-based interventions and non-adherence within SA groups (Patel et al, 2015; Kumar et al, 2016; 2018). Therefore, an overarching aim of the study was to extend the understanding of theories

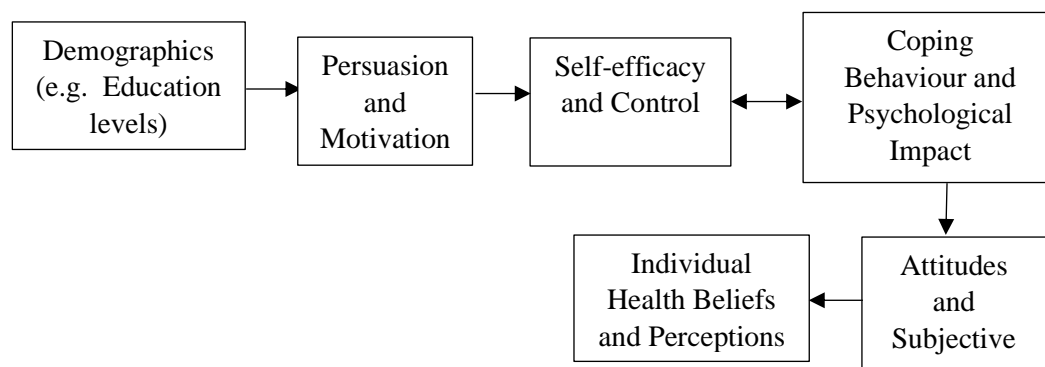
such as CS-SRM and the HBM. Subsequently, similar determinants were identified across participants, specific to adopting text messages. Some elements derived from other theories also discussed in Chapter Four, such as the TPB, ELM and TAM (Demographics; Attitudes; Subjective Norms; Health Beliefs and Perceptions; Coping Mechanism/Behaviours; Psychological Impact; Persuasion and Motivation; Self-Efficacy and Control).

The identified aspects were found to trigger individual engagement with FLO, their self-management behaviours, and their health-related beliefs. The determinants were outlined in Chapter Four (Box 4), and were found to influence both users and non-users. All constructs were found to be equally important to alter behaviour, and were interconnected to one another. However, to develop interventions that are likely to be accepted in future, the researcher realised that the order of the framework differed for all participants (users and non-users). For some non-users' cultural norms were most important for them before they could accept FLO; whilst, for other non-users coping strategies and belief in God helped them get through it and led them to turn away from FLO. This applied to users also, where demographics such as education and employment were seen to contribute to their uptake of technology. Diagram 10 and 11 present the same variables depicted in a varied order dependent on different participant contexts (i.e., users and non-users). This helps create an understanding of the relevant steps necessary to alter SA behaviours and the acceptance of text messages in certain participants from different contextual backgrounds (NU16 and U18).

**Diagram 11.** *Theoretical Framework Depicting Sequence of Behaviour Changes and Acceptance of Using Text Messages for NU16 (see exemplar of participant context in Table 29)*



**Diagram 12.** *Theoretical Framework Depicting Sequence of Behaviour Changes and Acceptance of Using Text Messages for U18 (see exemplar of participant context in Table 29)*



These interconnecting variables were appropriately applied by the researcher to understand SA's perspectives and attitudes towards their illness, and recognise the socio-cultural impacts on behavioural decisions, which in turn, could help facilitate interventions they would likely accept. For NU16 coping behaviours and psychological impacts were the driver to her self-management. She believed faith was the reason for her motivation, and expressed her belief in God being more important than using FLO, and the only factor that enabled coping. Hence, NU16 rejected the system.

In comparison U18, expressed that in order to accept and understand FLO, demographical variables such as having higher education levels were most important for optimal self-management. Although, U18 found comfort from religious factors similar to NU16, she elaborates education to be a key factor in her self-management and explains messages have helped encourage and educate her better with her self-management. This resulted in her coping better and accepting the messages received from FLO.

Factors from similar behavioural frameworks have been found to influence behaviours of SA patients with diabetes in a previous study by Patel et al (2012). Further research would be beneficial to determine whether the same constructs can be applied by health professionals to understand health behaviours of similar samples based on their context.

### **The Definition of a Tailored Intervention for SA Patients**

In general, participants (users of the system) were satisfied with the FLO system, however, they had recommendations of how the system can be improved and tailored to suit the wider SA community. Previous studies cite the lacking, and increasing need of culturally tailored interventions for reducing symptoms of LTCS, effective health promotion and optimal self-



management (Patel et al, 2015; Kumar et al 2016; Jiwani et al, 2018). Evidence has supported and investigated the use of tailored text messages in other countries, and found such systems to improve glycaemic control in type 2 diabetes or interventions to assist with maternal health (Dobson et al, 2017; Sahin et al, 2019). Dobson et al (2017), have demonstrated the importance of developing a culturally tailored mHealth intervention for multiple ethnic minority groups within New Zealand, this included SA samples. The intervention was called TextMATCH which was designed to monitor maternal health. A key feature was to offer translation for those not being able to speak English. Results showed positive responses in relation to personalization of messages, the provision of language preference and information relevant to each participant, making them feel supported.

Although there is literature based on culturally adapted text messages in varied regions of the globe, evidence of executing such interventions in the UK remains scarce, as there is not yet a system existing to suit the needs of ethnic minority groups such as SAs. Therefore, during interviews patients were specifically asked to define '*how interventions such as FLO can be tailored to your needs?*' or '*what should a tailored intervention entail?*' common suggestions made were language preferences, content of messages to include more information, and messages to be received at a preferred time (U1, NU1, NU3, NU15, NU18). Translation was a major concern for most as they were not able to understand messages, which affected their self-management and increased their reliance on other family members to translate for them (U10, U11). These individuals expressed that in order to achieve good health outcomes, it was important to understand what they had to do in terms of reading text messages and acting on them (NU1, NU10). Navodia et al (2019), highlights the importance of rethinking the ways in which SA groups are presumed to be a homogenous group, when in fact they are all heterogenous with varied health needs in terms of sociocultural factors (age, gender, culture, generation type, socioeconomic status, education levels). Thus, it is important to address the differences that exist when adapting and designing a culturally tailored text messaging intervention, appropriate for SAs, rather than the general population alone (Navodia et al, 2019).

Other participants felt that messages should be more detailed to include more information about dietary intake, foot care (for diabetic patients), and things to avoid whilst living with a certain LTC (NU19). They felt that such information would make them aware of what is and is not permitted. Ormandy (2008), also agrees that information that enables individuals to recognise and understand their symptoms is reassuring and reduces feelings of uncertainty.

There were also a few individuals who complained about messages being sent at inappropriate times, and articulated it would be beneficial for messages to be sent out of working hours (U12). This was so that they could adhere to and follow the advice sent promptly, during their spare time, as a lack of time may prevent an individual attaining their goals and meeting information needs even when motivated (Nicholas 2000; Ormandy et al, 2008).

As a whole, this research study demonstrates the importance to implement mHealth programmes that are tailored for ethnic minority groups, who face difficulty accessing appropriate support for their condition due to language and cultural differences allowing for positive behavioural modifications. Furthermore, it is also important to consider technological infrastructures, how such systems can be introduced to varied health sectors caring for ethnic minorities, and how these groups will respond to mHealth or text messaging technologies

### **Implementing PAM and Activation Levels of South-Asian People**

A fundamental objective of this study was to assess whether the PAM provides a useful indicator of SA participants' ability to self-manage, and whether they would benefit or engage with a text messaging intervention. The tool was a useful measure to show each individual's level of knowledge, skills and confidence to manage their LTC. This is important as it will determine whether an individual can independently manage their condition, or whether they are needing extra support from health services (NHS England, 2020). The PAM has proven to be a robust and valid instrument, first developed and used in USA (Hibbard et al, 2012, Smith et al, 2015), and then across European countries (Rademakers et al, 2016), including the UK (Gao et al, 2019). There was notably limited evidence of the tool assessing activation levels in ethnic minority groups. Only two studies were found (Gwyn et al, 2016; Zeng et al, 2019). Gwyn et al (2016), assessed activation levels of African-American samples in the USA, and Zeng et al (2019) across Chinese subjects with hypertension and diabetes. The PAM was verified to show good reliability and validity for measuring patient activation levels in both African-American and Chinese samples with LTCs. There were no studies found to employ ethnic minorities in the UK; making this the first study conducted in the UK, to utilise the PAM across a SA ethnic minority sample.

The findings from the quantitative phase demonstrate that the PAM scores were significant to patient use of text messages to aid self-management ( $p=0.00$ ). Activation varied between SA

subjects based on socio-demographical factors and whether or not they were using FLO. Individuals who were using the system, and had some sort of education obtained higher PAM scores (37.5%), compared to those who had lower literacy levels and were not using FLO (22.5%). An association between low activation levels (and scores) and literacy levels was also seen in African-American ethnic minorities (Gwyn et al, 2016).

Text messages have had positive effects on behaviour changes and self-management, in previous study samples (Ludwig et al, 2018). Users activated up to level 3 and 4 (n=17, 42.5%), expressed how FLO assisted with their self-management, confidence and motivation to maintain healthy behaviours. They had knowledge of their condition, understanding of their treatment regime, and when to seek support from healthcare providers when needed. On the other hand, non-users showed the opposite, with a lack of understanding of what a LTC is, how to manage it and when to seek support.

The results show the PAM to be a useful instrument to assess the spectrum of skills, knowledge and confidence of an individual to manage their LTC independently; and also support the use of text messages to enhance activation and positive self-management behaviours. Although, the body of evidence is growing, ethnic minority groups remain understudied. Further research is needed to extensively monitor these groups to help determine what they know, and whether they recognise their role in self-managing their condition, as everyone's ability to self-manage will vary considerably from person to person.

### **Self-Management of SA Family Members**

Findings from this study, as well as existing literature have noted SAs to place family and their society above themselves (Mines, 1988; Mendenhall et al, 2016). It was quite commonly observed that the SA community expected the family to be ultimately responsible for providing health support rather than the healthcare system. Whilst, these individuals navigate autonomously, the cultural backdrop results in patients to engage in less punitive health practices (Mendenhall et al, 2019). This can lead to a situation where people do not have much contact with the health care services or providers, resulting in poorer understanding of their illness and management (Megari, 2013). Such participants resulted to have low activation levels and scores, as they were less engaged with their self-management (U10 and U11). Instead, they were dependent on family members to help with medications, accompany them to appointments and respond to the text messages received. For this reason, family structures within the SA community were highly valued, as immediate and close members

were viewed as the main source of support (Davis et al, 2020). Although, many male participants had high activation levels, they reported that they maintained a healthy lifestyle though the assistance of their spouse and children (NU7). In many cases the wife was reported to be responsible to prepare healthier meals, encourage with exercise and remind their husband to take their medications on time (NU7). In contrast, certain female participants (U6 and U10) also received support from their husband with house chores and the management of their condition.

Other support systems perceived by SAs was from the larger SA community, involving the opinions and approvals of the wider family and friends who influenced adherence to medical regimen, advise and the attendance of appointments. There was also the notion of conditions such as diabetes being treated as a common occurrence amongst SA participants. Individuals facing such conditions were encouraged and comforted by close relatives, to accept that diseases such as diabetes are very common. Mendenhall et al, (2016), use an Indian sample to define conditions such as diabetes to be “normalized” in everyday life as a comfortable and non-foreign phenomenon that had become part of normal life. Similar findings were retrieved, where participants would use fatalistic aetiologies to remove personal blame from diabetes by referring to such illnesses as ‘inevitable’ due to fate or destiny. For example, NU17 reports God to have predetermined his illness and not needing to engage with FLO.

*NU17: If God has predetermined my illness, then only he will make it better, I don't believe in using a text messaging system to try improve my health. (58-year-old Pakistani male, Non- user, with Diabetes, Hypertension and CKD)*

Strong family ties have been found to shape the attitudes and experiences of SA patient groups (Patel et al, 2012). As a result, these relations exerted huge amounts of social and cultural pressures. Participants expressed that these assertions made it difficult to manage conditions such as diabetes, due to the social stigmas attached (U15). In a study by Ahmed et al (2018), SA participants perceived their illness as a punishment due to poor lifestyle; henceforth, individuals with diabetes attempt to conceal or hide the condition regardless of the consequences. Correspondingly, the sample of this study chose to compromise their diet, treatment regime and had poor activation levels due to fears of being labelled. As an alternative they adhered to their community's social norms and etiquettes.

Overall, this study collated valuable information on self-management experiences of SA subjects concerning family and social support networks. Family is the most vital source of

support for SAs, in terms of both emotional and physical management of an illness (Davis et al, 2020). Those who lacked this reported feeling distressed and a struggle to cope alone. Although, this was the case, some family members would impose their socio-cultural beliefs onto those living with the condition to overcome social stigma. These factors were found to lead to complexities in self-management, and were associated with low activation levels. The management of an illness was not only found to include the ‘self’ but is rather family-oriented. Therefore, for health advice to be followed it might be an idea to educate the family unit alongside the patient. Literature also supports this suggestion as participants from other studies suggested that a family-centred approach can improve health outcomes, provide education for both SA patients and family members, and optimise the management of a LTC (Macaden et al, 2015; Davis et al, 2020).

### **Information Provision and Educational Needs of SA Participants**

Low Activation levels were evident amongst individuals with limited or no education at all, this contributed to their ability to effectively self-manage and use the FLO system. Most SA participants were dissatisfied with the self-management plan advised by their GP, resulting in a lack of awareness regarding the prescribed treatment regime (NU13, NU15), as well as knowledge about their illness. There was unhappiness about delays in getting appointments, GPs using lay-language (or terms) whilst making a diagnosis, and not having a written plan of treatment to refer to (NU3, NU6).

*NU3: “It takes weeks to just be seen, by the time the doctors arrange to see me I feel like my health has gotten worse. If I’m honest I don’t think anyone cares [referring to the healthcare system]. I have a lot of uncertainties regarding my condition and regular appointments can be helpful to catch up with the doctor regarding my progress.” (70-year-old, Indian female Non-user, with Diabetes and Hypertension)*

*NU6: “I sometimes struggle with my regime and really think a written care plan, or information leaflet about my medications will help me remember why I am taking the medications I am, and how I am going to improve from it. Recently, I haven’t been doing too well with taking medications on time.” (53-year-old, Indian female Non-user, with Diabetes and Hypertension)*

Hence, individuals felt their educational needs were not being met. Some also reported dissatisfaction due to healthcare services unable to meet their cultural and religious needs. Such participants reported they wanted to cause less disturbances to healthcare systems due

to the cultural, language, and communication barriers. A SA sample in a study by Vydelingum et al (2000), also reported similar experiences of wanting to cause minimal disruption to the healthcare setting and tried to adapt to what they called an ‘English place’. Although, the study is quite dated findings are interesting and consistent with the present study.

Furthermore, there were also those individuals that had low levels of education but still had some awareness due to a high prevalence of conditions such as diabetes seen amongst family members (U15). Therefore, family was an important source of knowledge (NU7). However, participants did impose considerations for further culturally appropriate education sessions in their preferred language to address information needs, translate English written action plans (NU10), and some females requesting segregation from opposite genders during educational programmes (NU16).

In a previous study by Bhurji et al (2016), SA participants also preferred separate gender sessions with regards to exercise and physical activities, suggesting culturally-integrated interventions such as yoga and dance to have worked for Indian subjects.

Consequently, the findings conclude that there is a need for designing culturally tailored educational programmes, aimed at promoting the self-management of LTCs. This will benefit health care providers as it will create an awareness of the complex socio-cultural attitudes and perceptions, to effectively address SA individuals’ education needs. Interventions cited in literature such as “Khush Dil” (happy heart) or “Chini Kum” (less sugar) (Kumar et al, 2018) were culturally adapted for SA communities with CVDs and diabetes, and found improvements in self-management amongst those taking part. Perhaps the implementation of interventions intended specifically for SA ethnic minority groups, are more likely to lead to changes in behaviour and promote better health.

### **Satisfaction of SA Educational needs**

Patient activation scores correlated with levels of knowledge, those with adequate information regarding their illness were better activated than those that did not. As discussed above, many SAs were dissatisfied with the information they received and their education needs not being met. They also felt that they were not being provided appropriate information that could positively improve their treatment regime. A recurring concern expressed in some participants, was the lack of available information relating to the causes of their condition, treatment plan and their set goals. Non-users of FLO who were not able to read text messages

desired information to be provided via translated text messages or through other platforms such as videos, telephone calls or one-to-one consultations with their GP, to make it easier to understand and follow. Kumar et al (2018), found that information provided in English for non-English speaking SA participants, was not seen as useful due to not understanding what was advised and making it difficult to reach health goals. A lack of appropriate information provision resulted in people ignoring conventional therapies, and turning to traditional advice and medicines from practitioners abroad (U13, NU16).

*NU16: "I feel like I don't have enough time to discuss my health problems, the doctor always seems rushed. I have so many questions and uncertainties about my illness and medications. So, I don't really take all the medications, I mix it with some herbal remedies. This is when I don't understand the English medication labels." (60-year-old, Pakistani female Non-user, with Diabetes and Hypertension)*

There were also some individuals who felt the doctor's role was authoritative, which meant information given by them would be most beneficial for them compared to that provided by other healthcare professionals. This was common amongst first-generation patients, who reported not attending follow up appointments with the nurse, as they valued the doctors advise instead. Information given by healthcare providers that were of the same ethnic background (NU15), communicating in a language understood by patients were also valued.

*NU15: "I would much rather speak to a doctor who speaks Hindi or Punjabi. I think then I can get my point across, I can't always express myself with the English clinicians as I don't think they understand my English or what I am trying to say" (80-year-old, Indian male Non-user, with Diabetes and Hypertension)*

In a previous paper by Kumar et al (2019), participants articulated that they were able to build a better rapport with healthcare providers they shared common grounds with in terms of culture and language, compared to English speaking or Caucasian clinicians. This resulted in better satisfaction as they were able to address their concerns, ask for advice and more information if required. Additionally, subjects reported that translated and culturally tailored methods made it easier and effective to implement the goals set (NU10).

*NU10: "Translated information sheets, text messages and material can help people like me understand and learn more about my condition. English is not my first language so I don't comprehend with the information being provided by the doctor or nurse, unless*

*they are speaking Urdu or Hindi.” (65-year-old, Pakistani male Non-user, with Diabetes and Hypertension)*

Informed education for this patient group is essential to invoke an understanding of treatment regime and influence effective self-management of LTCs. Evidence regarding SA participant education seeking and needs is limited. Therefore, the findings of this study can help health care professionals to understand and develop strategies individualised to assist, meet education needs and map the journey of individuals with LTCs in a more successful and meaningful way.

### **Strengths and Weaknesses**

#### *Exploring Patient Experiences of Using FLO*

This research led to the collection of insightful data regarding user/non-user experiences of the FLO system along with patient activation levels. It could be argued that a mixed methods approach using both quantitative and qualitative methods is an effective research strategy and a considerable strength to achieve the aims of this study, which were to explore experiences and measure activation levels of SA ethnic minority groups within the UK. This methodology increased validity and rigour to the results, by adding a broader dimension to the quantitative findings where there is lacking context to describe and explain findings, as well as depth and meaning to the data extracted from the qualitative findings.

The strength of the data gathered from in-depth patient interviews allowed for a deeper understanding of real experiences of SA patients living with an LTC and the use of the FLO system to support their self-management. The incorporation of behaviour changes theories such as CS-SRM and HBM to the interview guide, provided an appropriate framework for understanding SA individual beliefs, perceptions and how SA participants make sense of and manage their illness using FLO. Furthermore, certain themes became pertinent which extended the determinants to explain certain health behaviours SAs practiced. These were very much relevant to factors such as culture, religion and health beliefs which were identified to influence and determine the acceptance to text-messaging technologies and patient activation levels in different participant contexts. While, transcribing interviews to English was a time-consuming task, they allowed a fuller explanation to individual patient activation levels, as participants would elaborate on certain responses to items of the questionnaire which helped with the scoring of the PAM tool.



Gaps still remain in the growing body of evidence regarding the implementation of suitable interventions for ethnic minorities within the UK, particularly SAs. However, there is a consensus between the findings of this study and other literature that has employed similar SA samples (Patel et al, 2012; Kumar et al, 2016; 2018; Prinjha et al, 2020), regarding particular participant characteristics, with respect to treatment adherence and self-management. This included demographics such as education and literacy levels, religion, age and cultural norms and traditions. This study measured these variables in acceptance to FLO and impacts on PAM levels in SA participants living with one or more LTCs. Interestingly differences were found between age groups and particularly education levels, which helped understand individual educational needs and what they desired from a text-messaging intervention to self-manage their LTC.

#### *Patient Activation Measure*

The PAM was quick and easy to complete, it was also very useful in identifying SA participants' levels of knowledge, skills and confidence to self-manage their LTC. Another valuable factor was that it is available in several different languages including those that were spoken by SA groups. Preference of language choice made it easier for participants to complete the survey. However, a majority chose to have a family member with them to assist them whilst completing questionnaires. Administering the PAM tool during face-to-face interviews was labour intensive, however, this enabled clarification of items and their meaning. Although, the PAM is a fairly recent development, it is being used extensively to understand people's self-management behaviours. The 13-item study instrument was used to initiate discussion and draw out specific participant education needs, and the necessity of having culturally tailored educational programmes to enhance their self-management.

A weakness of the study was the reliability and generalisability, as issues presented due to obtaining a smaller sample size than predicted. Analyses techniques were reviewed from other studies that had utilised the PAM, however, all studies employed samples much larger. Eventually, support was provided by a statistician in employing appropriate analyses techniques, which have been highlighted and discussed in Chapter Six. Prior to the analyses of the quantitative data, issues were also experienced in converting PAM responses to scores, categorising patients into a particular activation level, and obtaining translated versions of the PAM as a license was required. To obtain this, an application was to be completed and sent to NHS England for approval. Unfortunately, the license was rejected due to having a much smaller sample than recommended (n=200). Support was offered by the Patient Activation

team, who directed me to the local Connected Care team of the study site who granted a license. This took several weeks and caused delays in the analyses process of data from phase one.

This was the first study to employ the PAM across an ethnic minority group in the UK. It allowed participants to express their thoughts and perceptions regarding the facilities available to them from the healthcare system, their confidence to consult with their healthcare provider and their understanding of their treatment regime. Findings showed that the FLO system was seen to alleviate and optimise self-management, compared to those not using the system with lower activation scores. The majority of these participants had been referred to specialist doctors and nurses for support and follow-up of their progress. SA ethnic minorities have a higher risk of developing LTCs such as diabetes, hypertension and CKD; and have poorer health outcomes compared to Caucasian populations (Barbour et al, 2010). Therefore, the PAM was a useful indicator to monitor self-management abilities of participants, and can be used in future to identify healthcare needs of similar samples.

#### *Sample Recruitment*

Identifying a SA sample within the UK was the toughest element of this research study.

However, the sampling technique employed helped overcome this challenge, which involved me to contact previous authors to request whether they had recruited such samples.

Eventually, I came across Dr Parijat De, who was using the FLO across a SA population in the Midlands. This gave access to the target sample for this study. However, a disadvantage of this was the travel time and cost it took to get to the study site (Midlands). Nonetheless, the journey was worthwhile, allowing data collection essential for this thesis.

The study managed to recruit 40 participants, which was less than predicted. This imposed challenges to finding an appropriate statistical test for analyses, as a smaller sample ( $n=40$ ) than expected ( $n=50$ ) was obtained. Although, non-parametric tests were a useful option, analyses of a low statistical power can reduce the chances of detecting true effect (Button et al, 2013). Contributing reasons to the shortfall was firstly due to data becoming saturated during the qualitative phase, and secondly clinic visits reducing during the outbreak of COVID-19. Given that the SA community are an under-represented group (Ramachandran et al, 2013), valuable findings were obtained from the participants' experiences and the PAM tool, fulfilling the aims of the research.

A further weakness was the clinic times being limited, hence, some participants had to be interviewed after their appointment with the main clinician. Despite this, many participants were willing to wait as they expressed that a research study such as this, may help voice their concerns, and offer them support through better culturally tailored programmes. This study sample was representative of the wider SA community, and stressed the importance of having interventions such as FLO translated to help others just like them, particularly in regards to LTC self-management. To take this aspect forward, further research is needed across larger SA samples within the UK, through patient and public involvement implemented to study designs.

### *Importance of Topic*

Existing evidence relevant to ethnic minorities in the UK, particularly that of SA samples was found to be extremely depleted. As a result, this provides the justification of this study at the very beginning of this thesis, identifying the importance to examine and explore the experiences of SA ethnic minority groups living with a LTC, the use of FLO text messaging intervention to aid self-management; and the influences of socio-cultural factors regarding the acceptance of such platforms. This was confirmed by literature focusing on LTCs and the use of text messages to promote optimum self-management outcomes. Given text messaging and mHealth being extensively used amongst general populations to monitor and enhance health, it was further demonstrated that SA participant experiences and their use of text messages had not been previously investigated enough in the UK. The results from the study identified health beliefs that influenced SA's engagement with digital health (mHealth) interventions and their self-management. Therefore, developing policies and culturally appropriate education guidelines for healthcare providers can allow for the provision of culturally-sensitive interventions tailored to account for normative, cultural and religious beliefs; which in turn will address crucial aspects such as SA participants' educational needs to support their self-management journey.

The next section reflects on this PhD journey of utilising a mixed methods approach, recruiting a SA sample, completion of this thesis whilst being an NHS front-line worker during the Covid-19 pandemic, supervision sessions, and finally a reflection of my personal experiences of carrying out this research as an 'insider' of the SA community.

### **Utilising a Mixed Methods Approach**

Planning and implementing this mixed methods approach have been a valuable learning experience that has allowed me to enhance my skills and appreciate the intricacy of combining both quantitative and qualitative methods in research. Interviewing participants was the most enjoyable part of the field work. It was an insightful experience for me, as I was able to view SA experiences from a lens through which SA individuals were living with, coping and managing their LTC, along with their perceptions of digital health systems such as FLO. Furthermore, I have been able to build a rapport with people from the same background as myself, appreciate the health belief system of SA participants, as well as respecting the importance of cultural norms impacting their self-management regime. Although, the analytical process including the time, resources and analyses techniques have been challenging, it was a valued learning curve, which also helped me build my project management and organisation skills.

### **Experiences of being a Frontline Worker and Researcher During the Covid-19 Pandemic**

It has been an honourable experience to serve as a frontline worker within the NHS, to support patients, peers and other NHS staff during this time of uncertainty and stress. Providing care and being part of the hazardous hospital environment during the Covid-19 pandemic has been the most challenging time of my career till date. It has accompanied multiple experiences and emotions such as fear of exposure to pathogens, long-strenuous working hours, psychological and physical distress, anxiety, fatigue and also stigma from the outer society. None the less, I did not allow the stresses of work to intervene with the completion of the research and thesis write up, I remained motivated and committed throughout this journey. However, the pandemic led to implications of certain aspects of this project, as clinics were reduced or being cancelled, which limited recruitment opportunities.

### **Supervision Sessions**

Supervision sessions were an integral part during my PhD journey. Being a part-time student within the university and juggling a full-time job, I ensured I would arrange to meet with my supervisors regularly to discuss the progression of the study. From the discussions, targets and deadlines were set, leading up to the completion of this thesis. Additionally, the continuous support and encouragement of this research study has resulted in dissemination of my work to peer-review publications, and attendance to conferences. Future career prospects were also discussed regularly with my supervisors, regarding where I would like to be with

regards to my research and future work. The support offered by my supervisors helped shape me not only as a researcher, but also as the person I am today, for which I am very grateful for.

### **My Personal Experiences as a Researcher**

In Chapter One, I discuss my experiences as an ‘insider’ of the SA community witnessing poor adherence to treatment regimens amongst SA individuals living with a LTC. As a healthcare provider, I was never able to understand or grasp the experiences of SA patient groups, and their self-management beliefs of LTCs. However, going ahead with this research study provided insight to the complex factors associated with self-management, the uses and acceptance of text messaging for LTCs. Also, including the role of health beliefs, cultural and religious contexts influencing self-management, and the adoption to technology-based interventions amongst SAs. In addition, it was satisfying to find that this research adds and supports existing literature, and addresses the gaps of a text messaging system being a feasible tool to enhance positive behavioural outcomes of a SA sample living with a LTC.

This research has also contributed to knowledge about the importance SA individuals place upon the support provided by their family and the wider SA social network, to help them cope both physically and mentally. The results inform myself and other healthcare professionals that self-management is more a family matter for this population group, than of the ‘self’ and is to be dealt with together with one another, than alone or independently. Moreover, this study will aim to contribute to the formation of new policies, guidelines and implementation of mHealth interventions targeted to the needs of SA patients with LTCs.

### **Summary**

The focus of this discussion has been to bring together the key findings of the study and to make clear what the data revealed. Overwhelming evidence has formed and contributed to new knowledge through exploring and understanding SA participant experiences of living with an LTC and their use of the FLO text messaging system to enhance self-management behaviours.

This study has shown the feasibility of conducting research amongst under-represented samples such as SA ethnic minority groups. Not only did it explore individual experiences of FLO users and non-users, but also assessed its impact on patient activation levels to independently monitor and self-manage their condition. Supported self-management is comprised as part of the NHS long-term plan to enhance patient-led services. Hence, patient

activation is a recent, but key component for people with LTCs. The PAM tool was useful in identifying a SA individual's capability to self-manage autonomously, based on their level of skills, knowledge and confidence. A barrier for many SA participants was the lacking provision of appropriate information and education on self-management, leading to poor health outcomes. Such participants emphasised the need for suitable skills to manage their condition. To develop these skills, it is the responsibility of the health care professional to provide such groups with the adequate information they require regarding their treatment regimen (NICE, 2020).

The study identified a number of determinants influencing patient acceptance and use of FLO. Demographical factors such as age and education levels played a significant part of not wanting to or being able to use the intervention. Younger, educated people were better activated and able to use the FLO, compared to older subjects with lower literacy skills. Coping behaviours and health beliefs were interconnected with cultural and religious norms, which in turn influenced their use of FLO. For example, some individuals believed that God was their main source of support compared to a text messaging system, which could not make their health better. Many participants also reported health education and cultural needs were not being met as health care providers failed to understand them. Additionally, non-users expressed that a tailored and translated text messaging platform can be of benefit for them and help alter a non-adherent behaviour to a positive one. Thus, it seems reasonable to develop and introduce culturally tailored interventions incorporated with mHealth.

The wealth of information gathered from this research will inform and guide the evidence base for best practice through implementing policy and educational programmes tailored to meet the needs of SA ethnic minorities. There is a need for a more insightful approach in healthcare by observing experiences and behaviours of ethnic minority patient groups, to identify their healthcare needs, improve self-management and achieve better health outcomes.

The study was successful in achieving the set aims and objectives. It was the first study of its kind to be designed and conducted in the UK. The evidence from the study is a starting point, which provides researchers a platform upon which to build, with that being the arena of health informatics and mHealth. It highlights the need for further research on this subject matter, particularly the use of text messages and other mHealth interventions (for example, mobile apps) amongst SA participants with LTCs. Based on the findings collated

recommendations for future research, practice and policy are presented in the concluding chapter.

## Chapter Nine

### Implications and Conclusions

#### Introduction

This thesis explored and described SA participant experiences of engaging with the FLO text messages to enhance positive behaviours and promote self-management. Most importantly it addressed the gaps in literature by identifying contextual factors hindering self-management, affecting health behaviours and influencing adoption of mHealth technology. Evidence was gathered to help understand SA's self-management behaviours from a socio-cultural context, and why certain individuals may behave the way they do.

Examining experiences of this sample group assisted in identifying their healthcare needs and preferences of interventions that could assist their understanding of their LTC and self-management journey. This included the necessity of culturally-tailored services and text messaging systems, which have proven to be effective in studies previously conducted across other countries (Patel et al, 2017; Dobson et al, 2018). For healthcare professionals to have an awareness of engaging with, and supporting the needs of SA ethnic-minorities can improve self-management and the quality of health outcomes.

The findings collated within this thesis contribute to theory on multiple grounds. The exploration of SA individuals' perceptions, beliefs and views have allowed for a much deeper and broader understanding of their health behaviours. A definition of a 'tailored' intervention from a SA perspective, will provide a greater clarification of what this patient group desires regarding their condition. Integrating definition and a patient viewpoint will help inform future policy and guidelines to enhance self-management behaviours of this sample group. By exploring the influences of contextual factors and use of interventions such as FLO to encourage self-management, a pragmatic evidence base has been formed, which was once unknown, but now illuminates the field of digital health. This valuable evidence will inform future clinical practice, will help plan and facilitate culturally appropriate systems for SAs and wider ethnic minority groups in the UK.

In summary, this study has made a novel contribution to the study of self-management in SA groups through the use of text messages and the administration of the PAM for the first time. It also generates new knowledge relative to the field of health inequalities experienced in



ethnic minority groups and their self-management behaviours in relation to engaging with digital health intervention.

Implications emerge from the study findings with relevance to clinical practice, policy, and scope for future research.

### **Clinical Practice and Policy Suggestions**

- FLO was a successful platform that allowed for positive behaviour changes amongst SA ethnic minorities. Similar mHealth systems that are translated and tailored to suit the needs of SA samples are strongly recommended.
- Consider creating culturally-tailored platforms similar to FLO, better suited to SAs and other ethnic groups, who maybe facing inequalities such as language or cultural barriers. For example, translated text messages, which could help individuals engage better with mHealth systems, effectively follow advice given and self-manage their condition. Interestingly, individuals noted the use of other systems to self-manage. For example, Google OK and ALEXA (NU20), such systems are now using SA languages such as Hindi to translate for Hindi speakers (for example, Hindi Google). Perhaps FLO and other platforms can use similar features as a potential area for development.
- The meaning of a tailored intervention was defined by the SA participants, and their importance to help achieve set targets. Recommendations and preferences included translated services and culturally ‘tailored’ programmes. Therefore, it is necessary to integrate culturally-appropriate interventions for ethnic minority groups.
- A theoretical underpinning is provided identifying key concepts alongside ‘*tailoring*’ such as ‘*nudging*’, which needs to be taken into account when developing and implementing digital health platforms to promote positive behaviours and improved health outcomes.
- Training and development of clinicians and healthcare providers remain as a principal strategy towards achieving improved health outcomes and services. NICE (2020) suggests healthcare professionals be trained to understand patient-centredness as an approach to plan and develop interventions; as cultural competencies are required to gain an understanding of individuals’ skills, attitudes and beliefs of SA groups as well as other ethnic minority groups with varied health needs.
- There are currently no policies or guidelines aimed to support the self-management of ethnic minority groups with LTCs, along with factors contributing to their health such

as their culture, religion and social norms. Therefore, care and support must be person-centred, co-ordinated and tailored to suit the needs and preferences of the individual, their carer or family. For SA participants, support from family and social networks was integral. Perhaps it could be useful to consider strategies that are focused to support both the patient and their families, as the management of an illness was viewed to be more of a ‘family-centred’ approach, than of the self (Macaden et al, 2015).

- Although, the UK behaviour change guidelines are changing to better suit individuals with LTCs, it is recommended that further research studies on behaviour change focus on behavioural processes of ethnic minority groups. This will provide support and guidance for practitioners to modify culturally-sensitive beliefs rooted within SA samples.
- Clear healthcare documentation be developed, as participants complained about missing information or not having a record of their treatment regimen. This will allow for individual information and education needs to be captured, and health care advice to be recorded so that individuals are able to formulate a care plan, build their own knowledge through medical advice, pursue the suggested behaviours and develop techniques to prevent relapse; which will help increase their activation levels.

### **Future Research Suggestions**

Although this study adds to the growing body of evidence, there appears to be the need for copious amounts of research to overcome challenges faced by ethnic minority groups with regards to their health, implementing appropriate mHealth interventions (for example, FLO) and understanding SA self-management behaviours. Collaboration between digital health researchers, health care professionals and SA samples may well lead to a greater understanding of what this population desires from such interventions tailored to their needs to promote effective self-management. Suggestions for future research have been put forward for further examination building on the evidence developed from this study.

- Evidence was seriously lacking in terms of the PAM application across ethnic minority groups. Therefore, further assessment and distribution of PAM across larger SA samples and other ethnic minority groups is greatly needed, to determine their self-management levels.
- The PAM has proven to be an extensive tool to assess levels of skills, knowledge and confidence to be able to self-manage. However, it needs to be implemented more

thoroughly and extensively across ethnic groups such as SAs, to fully assess where the participant is at, to then tailor care plans and to make a track of their progress.

- To assess whether interventions used in the USA such as “Khush Dil” (happy heart) or “Chini Kum” (less sugar) implemented across Scotland, can be integrated into digital health (mHealth applications and text messages) and applied to the wider SA population in the UK to effectively aid self-management of LTCs.
- Conducting further exploratory studies employing SA samples to explore health beliefs, factors hindering self-management and perceptions of mHealth across larger samples for better generalisability.
- A mixed methodology that uses a combination of qualitative and quantitative measures to explore SA patient experiences, and understanding self-management behaviours has been useful, and recommended as an effective research approach to produce meaningful data surrounding this topic. However, longitudinal studies may be beneficial to assess the effects of mHealth interventions such as FLO over a longer period of time, across SA ethnic minorities and similar samples.
- To conduct a larger comparative study to explore differences across variables such as age, gender, education, socioeconomic/employment status and ethnicity; particularly differences that co-exist across SA sub-ethnic groups (Indian, Pakistani and Bengali participants). Through a comparative design it could be interesting to examine illness-related and self-management behaviours across sub-groups. Furthermore, it would be useful to fully understand the role and importance of family and social networks in SA communities.
- Develop further research using theoretical frameworks from behaviour change theories such as HBM and CS-SRM to explore contextual factors such as personality traits, attitudes, emotions and norms. This study was able to establish a theoretical framework outlining certain determinants (Demographics; Attitudes; Subjective Norms, Health Beliefs and Perceptions; Coping Mechanisms/Behaviour; Psychological Impacts; Persuasion and Motivation; Self-Efficacy and Control) to understand SA behaviours dependent on certain participant contexts, and their acceptance to FLO text messaging systems. Perhaps the constructs identified in this study can be applied in future studies as determinants to health management behaviour.

- Age was associated with the adoption and use of FLO. Further exploratory research is needed to understand the differences between different age groups (including different generations) and their preferences on certain interventions.
- Measure SA patient education needs and preferences regarding their appointments, condition, treatment regime and further health advice. It would be useful to look in to cultural preferences particularly, as participants wished to see health care professionals who could speak the same language as them, or females wanting segregation from males, and preferred seeing a female nurse or doctor instead (NU3, NU16). This would help improve information provision, ensure patient needs are met, enhance self-management and increase an individual's confidence through the development of a patient-centred healthcare service.

### **Conclusion**

Findings were collated from this mixed method approach throughout a five-year period. The study design has helped inform SA participant experiences of using the FLO text messaging system and their level of self-management. Being an insider of the SA community, I had always known people to struggle with their self-management regime. Therefore, a desire to overcome this enthused within me, resulting in the compilation of this thesis. After conducting participant interviews, it was made evident that the challenges faced by SAs was not just within people I knew, but also the wider SA community. A heterogenous SA sample was obtained including individuals from varied age, gender, religion, education levels, disease modality, socio-economic, and ethnic sub-groups. The subsequent data analysed revealed contextual factors that contributed to SAs self-management behaviours, their engagement of the FLO system and patient activation levels. These included health beliefs, attitudes, norms, education levels, psychological factors (depression and anxiety) and coping styles. The findings will hopefully endeavour to provide information to improve and guide practice, and generate interventions that will positively benefit self-management of SA ethnic minority groups.

This study contributes to the evidence base on mHealth as well as previous literature based on SA samples. It has achieved the set aims and much more than expected.

- Identifies experiences of SAs living with an LTC, including the challenges they face with the healthcare system, their self-management regimes, and their use of FLO text messages.

- Proves platforms such as FLO to be effective and useful to aid self-management, by providing patient education, motivational messages and important health reminders.
- Tests the PAM tool across an ethnic minority (SA participants) sample for the first time, and successfully assesses the level of knowledge, skills and confidence to self-manage their condition.
- Identifies and highlights personal and demographical factors that contribute to self-management behaviours and the adoption to technology-based interventions such as text messaging systems.
- Examines contextual factors such as the role of health beliefs, social norms, culture and traditions that were found to intervene and influence self-management and acceptance of text messages.
- Refines the definition of what SAs think a '*tailored*' intervention is, and what it should entail.
- Provides a theoretical concept (Chapter 4, Box 4) set to understand the health behaviours of SA ethnic minority groups from varied contextual backgrounds, by outlining determinants that became pertinent during SA participants' self-management journey.
- Contributes to behaviour change theory and interventions designed to alter negative health behaviours to positive.

## Appendices

**Appendix 1. Table 3.** *Data Extraction Sheet of Mobile Phone Interventions Utilised in the Management of LTCs*

<b>Author/Year</b>	<b>Intervention purpose</b>	<b>Intervention description</b>
Louch et al (2013)	Improve insulin administration in young adults with type 1 diabetes	Text content was related to the correct insulin administration  Texts were based on the Theory of Planned Behaviour (attitudes, subjective norms, perceived behavioural control, and intention)
Mulvaney et al (2012)	Motivate patients and remind them with their diabetes self-management tasks	Motivational-Customized messages related to diabetes
Dowshen et al (2012)	Improve adherence to antiretroviral therapy among youth	Interactive with follow-up messages with patients responding with number if they took their medication and if they did not.
Garofalo et al (2015)	Improve adherence to antiretroviral therapy among poorly adherent youth	Personalized by subject for both content and schedule to be timed with medication doses  Content of messages were culturally sensitive and meaningful to participants
Estepp et al (2014)	Improve adherence to hydroxyurea therapy in patients with sickle cell disease	Scheduled daily text message reminders for 12 months  Customizable in terms of content, frequency, and duration. Patients were also able to create their own messages
Ting et al (2011)	Visit adherence intervention Improve adherence to scheduled clinic visits or those with systemic lupus erythematosus (SLE) along with the use of hydroxychloroquine	Content was individualized for each patient and included the scheduled appointment time  Standardized daily text reminders for hydroxychloroquine intake daily or twice daily
Petrie et al (2012)	To investigate whether a text message programme targeted at changing patients'	Targeted text message was designed to increase adherence to asthma preventer inhaler.  Texts consisted of beliefs including: short time-line; Low personal control; Low illness identity (low symptom); High illness identity (High symptom); Low coherence

	illness and medication beliefs would improve adherence in young adult asthma patients	(poor understanding); Medication belief (Low necessary and high concern).
Peiris et al (2014)	Improving Hypertension outcomes	Text messages sent between patients and physicians to monitor blood pressure and patients given feedback on concerns regarding blood pressure
Hamine et al (2015)	Improving hypertension outcomes	SMS enabling interactive monitoring, where the provider set reminders for patients, collected data, and scheduled visits
Kannisto et al (2014)	Reminders enhancing positive health outcomes for patients with LTCs	SMS reminders sent out to different groups of patients with diabetes and HIV/AIDS to adhere to medications and attend appointments
De Jongh et al (2012)	Facilitating self-management of LTCs	Messages sent to patients with various LTCs to improve patient's self-efficacy through, medication reminders, therapy adjustments or supportive messages.
Coomes et al (2011)	Improve health outcomes in patients with HIV/AIDS	Tailored messages sent to encourage greater medication adherence
Goodarzi et al (2013)	Enhance patient knowledge regarding type 2 diabetes	Patients received educational messages informing them of ways to self-manage their diabetes
Mbuagbaw et al (2015)	To self-manage HIV and other chronic diseases	Messages were used to communicate health outcomes, results of medical investigation and self-management advice
Nglazi et al (2013)	Improve adherence of anti-tuberculosis medication	Reminder messages sent regarding appointments, clinical visits and taking medications
DeKoekkoek et al (2015)	To improve medication adherence	SMS prompting, reminding, educating and informing patients improve disease outcomes

**Appendix 2. Table 4.** *Data Extraction Sheet of Mobile Phone Interventions Utilised in the Management of Preventive Behaviours*

<b>Author/Year</b>	<b>Intervention purpose</b>	<b>Intervention description</b>
Boker et al (2012)	Improve adherence to recommended use of topical acne medication	Customized text message reminders sent at a specific time based on patient preferences and anticipated time of each medication use
Fabbrocini et al (2014)	Improve adherence to acne medications (text messages)	Texts focused on frequently asked questions about acne medications, such as administration, daily dose, and side effects
McKenzie et al (2015)	Improve participation in laboratory testing among youth who have had liver transplants	Automated laboratory tests text message reminders sent over 12 months
Free et al (2013)	SMS to reduce calorie intake and increase physical activity	Text messages tailored for weight-loss and increase of physical activity goals
Free et al (2013)	Smoking cessation	Messages created and sent to decrease abstinence rates and improve smoking habits
Free et al (2013)	Sexual behaviour	Text messages created to promote healthy sex behaviours; results showed statistically significant benefits on behaviour change
Whittaker et al (2016)	Smoking Cessation	Messages created and sent to decrease abstinence rates and improve smoking habits
Agarwal et al (2015)	Antenatal support	Messages encouraged mothers attend antenatal clinics
De Jongh et al (2012)	Appointment attendance reminders	Text messages were sent as reminders of attending health appointments
Bacigalupo et al (2013)	Increasing physical activity	SMS sent to prompt patients to reduce calorie intake and increase physical activity
Stephens and Allen (2013)	Increasing physical activity and weight reduction	Text messages sent regarding health promotion, exercise and weight- loss
Noordam et al 2011	Improving maternal health services	Messages sent to empower women to contact and access information
Owens et al (2010)	Prevention of self-harm	Messages conveyed and encouraged patients to feel that 'somebody cares', preventing attempts of suicide and self-harm
Moore et al (2013)	Reduce alcohol consumption	Messages were sent to help participants monitor their alcohol intake



**Appendix 3. Table 6. Studies Utilising Florence Text Messaging System**

Study Type/ title/ Author	Study Design	Sample and Data collection	Aim	FLO Intervention	Results, Outcomes, Conclusions	Strengths/ Limitations (critique)	Discussion
<p><b>A cross-sectional survey and service evaluation of simple telehealth in primary care: what do patients think?</b>  <b>Cottrell et al (2012)</b>  <b>Staffordshire</b></p>	<p>Mixed methods            The acceptability of, satisfaction with and ease of use of a Simple telehealth strategy was determined via text, cross-sectional questionnaire survey administered by telephone, case studies, discussion groups and informal feedback from practices</p>	<p>124 patients from Ten volunteers' general practitioner's (GP) practices in Stoke on Trent, UK, with poor health and high levels of material deprivation participated. Patients from each practice were contacted by telephone by practice staff to complete a cross-sectional questionnaire survey which, using a Likert scale as above and a selection of attitude statements, enquired about the patients' attitudes towards and satisfaction with using Florence.            Discussion groups were to provide feedback about their experiences of being involved in the intervention. The discussion groups were semi-structured and patients were asked questions about using telehealth in general, ease of use of the technology in this specific programme and satisfaction with seeing healthcare professionals less frequently given the</p>	<p>To determine the patient experience of using a simple telehealth strategy to manage hypertension in adults.</p>	<p>Patients received texts regarding regular BP throughout their time using the system.</p>	<p>Results revealed that: Patients were satisfied with the feedback they obtained through Florence            The Flo service provides 'Self-care' that suits the patient rather than the surgery            Florence provided reassurance for patients with uncertain diagnoses of hypertension            Reinforces care and advice from primary healthcare team            Florence was a companion to patients</p>	<p>As this is a service evaluation, the results obtained accurately reflect the actual use of the technology in the clinical setting. Due to the fact that this was a service evaluation, not all patients provided feedback using all the means employed and data collection did not continue until it reached saturation, and therefore there may be some missing data.</p>	<p>Systems such as FLO should be considered for widespread implementation for clinical management hypertension and other long-term conditions involving monitoring of patients' bodily measurements and symptoms as a large number of meaningful readings can be obtained from many patients in a prompt, efficient, interactive and acceptable way. This pragmatic service evaluation indicates that effective, flexible, affordable, acceptable and, in many cases, preferable, when compared with usual care. Not only does simple telehealth deliver a service that patients appreciated and believed in, it appeared to become a companion to some patients. Results indicate that careful selection and counselling of patients is required at</p>

		<p>closer monitoring using telehealth.</p> <p>Patient feedback obtained via the Likert scales was summarised descriptively and average scores were calculated.</p> <p>An overview of the patient experience of using Florence obtained through free text feedback on the questionnaires, written and verbal feedback from practice staff and during the discussion groups was summarised according to topics as they emerged</p>					<p>recruitment onto such a programme to ensure that they understand and agree with the nature and frequency of the processes involved and that they are physically and cognitively able to operate the simple equipment.</p>
<p><b>Use of an Innovative Technology Enabled Care Service (Tecs) “Florence” To Empower Patients and Enhance Adherence to Treatments in Diabetes</b> <b>De et al (2016)</b> <b>Midlands</b></p>	<p>Mixed methods Qualitative and quantitative outcomes (not enough detail provided regarding methods)</p>	<p>126 patients were recruited (100= for BP monitoring, 26=for glucose and insulin reminder). The protocols used focused on:</p> <ul style="list-style-type: none"> <li>• BP reminders (once weekly, once monthly) in CKD and diabetes patients,</li> <li>• High initial BP readings for diagnosis.</li> <li>• Poorly controlled hypertension.</li> <li>• Medication compliance</li> </ul> <p>Other study protocols also focused on weight management, blood glucose testing reminders, managing mood and anxiety.</p>	<p>To implement an innovative approach by adopting FLO to motivate, educate and engage patients in managing their own health</p>	<p>Reminder messages were provided regarding regular BP and glucose monitoring throughout their time using the system</p>	<p>Outcomes of using the FLO system amongst ethnic minority groups: Improved medication compliance through the use of technology and telemedicine. Improved ability and knowledge to adjust own BP medications/ insulin dose in complex patients with diabetes and renal disease. Flo provided useful education and insight gained from patients about lifestyle and habits impacting on adherence. Significant cost savings for the health economy through innovative technology adaptation. Using the system, patients felt they had</p>	<p>Study provides results in favour of the FLO system to improve adherence to BP treatment via engaging patients in their own health through text reminders and regular encouragement. Study methods were very brief not enough detail provided, particularly on data collection, data analysis, sample details, type of ethnic minority groups used and recruitment techniques</p>	<p>Systems such as FLO are likely to increase significantly as well as the number of users. It would be of great use to plan to involve the acute sector as well, to achieve faster clinical outcomes, improve team productivity and release non-urgent capacity.</p>

					<p>more freedom (patients felt they were no longer tied to a machine at home or visits to surgery or hospital. They take BP or BM readings at their convenience whether at home</p> <p>With family, or on holiday); More involved regular, personalised health advice and medication reminders are sent to patients based on their readings – they take more responsibility for their own healthcare); Patients felt an increase in confidence (frequent, short messages are unremarkable and help the patient feel more cared for, more involved, and more in control of their own healthcare).</p>		
<p><b>Enabling supported self-management of wound care in a community setting</b></p> <p><b>Poole et al (2016)</b></p> <p><b>Manchester</b></p>	<p>Quantitative study</p> <p>Survey</p>	<p>28 patients were recruited for the study. Patient experience surveys were used for data collection. Staff were also asked to anticipate the benefits to patients and the team of using Flo.</p> <p>Three questionnaires were utilised: 1) Patient Experience Survey, 2) FLO simple telehealth staff attitude survey, 3) FLO simple telehealth post-project survey</p>	<p>To promote self-management in the wound-care pathway using simple text messaging technology via the Florence text messaging system provided by Pennine Care.</p>	<p>The NHS text-messaging service Flo was used to give self-management guidance on wound care</p>	<p>Patients have benefitted from the new pathway. The findings suggest that healing rates were well within what would be expected on the standard care pathway. Participants said they felt competent to self-manage using Flo, felt fully included in their care and would recommend Flo to others. The staff questionnaires demonstrate overall acceptance of the new care pathway, with clear</p>	<p>More work is needed to identify whether self-management leads to a difference in wound healing time. In standard care, the patient would be exposed to a number of different community nurses, with variations in practice. In the self-management pathway these factors are eliminated, which could mean wounds healing more rapidly, though there is no</p>	<p>Supporting self-management has been shown to increase the quality and efficiency of service delivery. Using Flo has increased confidence among nurses to let go, and patients to be let go, when ongoing support was available through Flo. These findings will form the basis of broader work to redesign traditional wound-care pathways delivered by community nursing</p>

					views about patient and service benefits	evidence to support this.  Study methods were very brief not enough detail provided, particularly on data collection, data analysis, sample details, type of ethnic minority groups used and recruitment techniques  Study was very small, leading to issues regarding generalisation across other target groups  Study was conducted over a year; perhaps longitudinal studies are required to measure the effects of text messaging over a longer period	services within Pennine Care Foundation Trust as well as other organisations.
<b>Implementation of simple telehealth to manage hypertension in general practice: a service evaluation</b>  <b>Cottrell et al (2015)</b>  <b>Staffordshire</b>	Quantitative Study  Survey	2963 patients from general practices across England registered onto one of four AIM hypertension protocols from inception to January 2014. The AIM programme was rolled out across England in March 2013 in 425 general practices across 31 Clinical Commissioning Groups (CCGs) with a choice of ten clinical applications.	The aim of this service evaluation was to identify the extent to which predefined service outcomes, regarding ascertainment of a diagnosis of hypertension, and achievement of hypertension control, were	Florence sent hypertensive patients prompts via text messaging to submit readings, educational messages and user satisfaction questions.	79 % patients were eligible to have a diagnosis of hypertension confirmed/refuted, of which 740 (63 %) had a mean BP in the hypertensive range from one week's readings. BP control was achieved by only 5-22 % of 1495 patients signed up to one of the three monitoring protocols. Patient engagement with the monitoring protocols	Strengths- The strength of this evaluation is that it has examined real life use among a national primary care population, without the influence of programme-linked incentives or 'cherry picked' patients, as no inclusion/exclusion criteria were applied to the patients who clinicians signed up to the Florence system	Although simple telehealth may be an acceptable tool for diagnosing and monitoring hypertension among responding patient users, and can have a useful role in diagnosis of hypertension (particularly if ambulatory blood pressure monitoring (ABPM) is not possible or is

		<p>Patients with opportunistic raised BP in general practice or diagnosed hypertension were selected by their usual primary care providers to register onto diagnostic or monitoring hypertension protocols, respectively. Florence sent patients prompts via text messaging to submit readings to identify whether one of the primary aims of the AIM programme, to enhance patient experience, had been met, patients were sent up to complete three evaluation questions at the end of each month.</p>	<p>met for the hypertension protocols.</p>		<p>were initially good but reduced over time</p>	<p>The size of the sample was large compared with empirical studies examining similar interventions and results are likely to be generalisable across the primary care population in England.</p> <p>Limitations- Longer interventions are necessary, to optimise engagement need to be sought, these may include: reduced frequency of contacts to redress the balance between prompts and burden or implementation of strategies to boost motivation. For similar interventions to be successful in the future, it is essential to identify effective strategies to overcome therapeutic inertia. For those patients who supplied enough readings for a clinical assessment of BP control to be made, empirical work is required to establish reasons why their elevated BPs were not actively managed and controlled by their responsible clinician</p>	<p>declined), problems were identified. Reduced patient engagement over longer periods and acceptance of suboptimal BP control among patients on monitoring protocols need to be urgently addressed. Empirical work is required to identify barriers to achieving BP control among hypertensive patients using simple telehealth and, consequently, services be developed to address these issues</p>
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<p><b>Self-management: keeping it simple with “Flo”</b></p> <p><b>Cund et al (2015)</b></p> <p><b>East Midlands</b></p>	<p>Quantitative Study</p> <p>Survey Questionnaires</p>	<p>A convenience sampling approach<sup>32</sup> was implemented to capture the views of 37 patients and 33 community nurses involved in the project. All patients and staff involved in the study were asked to complete the questionnaire by the Flo team at the end of 6-month contact</p> <p>The questionnaire involves the patient completing 13 questions on their views of and perceived benefit of “Flo”</p> <p>on a five-point Likert scale (ranging from 1= strongly agree to 5= strongly disagree). Community nurses are then asked to rate the perceived benefit of the system to the patient and their management of the condition on a similar Likert scale.</p>	<p>To explore the use of the FLO system as an approach that allows self-reporting of conditions and clinician interaction via SMS text to and from the patient’s mobile telephone</p>	<p>Patients received educational messages from FLO regarding self-management of their long-term condition</p>	<p>The majority of patients find the service easy to use, reassuring, and reducing the number of contacts they had with their doctor. The results also show that staff did notice a reduction in consultation time, highlighting the potential of the system to save time; the majority viewed it as a support to existing approaches aimed at the management of long-term conditions</p>	<p>Strengths- the FLO system had a positive effect on patients’ health outcomes</p> <p>Limitations- A small sample was employed leading to issues with generalizability. No pilot study was undertaken to test the reliability and validity of the tool, thus, highlighting this as a key limitation</p> <p>Another limitation of this approach is that it could restrict both parties being open and honest about their experience to avoid discomfort or distress to the other</p>	<p>Living with a long-term condition is challenging for patients, particularly to sustain good health and stability against disease progression. Nurses play a key role in the lives of patients through education, support, and monitoring of symptoms and the person’s ability to cope. Simple Telehealth: Florence “Flo” not only provides the patient with the opportunity to take responsibility for their health condition, it allows the nurse to collect, monitor, and review the patient’s progress over time in a socially unobtrusive yet regular manner.</p> <p>The authors hope that this article will encourage clinical teams to reflect on their approach to home and community monitoring of patients, encouraging better self-management, and that clinical staff will consider how and where Flo could support patient groups</p>
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							in line with national protocols.
<p><b>Patient and professional user experiences of simple telehealth for hypertension, medication reminders and smoking cessation: a service evaluation</b></p> <p><b>Cottrell et al (2015)</b></p> <p><b>Staffordshire</b></p>	Quantitative	<p>3381 patients from 425 practices in 31 CCGs had registered onto 1 of the 10 AIM protocols.</p> <p>Patients were registered onto the Florence system by their general practice team; for hypertension and inhaler reminder protocols, they were given shared management plans, which provided information about actions to take if the patient's readings and/or clinical condition deviated from normal.</p>	To establish patient and professional user satisfaction with the Advice & Interactive Messaging (AIM) for Health programme delivered using a mobile phone-based, simple telehealth intervention, 'Florence'.	The AIM programme offered 10 clinical protocols, in three broad groups: (1) hypertension diagnosis/monitoring, (2) medication reminders and (3) smoking cessation. Florence sent patients prompts to submit clinical information, educational messages and user satisfaction questions. Patient responses were reviewed by their primary healthcare providers.	<p>Patient activity using Florence was generally good at month 1 for the hypertension protocols (71–80%), but reduced over 2–3 months (31–60%). For the other protocols, patient activity was 0–39% at 3 months. Minimum target days of texting were met for half the hypertension protocols. 1707/ 2304 (74%) patients sent evaluative texts responded at least once. Among responders, agreement with the adapted friends and family statement generally exceeded pre-project aspirations. Professional responders were generally positive or equivocal about the programme.</p>	<p>Strengths- The value of evaluation through feedback has been recognised by The King's Fund as it was highlighted as one of the eight priorities to transform individual involvement in healthcare.</p> <p>This service evaluation provides a snapshot of the real-life use of AIM across a national population. Patients were not 'cherry picked'; thus, the data from this evaluation are likely to be generalisable across the primary care population in England.</p> <p>As the data were gathered from both patient and professional users, recommendations made as a result of this evaluation is likely to meet both patient and clinical user priorities.</p> <p>Limitations-Patient engagement with the service was used as a proxy measure of satisfaction in this service evaluation. Although it is</p>	Further qualitative research may be of use to provide greater insights into the barriers faced by patient and professional users, and potential solutions and ideas for development in the future.

						<p>recognised that satisfaction and engagement may not perfectly align, that is, a patient may be satisfied with but not engaged in healthcare services, we feel it is unlikely that a patient would be dissatisfied and actively engaged in this optional service. Therefore, although active patient engagement is likely to indicate positive patient satisfaction, we recognise there are limitations with this assumption. There was a significant quantity of missing data from failure to respond to user satisfaction questions, from intentional alterations to protocols by individual clinicians or Clinical Commissioning Groups such that user satisfaction questions were omitted and from patients stopping protocols early. Qualitative work with both patients and professionals would help to gain a richer understanding of what happened to these patients.</p>	
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<p><b>Stop with the FLO: using text messaging to improve retention rates in University Students</b></p> <p><b>Boath et al (2016)</b></p> <p><b>Staffordshire</b></p>	<p>Mixed methods</p>	<p>The prospective participants were informed about the project during an interactive question and answer session with a member of the FLO Team who was not involved in their programme. The information given was supplemented through use of a written study information sheet. It was made clear that the FLO project was not part of their core curriculum, that they could choose whether to participate in the project, or not, and if they decided not to take part, they would suffer no penalties</p> <p>Qualitative and quantitative evaluation was conducted using an open-ended questionnaire designed specifically for the study. The sample were 39 first year, undergraduate, Level 4 students from Social Welfare Law (n=16) and Sport and Exercise (n=23) who signed up to receive texts from FLO. The questionnaire was administered in a classroom situation one week after use of FLO had ceased.</p>	<p>To evaluate how use of automated mobile phone texts using a system known as FLO could usefully supplement the pastoral support currently offered to new undergraduate students</p>	<p>Mobile phone automated texts were sent to participating students that were designed to provide information, support and reassurance, to help alleviate the stress and anxieties that students often experience in the early stages of their studies and foster a sense of belonging.</p>	<p>Sixteen (70%) of the total cohort of 23 undergraduate social welfare law students signed up for FLO and of the 16, 11(69%) completed the evaluation form. 23 (51%) of the total cohort of 45 Level 4 Sport and Exercise students signed up to FLO and of the 23, 14 (61%) completed the evaluation. The results for the two cohorts were overall very similar and were therefore combined across both cohorts.</p> <p>Two key themes emerged from the data. Theme 1 that FLO text messages were helpful and supported time management skills and a second theme emerged suggesting that FLO increased a sense of belonging to the University and encouraged retention.</p>	<p>Strengths- The evaluation indicates that future use of FLO may be helpful in retaining undergraduate students. Early indications are that FLO can help foster a sense of belonging when students first enter the sometimes-disconcerting culture of university life</p> <p>Limitations- A very small sample size was used and no data was collected on the socio-demographic makeup of participants</p>	<p>It is concluded that FLO or use of similar mobile phone protocols may be a useful addition to approaches to improve undergraduate student retention rates.</p>
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<p><b>Using simple telehealth in primary care to reduce blood pressure: a service evaluation</b></p> <p><b>Cottrell et al (2012)</b></p> <p><b>Staffordshire</b></p>	<p>Mixed Methods</p> <p>Prospective service evaluation</p>	<p>Practice staff identified 124 intervention patients and invited them to participate based on two inclusion criteria: (1) patient has chronic kidney disease (CKD) stages 3 or 4 with BP persistently &gt;130/85 mm Hg or (2) patient is &gt;50 years-old (without CKD stages 3–5) with BP persistently &gt;140/90 mm Hg despite prescribed antihypertensive medication. Three selected hypertensives control patients per intervention patient underwent usual clinical care (n=364).</p> <p>Baseline data were collected by practice staff using a proforma for all intervention and control patients. This requested information about demographics, medications, comorbidities, BP at recruitment, most recent BP prior to recruitment and BP 1 year before, most recent estimated glomerular filtration rate (eGFR) and healthcare service use over previous 12-month period</p> <p>Qualitative data were collected at various stages throughout the</p>	<p>This service evaluation examines how efficiently an innovative, simple and interactive blood pressure (BP) management intervention improves BP control in general practice.</p>	<p>Intervention patients used ‘Florence’, a simple, interactive mobile phone texting service with BP management intervention for 3 months, or for less time if their BP became controlled. Patients measured their BP, text their readings to Florence, received an immediate automatic response and had results reviewed by their GP/ practice nurse at least weekly.</p>	<p>Control and intervention patients were well matched except that intervention patients had significantly greater baseline BP. Greatest BP reductions were among hypertensive intervention patients without CKD stages 3–5. Intervention patients had significantly more BP readings and more changes in medication over the 3-month data collection period.</p>	<p>Strengths- As this is a service evaluation, the results obtained accurately reflect actual use of the technology in the clinical setting.</p> <p>Limitation- Aside from BP measurements in intervention patients, no measurements or tests were undertaken in any patient specifically for this service evaluation, therefore there were some missing data.</p> <p>Control patients were less hypertensive at baseline than intervention patients and may have been fundamentally different to intervention patients—it appeared that intervention patients were more likely to have been difficult to control in the past.</p>	<p>Simple telehealth is acceptable and effective in reducing patients’ BP. In future, poorly controlled patients could be targeted to maximise BP reductions or broader use could improve diagnostic accuracy and accessibility for patients who struggle to regularly attend their GP surgery.</p>
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		programme using questionnaires, text messages and a discussion group, the results of which are discussed in an accompanying paper.					
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Appendix 4. Table 10. Search Results (2010-2016)

Database	Search Terms	Abstracts relevant before limitations	Limitations	Full paper- review inclusion/exclusion criteria, English only	Articles excluded	Relevant articles selected
<b>British Nursing Index (ProQuest)</b>	(Ethnic minorit* OR minority group OR racial minority) AND (Long-term condition OR chronic condition OR chronic disease OR longterm condition) NOT (Caucasian) AND (Compliance* OR Health management OR disease management OR adherence*) AND (Text message* OR SMS OR short messaging service) NOT (child*)	150	>Peer reviewed >Last 10 years >English language	132	18	5
<b>PsychInfo (OVID)</b>	(Ethnic minorit* OR minority group OR racial minority) AND (Long-term condition OR chronic condition OR chronic disease OR longterm condition) NOT (Caucasian) AND (Compliance* OR Health management OR disease management OR adherence*) AND (Text message* OR SMS OR short messaging service) NOT (child*)	372	>Peer reviewed >Last 10 years >English language	328	44	2
<b>CINAHL Plus (EBSCO)</b>	(Ethnic minorit* OR minority group OR racial minority) AND (Long-term condition OR chronic condition OR chronic disease OR longterm condition) NOT (Caucasian) AND (Compliance* OR Health management OR disease management OR adherence*) AND (Text message* OR SMS OR short messaging service) NOT (child*)	148	>Peer reviewed >Last 10 years >English language	118	30	6
<b>MEDLINE (OVID)</b>	(Ethnic minorit* OR minority group OR racial minority) AND (Long-term condition OR chronic condition OR chronic disease OR longterm condition) NOT (Caucasian) AND (Compliance* OR Health management OR disease management OR adherence*) AND (Text message* OR SMS OR short messaging service) NOT (child*)	152	>Peer reviewed >Last 10 years >English language	138	14	8

**Appendix 5. Table 11. Search Results (2016-2020)**

<b>Database</b>	<b>Search Terms</b>	<b>Abstracts relevant before limitations</b>	<b>Limitations</b>	<b>Full paper- review inclusion/exclusion criteria, English only</b>	<b>Articles excluded</b>	<b>Relevant articles selected</b>
<b>British Nursing Index (ProQuest)</b>	(Ethnic minorit* OR minority group OR racial minority) AND (Long-term condition OR chronic condition OR chronic disease OR longterm condition) NOT (Caucasian) AND (Compliance* OR Health management OR disease management OR adherence*) AND (Text message* OR SMS OR short messaging service) NOT (child*)	38	>Peer reviewed >Last 10 years >English language	23	15	5
<b>PsychInfo (OVID)</b>	(Ethnic minorit* OR minority group OR racial minority) AND (Long-term condition OR chronic condition OR chronic disease OR longterm condition) NOT (Caucasian) AND (Compliance* OR Health management OR disease management OR adherence*) AND (Text message* OR SMS OR short messaging service) NOT (child*)	60	>Peer reviewed >Last 10 years >English language	32	28	2
<b>CINAHL Plus (EBSCO)</b>	(Ethnic minorit* OR minority group OR racial minority) AND (Long-term condition OR chronic condition OR chronic disease OR longterm condition) NOT (Caucasian) AND (Compliance* OR Health management OR disease management OR adherence*) AND (Text message* OR SMS OR short messaging service) NOT (child*)	44	>Peer reviewed >Last 10 years >English language	18	26	6
<b>MEDLINE (OVID)</b>	(Ethnic minorit* OR minority group OR racial minority) AND (Long-term condition OR chronic condition OR chronic disease OR longterm condition) NOT (Caucasian) AND (Compliance* OR Health management OR disease management OR adherence*) AND (Text message* OR SMS OR short messaging service) NOT (child*)	115	>Peer reviewed >Last 10 years >English language	38	77	8

Appendix 6. Table 12. Data Extraction Sheet

Study Type/ title/ Author	Study Design	Sample and Data collection	Aim	Intervention and Theory of Behaviour change used	Data Analysis and Results/Conclusions	Strengths/Limitations(critique)	Discussion
<p><b>1. Strategic management of behavioural change in type 2 diabetic patients</b> <b>Lin et al (2012)</b> <b>Taiwan</b></p>	<p>Mixed methods Cross-sectional surveying and interviews</p>	<p>317 outpatients with type 2 diabetes in Taiwan. Focus groups were conducted and questionnaires were collected from outpatients Purposive Sampling method</p>	<p>To explore the gaps between perception and performance of daily blood glucose monitoring, regular exercise along with diet regimen within individuals with type 2 diabetes; and to help develop patient-centred care and health management strategies.</p>	<p>No mobile phone intervention used The IPGA matrix was used to develop patient-centric healthcare strategic management for type 2 diabetes. Which enables the comparison of perceived importance against performance that is expected to help make service decisions through simpler strategic matrix, it also includes the gap theory enabling service failures to be identified based on the user's expectation against the perceptions of service providers. This enabled effective management of diabetes.</p>	<p>Paired sample <i>t</i>-tests, importance–performance gap analysis and regression analysis were performed. Preservation was a key aspect that affected blood glucose monitoring and regular exercise; this was more common in men than women. The critical factor in diet control was the desire to eat. Patients' perceived severity of diabetes and limited daily activities due to diabetes correlated with regular exercise, patients' compliance correlated with glucose monitoring, and perceived health status correlated with diet control.</p>	<p>Strength-Cross-sectional design conducted, in which questionnaires were administered, where they can reach a large number of people. They are also a cheap method of data collection (Parahoo, 2004) Focus group interviews were used enabling researchers to explore particular phenomena or experiences of individuals with diabetes. This study was useful to find that the factors influencing healthy behaviour could be divided into physical and psychological factors (Lin et al, 2012). Limitations: No mobile phone intervention used to make it difficult to assess its credibility. Cross-sectional study used, A cross-sectional design was used, however a Longitudinal approach would be of greater benefit to study how patients manage diabetes over time The study participation depended on the patient's consent leading to the possibility of sample biases. Also results from a single</p>	<p>The cultivation of determination and strengthening psychological coping is critical. Health care professionals should design tailored services, avoid educational intervention and develop a 'meaning-centred' rather than a 'message-centred' philosophy of exercise. Such a campaign may help to improve self-management and promote health behaviours for people with type 2 diabetes.</p>

						hospital may not be generalizable.	
<p><b>2. Exploring the use of mobile phone technology for the enhancement of the prevention of mother-to-child transmission of HIV program in Nyanza, Kenya: a qualitative study</b></p> <p><b>Jennings et al (2013) Kenya</b></p>	<p>Qualitative study Focus group interviews/ Semi-structured discussion guides</p>	<p>Ethical Approval gained from Kenyatta National Hospital, University of Nairobi Ethics and Research Committee in Nairobi, Kenya. Written informed consent was obtained for participation in the study as well as audio recording of the discussion. Participants were also asked to keep all discussions confidential Study conducted in two district hospitals in Nyanza Province, Kenya A total of 45 participants selected, that included HIV-positive women already enrolled within clinical services for prevention of mother-to-child transmission (PMTCT) and their male partners, community health workers, and nurses Purposive sampling method focus groups and in-depth interviews were conducted in two</p>	<p>To Explore the use of mobile phone technology for the enhancement of the prevention of mother-to-child transmission of HIV program in also to examine participants' view on platform design and gender-tailored short message service created for improving PMCT communication and male involvement</p>	<p>Mobile phone text messaging. The perceived receiving information and reminders. Focus group interviews conducted with pregnant women who are HIV-positive and their male partners and community health workers. In-depth interviews with facility-based nurses providing PMTCT services</p>	<p>Focus group discussions transcribed and translated verbatim to English by research team. Thematic approach used for data analysis of the narrative. In the second phase, a manual preliminary analysis of the narrative data aimed to assemble the responses according to the pre-set themes in the FGD topic guide, which were then refined according to emergent themes. The final step of the analysis was to highlight relevant quotes provided in the text to illustrate key findings. Majority of the participants had access to mobile phone and were able to receive and send SMS, however phone sharing was common among couples. The perceived benefits of this intervention included linking with health workers, protecting confidentiality and receiving information and reminders. Men and women considered the gender-tailored SMS as a channel for improving PMTCT male</p>	<p>Strength-This study found that a safe, comprehensive, and gender-tailored platform with voice and SMS components linked to existing in-person PMTCT services would be acceptable among intended participants. Preferences for male involvement SMS may reflect women's and health workers' desires to address partner disclosure and promote partner support for aspects other than PMTCT. The findings suggest that having, SMS tips or reminders can be seen as a channel to initiate dialogue with male partners. Qualitative data collection methods were used, such as focus group and in-depth interviews in which researchers are able to generate a lot of dialogue in which a lot of rich, in depth data can be collected regarding participant experiences Limitations- The study failed to explore the communication received by participants through existing sources of media including brochures, radio, women's groups or counselling. Study participants were selected from those</p>	<p>Given the growth of mobile phones in Kenya and current health-related uses of mobile phones, a PMTCT mobile communications platform holds considerable potential. This pre-intervention assessment of community and health workers, yielded valuable information on the complexities of design and implementation. Further information is needed to validate the safety of proposed SMS messages among HIV negative populations. An effective PMTCT mobile platform engaging men and women will need to address contexts of non-disclosure, phone sharing, and linkages with existing community and facility-based services</p>

		<p>district hospitals in Kenya.</p> <p>Semi-structured discussion guides used to elicit participants' use of mobile phone for PMTCT and their perceived benefits and challenges.</p> <p>Each session lasted approximately 90 to 120 minutes. Focus groups were selected to provide an interactive format to capture multiple views on each proposed thematic area as a result of the dynamics and discussion of each group.</p>			<p>involvement and communication between couples. However informative messaging relayed safely to the intended recipient was critical. In addition, health workers emphasized the continuous need for counselling rather than mobile phone usages alone.</p> <p>As a whole integrated text messages provided antenatally and post-natally was most preferred</p>	<p>communities who were actively engaged within PMTCT program close to the hospital, the sample was not representative of couples with more remote areas with differential PMTCT outreach services, mobile phone literacy or disclosure status. Those lost to follow up were not included.</p> <p>Due to the study being designed as a pre-intervention formative research; the positive findings may reflect biases upon participants envisioned responses rather than actual experiences or responses to the researcher's role in guiding the discussion and developing future PMTCT support services</p> <p>The use of focus group interviews may not have been the best method of data collection, as HIV is a sensitive issue to discuss some participants may have felt uncomfortable about sharing their views and experiences in front of the group.</p> <p>Purposive sample is not representative of the whole population as the researchers have selected a prespecified group</p>	
<b>3. Reinforcement of Adherence to</b>	Quantitative Study	A total of 215 subjects being treated as outpatients were	To investigate the acceptability and feasibility of	Text messages sent via mobile phones. Messages were	Baseline variables compared and analysed	Strength- the pilot study in a group of randomized type 2 diabetes patients indicated	This pilot study indicated that regular communication via



<p><b>Prescription Recommendations in Asian Indian Diabetes Patients Using Short Message Service (SMS)-A Pilot Study</b> Shetty et al (2011) India</p>	<p>Randomized Controlled Trial Questionnaires</p>	<p>selected and were randomized either to receive SMS (n=110) or assigned to control group (n=105). Randomization was assigned via a computer system where participants were assigned a computer-generated number Written informed consent was obtained from the participants at the baseline visit. Questionnaires were administered to collect baseline data such as physical activity, diet habits and adherence to drug prescriptions were assessed using a validated at randomisation Simple Random sampling. Intervention group as a received SMS once in 3 days as a reminder to strictly follow regimen of dietary modifications, increase of physical activities and drug schedules. The Control group received standard care within which participants received medications based on clinical and lab</p>	<p>using short message services (SMS) via cell phones to ensure adherence to management prescriptions by diabetic patients.</p>	<p>written in English consisted of varied instructions on medical nutrition therapy (MINT), physical activity and reminders.</p>	<p>using student 't' stest <math>\chi^2</math> test Adherence was seen in 34.3%. 33.6% were using OHA+insulin respectively. Physical activity: At the baseline, adherence to diet prescriptions was satisfactory in 54.5% and 60.3% in the control and SMS groups respectively. At annual visit, no significant changes were seen in either group (control 52%, SMS 58.4%). The intergroup difference was not significant at these time points. Diet: In the SMS group the adherence improved marginally from 47% to 56% and the change was statistically non-significant.</p>	<p>that reminders related to principles of diabetes management were acceptable to the patients using SMS. Limitations- the study used small sample size may have affected the outcomes in subgroup analysis, also making results less representative and generalizable to other populations</p>	<p>SMS was acceptable to diabetic patients and helped improve the health outcomes, possibly due to continuous adherence to behavioural modifications advised. More studies using SMS are required for improving health behaviour in patients with chronic disorders, SMS interventions may be more cost effective than other telephone and internet communications and interactions between patient provider at desired frequencies</p>
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		investigations and advice on diet modification and physical activity					
<p><b>4. Improving treatment adherence for blood pressure lowering via mobile phone SMS-messages in South Africa: a qualitative evaluation of the SMS-text Adherence Support (StAR) trial</b></p> <p><b>Leon et al (2015)</b> <b>South Africa, Cape Town</b></p>	Qualitative Approach Semi-structured focus Interviews	<p>This study was approved by the Human Research Ethics Committee of the University of Cape Town. The trial took place among the general adult population attending an outpatient chronic disease services in a single large public-sector clinic that provides comprehensive primary health care services to an ethnically diverse, socio-economically deprived population. Individuals were either Black African (51%) or mixed ancestry (48%). A combination of convenience and purposive sampling was used to recruit 22 participants in total</p>	To assess the effects of an adherence support intervention delivered via SMS-texts, on blood pressure control and adherence to medication, for hypertensive patients.	<p>An SMS intervention was delivered over 12 months to provide adherence support by facilitating closer communication between patients and the health care system. Messages were designed to address common potential issues with treatment adherence that may lead to changes in treatment adherence behaviour improving health outcomes. Classifications of behaviour change techniques were mapped, content of messages focused on goal planning techniques, repetition and substitution, social support and natural consequences. Messages were semi-tailored to patients from specific clinic and personalised with names of clinical managers. They were sent in three local languages English, isiXhosa and Afrikaans.</p>	<p>Thematic analysis used in relation to patient experiences and effect of SMS text messages. Most participants felt comfortable using the mobile phones for receiving SM-text messages. Participants felt cared for due to the, respectful tone and the delivery, timing of reminders and frequency and the relational aspect of trial participation which were all highly valued. Patients who had been struggling with adherence due to high levels of stress found the service most beneficial. The intervention appeared to coincide with their readiness for change, and provided practical and emotional support for improving adherence behaviour. Complex interaction of psycho-social stressors and health service problems were reported as barriers to adherence behaviours.</p>	<p>Strength- The use of a mixed method approach on the interpretation of findings and robust engagement increased meaningfulness and credibility of the findings. Participants found the intervention valuable and benefited from it, leading to improved behaviour changes. Interviews were useful in addressing study aims i.e., exploring the effects of text messages to aid in the self-management of hypertension. Limitations-Sampling methods used obtained a Small homogenous sample for interviews, their experiences may not reflect upon the wider population making finding less generalisable Interviews were carried out as the trial was drawn to a close, so some may have had difficulty with recalling details of their initial trial experiences over the past 12 months. Therefore, vital information or details about experiences faced when taking part in the intervention may be left out by participants</p>	<p>Adherence support for treatment of hypertension, delivered via SMS-text message intervention was found to be acceptable, relevant and helpful. This study identifies the appropriate audience and core elements of the SMS-text message intervention appear to work best and issues that future research should explore in greater depth. It highlights the vitality of both practical utility and relational aspects of an SMS-text message adherence intervention in an operational setting, and the potential for it to improve adherence behaviour. This study also underpins the future mobile phone-based adherence interventions incorporated with behaviour change theories</p>

				Focus group interviews investigated the wider potential health interventions delivered via mobile phone by exploring patients' experience of the trial, including use, of interpretation and response to SMS-text messages, as well identifying barriers and facilitators to delivering treatment support.			that take cognisance of the complex mix of psychosocial and health service influences on adherence behaviours.
<p><b>5. The Cameroon Mobile Phone SMS (CAMPS) Trial: A Randomized Trial of Text Messaging versus Usual Care for Adherence to Antiretroviral Therapy (ART)</b></p> <p><b>Mbuagbaw et al (2012) Cameroon</b></p>	<p>Mixed method approach RCT, Two arm parallel design Focus group discussions</p>	<p>200 consenting subjects were recruited from the Yaoundé Central Hospital (YCH) Accredited Treatment Centre (ATC). Participants were to be aged above 21 years, owning a cell phone, enable to read text messages and who had been on Antiretroviral therapy for at least 1 month. Ethical approval was gained from the Cameroon National Ethics Committee All participants included both verbal and written consent. Simple random sampling. A computer-generated randomization list was established using</p>	<p>This trial investigates the use of motivational mobile phone text messages (SMS) to improve adherence to antiretroviral therapy</p>	<p>Short messages sent to participants in the intervention group once a week in their preferred language which was either French or English. Messages were developed based on data collected from focus group discussions and health belief model behaviour change. The content of the message was motivational with reminder component. The messages contained a phone number that they could call back if they needed help The control group received only usual care. They did not receive any text</p>	<p>t-test to compare groups on continuous outcomes and the chi-squared test for binary outcomes. All statistical tests were performed using 0.05 level of significance. Both groups were similar regarding baseline characteristics. Text messages showed no significant adherence to ART.</p>	<p>Strength- A useful study as it identifies the need for further research on this intervention. Focus group interviews were used to gather important information regarding participant details such as demographics etc. Limitations-Primary measures of adherence (by interviews) might have resulted in overestimates of the true adherence rate and the adherence reported for the last week may not adequately reflect adherence behaviours over longer periods because patients may become more adherent in the few days preceding their appointment The sample size was powered to detect a 20% difference in adherence between both arms. The</p>	<p>Interactive SMS associated with access to health advice has not led to significant improvements in adherence to ART in this study. Further research is required to determine how motivational content can be delivered by SMS alone. Text messages may come with a small risk of disclosure of status. Further trials are critical to determine what interventions should be taken to scale</p>

		<p>random block sizes of 2, 4 and 6.</p> <p>Randomized to either the randomized or control group</p> <p>The interaction term for the intervention variable and the following covariates: age group, gender, level of education and regimen were included. These covariates were reported to affect adherence rates to ART.</p> <p>Participants were followed up from December 2010 to May 2011, when the intervention was stopped.</p>		<p>messages but were interviewed at baseline 3 months and 6 months. Data on satisfaction was obtained for only the intervention arm to discover whether they were satisfied with the intervention</p> <p>Health belief Model</p>		<p>differences were found to be much less.</p>	
<p><b>6. Acceptability and factors associated with willingness to receive short messages for improving antiretroviral therapy adherence in China</b></p> <p>Xiao et al (2014) China</p>	<p>Quantitative approach</p> <p>Cross-sectional survey</p>	<p>A total of 801 adult patients owning a mobile phone were included from Anhui, China, where most existing HIV infections (over two-thirds) were caused by paid plasma donation in the early 1990's</p> <p>Background variables were collected including age, gender, education, residential status, marital status, occupation, income, family size, drinking, reading, and ART dosing habits (daily frequency, time, and</p>	<p>To understand the acceptability of short message service (SMS) as a reminder for improving antiretroviral therapy (ART) adherence and determine the factors associated with willingness to accept SMS among people living HIV (PLH) in China.</p>	<p>The PLH participated in a 15-minute survey in a private room at CDC or the clinic from April to June 2012. Adherence was assessed using two questions: whether they missed a dose in the last 30 days and/or whether they took a dose two or more hour late in the last 30 days.</p> <p>Patients who were willing to accept SMS, were asked (1) if free daily SMS as reminders to taking medicine would be</p>	<p>Data were analysed using SPSS (v10.01; SPSS). The background information and mobile phone usage was analysed descriptively. Bivariate logistic regression was used to assess the unadjusted log odds of willingness to receive messages. Final model was assessed using the Hosmer–Lemeshow test</p> <p>49.6% read every short message and 16.2% read only if the phone number was familiar, 79.5% reported daily SMS to remind taking medicine</p>	<p>Strength-The study has identified important factors regarding demographics it found SMS to be more acceptable in areas with high prevalence, such as middle and north Anhui, and rural areas. The high acceptance might be due to the fact that disease is less stigmatized in the areas where AIDS popularity is clustering (Cao, Sullivan, Xu and Wu, 2006; Sullivan et al, 2010).</p> <p>Limitations- The study was conducted in Anhui and only selected participants from there; over half the sample were former plasma</p>	<p>SMS as a reminder for improving ART adherence is acceptable. The survey results indicate that to be effective, perhaps messages need to be tailored to address to elderly patients, urban residents, individuals with earlier stage of HIV disease, and individuals not experiencing side effects. Nonetheless, these results suggest that for a high proportion of PLH in</p>

		methods of reminder) were collected Stratified Random sampling procedure obtained from 6 cities (three cities from among eight cities in Anuhui.		helpful, (2) would be willing to receive daily SMS to remind taking medicine, (3) think free regular SMS to remind physical examination or testing would be helpful, and (4) would be willing to receive free re regular SMS to remind physical examination or testing.	would be helpful, and 68.9% were willing to receive them. In the final model, willingness to accept was positively associated with being young (p = 0.048), living in the middle or north region (p < 0.001), having primary or “junior or higher” education (p = 0.021), having serious disease condition of stage (p = 0.004), being a rural resident (p < 0.001), having side effect (p = 0.023), and taking a dose two or more hours late in the last 30 days (p = 0.009).	donors. Thus, the findings might not be generalizable to PLH in other areas and with different routes of infection. self-reported data might be subject to social-desirability and imposes the possibility of bias The cross-sectional design of this study makes it difficult to assess causal inferences on association, also the study was conducted over a period of 3 months only. Perhaps longitudinal study design is more effective on investigating causal inferences over a longer period of time.	China, reminder messages through mobile phones would be useful for increasing compliance with HIV regimens.
<b>7. Development and Feasibility of a Text Messaging and Interactive Voice Response Intervention for Low-Income, Diverse Adults with Type 2 Diabetes Mellitus</b> <b>Osborn and Mulvaney (2013)</b> <b>USA</b>	Mixed Method approach Intervention al study, and interviews and surveys used	Each round of testing included baseline procedures in which a trained Research assistant. A performed informed consent to eligible and interested patients. 20 eligible participants were recruited from a federally qualified health centre. Eligible patients were English-speaking adults diagnosed with Type 2 Diabetes Mellitus who were currently taking diabetes medications, owned a	1) Creation of Messaging for Diabetes (MED) intervention Advancing and adapting an existing text messaging system to include interactive voice response functionality and supporting medication adherence barriers of low income, diverse adults with type 2 DM	‘Messaging for Diabetes’ was the intervention the researchers aimed to create which consisted of 3 different communication measures: 1. Daily automated, one-way, tailored text messages addressing users’ barriers to medication adherence 2. Daily two-way text messaging service which assessed medication adherence for the day, where users were asked	Insufficient details regarding data analysis The average age of the 20 participants was 51.6 ± 8.8 years, 65% were female, 45% were African American, average years of education was 13.6 ± 2.4 years, 25% had an annual household income <\$10,000, 35% did not have health insurance, and the average A1C was 7.6% ± 1.8%. Participant characteristics for the overall sample and for the top 3 barriers to medication adherence	Strength- This text messaging intervention enabled researchers to identify barriers to implementation and obtain patient input on the content and experience of mobile phone interventions along with its perceived benefits Limitation-The sample size was small precluding differences to be examined by patient factors such as race, income, duration of diabetes, or controlled versus uncontrolled glycaemia. Sampling methods could be more purposive or stratified approach, which could	This intervention encountered challenges faced by patients in relation to medication adherence by designing messages that provided information and support for patients. a mixed method approach has provided insight into legitimate VS illegitimate missing data, patterns of use and subjective user experiences. The results obtained provide a potential

		<p>cell phone with an active plan and text messaging capabilities, and had a gyrated haemoglobin Arc (ARC) value in the medical record. Purposive sampling technique Validated questionnaires used the Diabetes Medication Knowledge Questionnaire (all 5 items used),<sup>36</sup> the Medicines for Diabetes Questionnaire (10 out of 14 items used) the Barriers to Diabetes Adherence measure (4 out of 21 items used), and the Medication Adherence Self-Efficacy Scale (19 out of 26 items used)</p>		<p>whether or not they had taken their medications with either a ‘yes’ or ‘no’<sup>3</sup>. Interactive voice response Call that gave weekly adherence feedback, providing an automated reinforcing/encouraging message based on changes in adherence from prior weeks and requested qualitative information about adherence successes and failures to promote problem solving by overcoming barriers of adherence for future adherence Motivational interviews were conducted to discuss patients’ medication adherence challenges and to help them formulate a realistic, adherence-related goal. Participants were then interviewed after intervention phase to gain feedback and patient experiences and opinions about the MED intervention functionality, content, and technical problems encountered.</p>	<p>out of the 17 barriers that were assessed. These included: Lack of information about medication, cost of medication and fear of side effects</p>	<p>enable a better understanding of how beneficial the system is in aiding patients to control their diabetes The researchers could be more efficient by adding a function to the administration portion of the intervention that monitored system failures or missing data that could be valuable (Osborn and Mulvaney ,2013)</p>	<p>template for other teams that aim to design technology-based self-care support solutions for comparable patient population.</p>
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<p><b>8. Mobile Phones: The Next Step towards Healthcare Delivery in Rural India?</b> <b>DeSouza et al (2014)</b> <b>India</b></p>	<p>Mixed method approach Exploratory study Interviews and questionnaires</p>	<p>488 participants residing in Karnataka a village in Bangalore city, South India were surveyed and interviewed. Participants were selected from a public primary healthcare facility and a private non-profit, faith-based secondary healthcare facility. Inclusion criteria of participants were patients above 15 years who owned a mobile phone. Questionnaires were adapted from the HIVIND study questionnaire that explored mobile phone usage in people living with HIV/AIDS at an infectious disease clinic in Bangalore, India. The questionnaires covered demographic profile, mobile phone usage patterns and the acceptability of healthcare interventions delivered via mobile phones</p>	<p>To explore the acceptability of delivering healthcare interventions through mobile phones among users in a village in rural Bangalore.</p>	<p>A pretested, translated, interviewer-administered questionnaire was used to obtain data on mobile phone usage patterns and acceptability of the mobile phone, as a tool for health-related communication that would enable health promotion, management of chronic/acute illnesses as well as providing reminders for patients on certain medications</p>	<p>Data analysed using IBM-SPSS version 20. Chi-square, Kruskal Wallis test and bi-variate logistic regression models, used to assess associations between demography and outcome variables such as preference for voice call to SMS reminders, more frequent or less frequent medication reminders in chronic illnesses/disease management and preference for calling a doctor rather than the mobile phone in times of acute illnesses. The primary use of mobile phones was to make or receive phone calls (100%). Text messaging services were used by only 70 participants out of 488. Majority of the participants, 484 (99%), preferred to receive health-related information on their mobile phones and did not consider receiving such information, an intrusion into their personal life. While receiving reminders for medication adherence was found to be acceptable to a large number of respondents 479 (98%); 424 (89%)</p>	<p>Strength- The study consisted of a large sample population making the results generalisable to similar settings. The study was useful in investigating the effects of SMS intervention in different health care contexts such as health promotion, management of chronic/acute illnesses as well as providing reminders for patients on certain medications. The use of interviews enables researchers to gain an insight of user-experience. Limitations- The study was limited to two healthcare practices in south India suggesting that results may not apply to population from other parts of India Healthcare personnel were responsible for data collection, imposing possibility of biases, for this social desirability bias or acquiescence must be considered (DeSouza, 2013) There is no mention of sampling techniques employed. The sample was largely representative of women making sample androcentric.</p>	<p>The mobile phone, as a tool for receiving health information and supporting healthcare through mHealth interventions was acceptable in the rural Indian context. Although it is important to address factors such as English literacy, education, employment status, and sex of the end user would only serve to improve the efficacy of Mhealth. Findings of this study have generally corroborated the acceptability of Mhealth interventions and may even direct future research into this field</p>
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					preferred voice calls alone to other forms of communication. Nearly all were willing to use their mobile phones to communicate with health personnel in emergencies and 367 (75%) were willing to consult a doctor via the phone in an acute illness. Factors such as sex, English literacy, employment status, and presence of chronic disease affected preferences regarding mode and content of communication.		
<p><b>9. A Text Messaging-Assisted Randomized Lifestyle Weight Loss Clinical Trial Among Overweight Adults in Beijing</b> <b>Lin et al (2014)</b> <b>China</b></p>	Quantitative approach randomized two arm clinical trial Questionnaires	123 adults were randomised in Beijing; they were recruited via posting advertisements and distributing flyers in local neighbourhoods, hospitals, health centres, and commercial buildings. Giving individuals a choice to participate Inclusion criteria: BMI > 24, age 30-50, current use of a mobile phone and hose motivated in losing weight. Exclusion Criteria: Women who are pregnant or planning to become pregnant within 6 months of recruitment, current lactation, having a	To examine the impact of a text messaging-assisted lifestyle weight loss intervention on weight change amongst overweight adults in Beijing.	Participants were firstly asked to complete self-administered questionnaires regarding health conditions, medications, and relevant psychosocial variables. A self-report measure of intervention satisfaction was included in the 6-month follow-up survey for the intervention participants. Participants were randomized to either the intervention group or the control group. Intervention group: were assigned a series of personalized	Differences within baseline variables and all categorical variables were compared using Chi-square tests. Univariate analyses of continuous variables were conducted to examine distributional assumptions. Pooled-variance t-tests were used to test for between group differences in baseline characteristics. At 6 months participants within the control group gained $0.24 \pm 0.28\text{kg}$ whilst those in the intervention group lost $1.6 \pm 0.28\text{kg}$ ( $2.3\% \pm 0.38\%$ ) ( $P < 0.0001$ ). Intervention group participants had a reduction in waist circumference	Strength- This study produced clinically meaningful improvements in improvements in cardio metabolic markers for CVD, particularly BP and weight loss was observed in 2.3% at 6 months The results of this study hold promise and show positive behavioural changes amongst this population. There was significant reduction in WC, SBP, and DBP observed in this particularly in light of the fact that hypertension is a major risk factor for stroke which is suggested to be associated with obesity in China (Yong et al, 2013) Limitations- The intervention duration was relatively short, and the sample size was small and	Although this study holds promise by presenting a high engagement rate with text messaging as well as significant weight loss, further research is needed to test and develop long-term sustainability strategies This study demonstrates feasibility to develop similar approaches and interventions that utilize text messaging, in the means to establish behaviour change strategies, to influence weight loss. In light of the growing obesity



		<p>close family member (spouse or member of the same household) participating in the study, occurrence of a major CVD event in the past 6 months, current cancer treatment, and major psychiatric or cognitive condition</p> <p>Voluntary and random sampling</p> <p>All measurements were performed at clinic visits by trained, certified study personnel who were blinded to intervention assignment</p> <p>Validated questionnaire instrument adapted by the Global physical activity questionnaire (GPAQ)</p> <p>Participants were also asked to complete self-administered questionnaires to provide information on health conditions, medications, and relevant psychosocial variables. A self-report measure of intervention satisfaction was included in the 6-month follow-up.</p>		<p>behaviour change goals (explained below) and were asked to self-monitor their adherence to these goals via a daily text message.</p> <p>participants were also asked to attend three group sessions and receive five coaching calls throughout the study.</p> <p>Control group: received a brief information session immediately after randomization. They were also offered a similar version of the lifestyle intervention for 4 months after completing the final data collection visit. A self-administered survey was completed that determined the need and self-efficacy to change a series of 11 behaviours associated with weight management that were translated in Chinese; the 11 goals were derived from previously used tools by US population and represented a mix of the Interactive Obesity Treatment Approach (iOTA) and the DASH eating pattern</p>	<p>(<math>P &lt; 0.0001</math>) and body fat percentage (BF %) (<math>P &lt; 0.0007</math>), systolic/diastolic blood pressure (SBP/DBP) significantly while the controls had no change in waist circumference and BF% and had an increased SBP/DBP (<math>P = 0.01</math>).</p>	<p>unrepresentative making it difficult to generalise findings across other settings and populations. The use of translating of surveys and questionnaires as mentioned may not have captured most effective components, meaning of thoughts, attitudes and experiences may have been lost in translation</p>	<p>trend in China and other places across the world, future studies should assess the limits of reach and long-term effectiveness of this type of intervention on weight loss and clinical outcomes in a larger and more representative population.</p>
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<p><b>10. Efficacy of a text messaging (SMS) based intervention for adults with hypertension : protocol for the StAR (SMS Text-message Adherence suppoRt trial) randomised controlled trial</b></p> <p><b>Bobrow et al (2014)</b> <b>South Africa</b></p>	<p>Quantitative approach Parallel 3-Arm group randomized controlled trial Questionnaires</p>	<p>Participants recruited from the community health centre within Cape town, South Africa, serving two diverse low middle-income communities, Langa and Bonteheuwel. Written consent was gained to confirm participation in study and detailed contact information including patients mobile phone numbers. Participants consented to attend baseline consultations with trained research assistant for 20 minutes. 1372 were randomly allocated to information-only SMS text messages (n=457), interactive SMS text messages (n=458) or the usual care (n=457) Simple random sampling via Web-based randomization database. Inclusion criteria: adults <math>\geq 21</math> years of age, diagnosed with hypertension, prescribed blood pressure-lowering medication, and with a systolic blood pressure (SBP) <math>&lt; 220</math> mm Hg and a</p>	<p>To assess whether a structured intervention delivered by an automated system of SMS- text-messages providing clinic appointment, medication pick-up reminders, medication adherence support and hypertension-related education delivered via interactive SMS text-messages is more effective than usual care in controlling blood pressure.</p>	<p>The SMS Text-message Adherence suppoRt trial (StAR) is a twelve-month, pragmatic three arm parallel group trial. Participants are individually randomised to one of two trials intervention groups or an enhanced usual care group All participants received written information and care regarding hypertension from the clinic. Personalized SMS text messages were sent to information-only message and interactive message group participants at weekly intervals at preferred times and languages selected by the participant. The researchers designed, developed, and tested 2 SMS text messaging-based interventions with clinical staff and patients with high blood pressure who were working and living in low-income communities around Cape Town. The addressed a range of common issues with adherence to and</p>	<p>Intention- to -treat framed the analyses There is mention of primary and secondary outcome analysis also subgroup analysis. Insufficient details on methods used for statistical analysis At 12 months, the mean adjusted change in systolic blood pressure compared with usual care was <math>-2.2</math> mm Hg (95% confidence interval, <math>-4.4</math> to <math>-0.04</math>) whereas within the information-only SMS <math>-1.6</math> mm Hg (95% confidence interval, <math>-3.7</math> to <math>0.6</math>) within interactive SMS. In this randomized trial a small reduction in systolic blood pressure (SBP) control compared with usual care at 12 months. There was no evidence found to indicate that an interactive intervention increased this effect.</p>	<p>Strengths- a detailed statistical analysis procedure was constructed along with the provision of detailed descriptions of the intervention and its delivery, in line with guidelines that will enable comparison with other SMS text messaging-based systems and support development of new interventions. The system developed and utilized within this intervention was innovative and of low-cost. A large and representative sample was used allowing generalizations to be made Limitations-The provision of free medication and recommendations for regular follow-up at the clinic made it difficult to identify barriers to non-adherence The trial was not powered to identify the observed difference in SBP observed between groups, the sample size calculation was based on the effect sizes found in published trials of other behavioural interventions to support adherence to treatments for high blood pressure. Limitations-In addition, the measure of adherence used reflects only dispensing in the clinic, not the act of taking medication. Therefore, making it</p>	<p>This trial has demonstrated that a behavioural intervention supporting adherence to blood pressure treatment delivered via SMS text message can improve adherence and may modestly decrease blood pressure at 12 months. The optimal frequency of the different categories of text messages and the incremental costs of modifying messages for their effectiveness and implementation within the wider communities with other long-term conditions requires further study.</p>
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		<p>diastolic blood pressure (DBP) &lt;120 mm Hg at enrolment. Those attending the primary care clinic, resided in 1 of the 2 study communities, and had regular access to a mobile phone</p> <p>Exclusion criteria: Those requiring specialist care for their hypertension in secondary care; pregnant or 3 months post-partum; and those with very high blood pressure (SBP &gt;220 mmhg or DBP &gt;120 mmhg)</p> <p>Secondary outcomes were measured via questionnaires developed to capture patient satisfaction with hospital admissions, a Visual Analogue Scale for self-reported adherence to medication, and an adapted four-point scale evaluating basic hypertension knowledge. The questionnaires were also used to collect data on the demographics, type of medication changes made during the trial and reported side-effects of medication.</p>		<p>persistence with treatment. 13 We developed a library of SMS text messages, which were mapped to a taxonomy of behaviour change technique. Most of the messages focused on the techniques of goals and planning, repetition and substitution, social support, and natural consequences.</p> <p>The SMS text messages developed were translated, and tested in common spoken languages: English, isiXhosa, and Afrikaans.</p> <p>The information-only adherence support group members were sent messages to motivate collecting and taking medicines and to provide education about hypertension and its treatment. Additional reminders were sent when medications were ready for collection or for scheduled clinic appointments. They received the same messages as the other groups. All trial participants were</p>		<p>difficult to truly identify the barriers of adherence within this population.</p> <p>Targeting a group of people diagnosed with hypertension rather than those with a diagnosis of poorly controlled blood pressure may have also limited the extent to which improvements in blood pressure were possible.</p>	
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		All staff (clinicians and researchers) masked to allocations.		given a phone number to contact the research team			
<b>11. Supporting Adherence to Antiretroviral Therapy with Mobile Phone Reminders: Results from a Cohort in South India</b> Rodrigues et al (2012) India	Quantitative approach Quasi-experimental cohort study Surveys	Ethical approval was gained by institutional review board at St. John's National Academy of Health Sciences, Bangalore, India. Written informed consent was obtained from all participants prior to enrolment The quasi-experimental cohort study was implemented at the Infectious Disease Clinic, St. John's National Academy of Health Sciences, Bangalore, South India. 231 eligible participants invited to participate in the study Purposive sampling method Eligibility criteria: (i) Adults infected with HIV (ii) had access to a mobile phone (iii) were on ART for at least a month prior to enrolment. Those who were participants of other adherence studies were excluded This study was conducted between March 2010 and July 2011	To support adherence to Antiretroviral Therapy with Mobile Phone Reminders in South India	The intervention studied was adherence support with mobile phone reminders. Which comprised of two components, which offered reminders via: (i) an interactive voice response (IVR) call and (ii) a non-interactive neutral picture delivered as a short message service (SMS). All participants received both components of the intervention once a week for 6 months from the date of enrolment. Each component was received on two separate days in a week at a time chosen by the participant. Both components were demonstrated to participants at recruitment. All participants were trained to respond to the IVR and to access the pictorial message. The interactive call component required participants to respond to the question "have you taken all your	Demographic characteristics, adherence and participant experiences were expressed using frequencies; measures of central tendency and dispersion. Binary logistic regression was used to assess the association between socio-demographic variables and baseline adherence. The mean age of the participants was 38 years, 27% were female and 90% urban. Overall, 3,895 IVRs and 3,073SMSs were sent to the participants over 6 months. Complete case analysis revealed that the proportion of participants with optimal adherence increased from 85% to 91% patients during the intervention period, an effect that was maintained 6 months after the intervention was discontinued ( $p = 0.016$ ). Participants considered both IVR calls and SMS reminders nonintrusive and not a threat to privacy. A significantly higher proportion agreed that	Strength- This study contributes to the growing body of evidence on the capacity of mobile phone reminders to influence medication adherence in HIV infected individuals. This intervention led to improvements in adherence. Limitations- Study sample was fairly small and only represented population from South India, sample not representative results may vary within other regions of India. As patients were under study and so closely followed up, the Hawthorne effect on adherence could not be ruled out.	Although adherence was the outcome of interest in this study, the technology also has the potential to improve other aspects of HIV care like clinic attendance. An RCT intervention would be more effective in providing stronger results, it can also be explored and utilized for improving adherence in communicable and chronic disease like tuberculosis and diabetes

		Participant experiences within the intervention group were assessed on a five-point Likert scale at the end of the intervention period Five-point Likert scale used to assess patient experiences		medicines yesterday?" with a "1" if they had not missed any doses within the 24 hours and "2" if they had. Participants could receive messages in 1 of the 5 languages English, Kannada, Telugu, Tamil or Hindi. These languages were those commonly spoken in south India.	the IVR was helpful and supportive in comparison to the SMS (P<0.001). This study demonstrated mobile phone reminders to improve medication adherence in HIV infected individuals within this setting.		
<b>12. Effectiveness of Electronic Reminders to Improve Medication Adherence in Tuberculosis Patients: A Cluster-Randomised Trial</b> <b>Liu et al (2015)</b> <b>China</b>	Quantitative approach A Clustered Randomised Trial. One control and three intervention arms 36 districts/counties (each with at least 300 active pulmonary TB patients registered in 2009) within the provinces of Heilongjiang, Jiangsu, Hunan, and Chongqing, China.	The study was approved by the ethics committees of the Chinese Centre for Disease Control and Prevention. All patients provided written consent prior to taking part in the study. Informed consent was gained from 4,292 participants from within each cluster; Participants newly registered at the public TB clinic were screened for study from within each cluster. Eligibility criteria included: no communication impairment (mental, visual, auditory, or speech), patient >18-year-old, and patient able to use mobile phone to read SMS	To assess the effectiveness of text messaging and medication monitors to improve medication adherence in TB patients.	All patients were treated in line with National Tuberculosis Control Program guidelines including the use of isoniazid, rifampin, ethambutol, and pyrazinamide for 2 months, followed by isoniazid and rifampin for 4 months. Patients received blister-pack medications in a medication monitor box that electronically collected the date and time of each opening. In the control and text messaging arms, the medication monitor box was in silent mode and was not used as a reminder tool for patients. At each monthly visit, patients were dispensed enough medications for a month.	Analysis was conducted using Strata version 13. Insufficient information on methods/techniques used. The cluster geometric mean of the percentage show that 29.9% of doses were missed in the control arm; in comparison, this percentage was 27.3% in the text messaging arm (adjusted mean ratio [aMR] 0.94, 95% CI 0.71, 1.24), 17.0% in the medication monitor arm (aMR 0.58, 95% CI 0.42, 0.79), and 13.9% in the combined arm (aMR 0.49, 95% CI 0.27, 0.88). Patient loss to follow-up was lower in the text messaging arm than the control arm (aMR 0.42, 95% CI 0.18–0.98).	Strengths-This study design demonstrates the effectiveness of a medication monitor to improve medication adherence in TB patients. Large sample obtained from across 36 different provinces in China, making findings representative and generalisable Limitations-There were technical issues such as battery problems with the medication monitors within the study leading to loss of data in some patients, potentially resulting in an over-estimation of poor adherence Intensive case-management approaches were underutilised, possibly due to doctors disregarding information from the medication monitor or SMS feedback. In addition, the financial incentive given to the doctors to perform more	This demonstrates the effectiveness of a medication monitor to improve medication adherence in TB patients. In a setting such as China where universal use of DOT (directly observed treatment) is not always feasible; innovative approaches to support patients in adhering to TB treatment, such as this, are needed. Innovative approaches that help patients adhere to TB treatment are required along with low-cost, reliable medication monitor to improve clinical outcomes that could enable widespread use of medication

		<p>text messages and use the medication monitor after training. Stratified Random sampling using strata version 12.0</p>		<p>Patients were randomised using stratification and restriction to one of four management approaches in which patients received reminders via text messages, a medication monitor, combined, or neither (control). Patients in the intervention arm received text messages as reminders for monthly follow-up appointments and taking medications on time preferred by the times chosen by patients. Non – adherent patients were switched to more intensive management or DOT (directly observed treatment)                  In all arms, patients took medications out of a medication monitor box, which recorded when the box was opened, but the box gave reminders only in the medication monitor and combined arms. Patients were followed up for 6 months                  Due to the nature of the interventions were</p>		<p>intensive management may have been inadequate                  For the adherence endpoints, we assumed that opening the medication monitor box was the same as drug intake, which may not have been the case, though our measure of poor adherence using a combination of this and pill count is arguably more robust than pill count alone. Other studies have shown pill counts to be associated with poor adherence (Vixens et al, 2014)                  Interventions were not masked to study staff and patients could lead to potential of biases and Hawthorne effect</p>	<p>monitors in national TB control programmes.</p>
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				not masked to study staff and patients.			
<p><b>13. Text Messaging for Exercise Promotion in Older Adults from an Upper-Middle-Income Country: Randomized Controlled Trial</b></p> <p><b>Müller et al (2016)</b> <b>Malaysia</b></p>	<p>Mixed methods approach</p> <p>24-week, 2-arm, parallel randomized controlled trial.</p> <p>Semi-structured interviews also used to explore the experiences of participants taking part in the SMS arm.</p>	<p>Informed consent was gained from 43 eligible participants were recruited from local resident associations and religious facilities between April and May 2014.</p> <p>Convenience sampling method. Eligible participants were English-speaking Malaysians aged between 55 and 70 years, who were not exercising regularly (no structured exercise more than once weekly), with no health conditions that would restrict moderate exercise, used a mobile phone with SMS text-messaging function, and were interested in health-promoting exercise.</p> <p>Participants were given an information sheet and asked to provide contact details so that a study team member could call them later.</p>	<p>To examine the short- and long-term effects of SMS text messaging on exercise frequency in older adults and to how SMS text messages impact study participants' exercise frequency and the effects of the intervention on secondary outcomes.</p>	<p>43 participants were randomized into the SMS texting arm (n=22) and the non-SMS texting arm (n=21). Participants allocated to the SMS texting arm received an exercise booklet and 5 weekly SMS text messages over 12 weeks. The content of the SMS text messages was derived from effective behaviour change techniques. Text messages automatically sent via an online tool specifically developed for this study, allowing the research team to schedule the SMS text messages for every participant and it was also used to confirm delivery of the SMS text messages. Text messages were sent during morning hours between 8 am and 11 am accordingly with participant preference. The non-SMS texting arm participants received only the exercise booklet. Follow-up home visits were conducted in</p>	<p>Statistical analysis using SPSS version 21. Descriptive statistics and analyses of variables including age, sex, education, employment status, health status, and marital status. The intention-to-treat principle framed the analyses. Interviews transcribed and translated into English (not verbatim). Thematic analysis performed where themes were further divided into subthemes derived from the responses of the participants (e.g., exercise benefits, perception of how the SMS text messages affected exercise). Finally, a co-author checked the interview analysis results for accuracy and discrepancies</p> <p>In total, 43 participants were randomized into the SMS texting arm (n=22) and the non-SMS texting arm (n=21). Study-unrelated injuries forced 4 participants to discontinue after a few weeks (were not included in any analyses). Overall retention was 86%</p>	<p>Strengths-this study effectively investigated behavioural change maintenance in older adults after SMS messages were removed, which filled in gaps in literature, also contributing to the growing body of literature on Mhealth interventions</p> <p>Limitations-This study was limited by a lack of statistical power and the sample was small making it difficult to generalise</p> <p>Although a rigorous randomization process, drop-outs of participants was reported to be unexpected.</p>	<p>This study demonstrates the evidence to suggest that SMS text messaging is effective in promoting exercise in older adults from an upper-middle-income country. Although the effects were not maintained when SMS text messaging ceased, the results are promising and warrant more research on behavioural mobile health interventions in other regions of the world.</p>

				<p>which semi-structured with all research participants t, to explore We were how SMS messages were perceived by participants within the SMS texting arm messages, and their impact on exercise frequency were conducted at weeks 12 and 24. Outcome data collected included: (1) exercise frequency at 12 and 24 weeks, (2) secondary outcome data (exercise self-efficacy, physical activity-related energy expenditure, sitting time, body mass index, grip and leg strength) at baseline and at 12 and 24 weeks.</p>	<p>(37/43). After 12 weeks Texting arm participants exercised significantly more than non-SMS texting arm participants (mean difference 1.21 times, bias-corrected and accelerated bootstrap [BCa] 95% CI 0.18-2.24). Analysis of interviews revealed that SMS text messages had a positive influence on SMS texting arm participants that had previously experienced exercise barriers. They described the SMS text messages as being “encouraging, a push and a reminder”. After 24 weeks, there was no significant difference between the research arms (mean difference 0.74, BCa 95% CI -0.30 to 1.76).</p>		
<p><b>14. Efficacy of Interventions for Improving Antiretroviral Therapy Adherence in HIV/AIDS Cases at PIMS, Islamabad. Uzma et al (2011) Pakistan</b></p>	<p>Quantitative approach 2 –arm Randomized controlled trial Questionnaires</p>	<p>There were 76 eligible subjects for the study that were randomly halved within the intervention group of the control group; those registered with HIV/aids cases receiving care at HIV treatment centre, Pakistan Institute of Medical Sciences, Islamabad was included Simple random sampling Using a</p>	<p>Assess the efficacy of tailored interventions for improving Antiretroviral Therapy Adherence in HIV/AIDS in Islamabad</p>	<p>The study duration was 10 weeks Participants randomised to either the intervention group or the control group. Intervention group received subject involvement, weekly phone reminders in addition to routine counselling, while Comparison group received routine counselling only.</p>	<p>Data analysed using SPSS 15 The data was analysed on an intention-to-treat basis, to provide a realistic indication of effectiveness of the intervention. Analysis of variance (ANOVA) used to detect differences between the intervention and comparison groups (IG) and comparison McNemar’s test for paired data was used to test the significance of differences in key</p>	<p>Strengths-This intervention improved compliant rates within the Pakistani population receiving ART Limitations-Small sample size included making it difficult to make generalisations Follow-up assessments of adherence based on patients’ self-response may be affected by social desirability and recall bias</p>	<p>It is imperative to prove efficacy of tailored interventions and translate the efficacious ones into clinical strategies for achieving good ART adherence. The intervention utilized within this trial shows promise to improving adherence rates to ART treatment. Interventions as such</p>



		<p>computer-generated list of random numbers</p> <p>Ethical consent was obtained via a verbal consent form translated in Urdu</p> <p>Self-reported adherence (SRA) questionnaire and pill identification test (PIT) conducted at both baseline and follow-up in addition to CD4 count and viral load</p> <p>The questionnaires adapted from the questionnaire on medication adherence and side effects and the AACTG-CAPS Tool.</p> <p>The questionnaire was divided into three parts. The first part was to obtain information on the baseline socio-demographic, behavioural, and clinical characteristics of study participants.</p>			<p>outcome variables at the follow-up phase. <math>P &lt; 0.05</math> was considered as statistically significant.</p> <p>Results showed significant differences there was found to be <math>\geq 95\%</math> improvement in both self-reported adherence questionnaires and pill identification test when conducted during follow up</p>		<p>should be developed in the overall treatment strategy for HIV/AIDS in Pakistan as well as other places</p>
<p><b>15. Feasibility and Usability of a Text Message-Based Program for Diabetes Self-Management in an Urban</b></p>	<p>Mixed method approach</p> <p>Surveys and interviews used for data collection</p>	<p>After gaining ethical approval from the University of Chicago Primary Care Groups (PGC) Internal Medicine Resident Clinic, Patients were recruited from November 2009-</p>	<p>To investigate the feasibility of using a text message-based diabetes care program in an urban African-American population in which automated</p>	<p>Text messaging intervention "SMS-McRae"</p> <p>Text messages were based on current American Diabetes Association recommendations for self-care and treatment regime such</p>	<p>Mixed method Analysis of both quantitative and qualitative data.</p> <p>Quantitative analysis: Wilcoxon in signed-rank test used to compare baseline survey responses regarding self-management activities to</p>	<p>Strengths- This study demonstrates a text-messaging intervention to be a feasible and useful approach to improve diabetes self-management within African American population</p> <p>Data collection measures such as interviews</p>	<p>An SMS-based approach utilised within health information technology (HIT) may be particularly well-suited to improve care delivery and health outcomes among</p>

<p><b>African-American Population</b> <b>Dick et al (2011)</b> <b>USA</b></p>		<p>January 2010 for a 4-week study by posting leaflets within examination rooms to advertise the study and attract patient attention Voluntary sampling 18 participants took part. Surveys were conducted to collect data regarding demographics, history of cell-phone usages and adherence to diabetes care measures. Weekly interviews also took place via telephone by a certified diabetes educator to ask participants regarding issues with adherence, and also experiences of using text messages to manage diabetes. Inclusion criteria: Adults 18years or over, with type 2 diabetes, taking diabetes medication (oral hypoglycaemics and insulin), individuals owning a cell phone. Exclusion criteria- no recent hospitalizations or inpatients.</p>	<p>text messages were sent to participants with personalized medication, foot care, and appointment reminders and text messages were received from participants on adherence. To identify the perceived benefits and challenges of such a system on diabetes self-management within this population.</p>	<p>as medication adherence, foot care, and blood sugar monitoring. Text messages were tailored accordingly with time, frequency of message delivery and also wording and content. Participants received \$25 to cover expenses of an unlimited text messaging plan and rewarded \$30 for their participation Example messages included “Did you take your diabetes medications today” and “How many times did you check your feet for wounds this week?” Participants averaged 220 text messages with the system, responded to messages 80% of the time, and on average responded within 6 minutes.</p>	<p>participants at the pile’s 1-month follow-up Qualitative analysis: Interviews were audio-taped, transcribed verbatim and analysed into ATLAS. Ti 4.2 software. Transcripts were coded by two randomly assigned reviewers, who then met to It solve coding discordance. Thematic analysis performed where concepts and themes were discussed by research team in an iterative fashion The average age was 55 with and the average number of years with diabetes was 8. 50% of participants felt uncomfortable with text messaging, although this was the case, they strongly agreed that this intervention was easy to perform and helped with diabetes self-care. There was a reduction in missed doses of medication from 1.6 per week to 0.6 (P=0.003). Patient confidence in diabetes self-management significantly increased within 1 month after the study (p = .002, p = .008).</p>	<p>Interviews were used to gain feedback on the experiences of participants to make amendments to their tailored text messages, enabling therapeutic relationships are initiated and developed (Parahoo, 2006) Limitations- Patients were recruited from a single site from within an academic medical centre, the sample was very small and homogenous, all participants were black African-Americans, who had health insurance and were relatively well-educated. Making it difficult for generalisations to be made amongst different populations of other ethnic background with varying demographic factors. The pilot study included significant interaction with a diabetes educator it is difficult to assess whether improvements in adherence and self-care is determined by the SMS intervention or by the diabetes educator. Therefore, integrating a text message-based system within the current health care infrastructure may be the most beneficial use of this technology. The intervention was assessed for a very short period of time. Longitudinal</p>	<p>racial/ethnic minorities. SMS programmes can be used to improve self-management of chronic illness. All of these represent potential advantages of incorporating an SMS-based patient outreach component into care delivery systems</p>
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						study would be more beneficial to assess the effect of this intervention over time Adherence outcomes during, and after the study were self-reported at a single point in time, resulting in recall bias and social desirability bias.	
<p><b>16. The effect of mobile phone short messaging system on healthy food choices among Iranian postmenopausal women</b></p> <p><b>Vakili et al (2015)</b> <b>Iran</b></p>	Quantitative approach Randomized controlled trial Questionnaires	Ethical approval gained from the ethics committee in Ahvaz, Iran. Written informed consent was gained from participants 100 women recruited from a public health centre randomized with simple random sampling technique via Excel program for randomization- Allocation was made to either group A (intervention group) or group B (control group) Inclusion criteria: women aged 40-60 years, are able to use mobile phone and sending and receiving a short message, cessation of menstruation for at least 1 year, having basic literacy. Questionnaires were used to collect socio-demographic data. A valid food frequency	To evaluate the impact of mobile phone short messaging system on healthy food choices among Iranian postmenopausal women	50 participants were allocated to the intervention group (group A) and 50 in the control group (group B) 16 text messages were sent to participants within the intervention group over 4 months, messages in the study were developed accordingly with health guidelines on healthy diet for middle-aged women and postmenopausal women from Krause's Food and the Nutrition Care Process textbook [14] and were tailored by two nutritionists in terms of the culture of Iranian women. The purpose of these messages was to motivate participants to enhance their consumption of dairy products, green leafy vegetables, Vitamin A	The descriptive, independent <i>t</i> -test and Chi-square test were utilized for statistical analyses There was a significant increase in the consumption of Vitamin A, fruits and vegetables in comparison to the control group ( $P < 0.001$ ). there was also an increase in the number of women from the intervention group consuming food with proteins such as fish, after the intervention ( $P = 0.02$ ). there were no significant differences in the consumption of green leafy vegetables within the intervention group	Strengths- this study was the first of its kind to be conducted within Iran, it has successfully assessed the effectiveness of a short messaging system that enhanced healthy food choices among postmenopausal women Limitations- The study sample was small, making the sample less representative. The study was also conducted over a short period of time of 4 months, making it difficult to assess the full effect of this intervention.	Using mobile phone short messages interventions can improve healthy food choices and increase the consumption of Vitamin A rich fruits And vegetables and proteins amongst postmenopausal women. Using SMS for further training among postmenopausal women should be recommended.

		questionnaire was also used. Consumptions of food was checked at baseline and repeated after 4 months with the same questionnaire		rich fruits, and seafood to achieve their daily nutrient requirements of some micronutrients such as Vitamin A, folate, Vitamin C, calcium, and eicosapentaenoic acid and docosahexaenoic acid essential fatty acids. The short messages were classified into three types: Informing, instructions, and encouraging.			
<b>17. Effects of a mobile phone short message service on antiretroviral treatment adherence in Kenya (WelTel Kenya1): a randomised trial</b> <b>Lester et al (2010) Kenya</b>	Quantitative approach Randomised controlled trial conducted within three clinics within Kenya	538 participants were recruited across three clinics within Kenya Inclusion criteria: adults > 18years, infected HIV and initiating ART; individuals who own a mobile phone. Simple randomisation with a random number generating program The investigators were masked to treatment allocation whereas the participants and clinical staff were not masked to treatment Conducted between May 2007, and October 2008.	To assess whether mobile phone communication between health-care workers and patients starting antiretroviral therapy in Kenya improve drug adherence and suppression of plasma HIV-1 RNA load.	'WelTel Kenya1' Intervention group n=273 standard care n=265 Intervention group: received weekly SMS messages from a clinic nurse, messages were sent as medication reminders to improve drug adherence in HIV patients. participants were required to respond within 48 hours Control group: participants only received standard care	The primary analysis was framed by intention to treat. No further details provided on methods During follow ups primary outcomes were self- reported, improvement was shown in ART adherence within the intervention Adherence to ART was reported in 168 of 273 patients receiving the SMS intervention compared with 132 of 265 in the control group ( $P=0.006$ ); suppressed viral loads were reported in 156 of 273 patients in the SMS group and 128 of 265 in the control group( $P=0.04$ ).	Strengths- the study was conducted across three clinics within Kenya, with a fairly large sample making the results representative allowing generalisations to be made with other similar regions Limitations- the study was conducted over a year, which may not be long enough to assess the effectiveness of the intervention Participants and the clinical staff were not blinded during the intervention, possibly leading to Hawthorne effect	This study demonstrated that patients allocated within the SMS support had significantly improved ART adherence and rates of viral suppression in comparison to the control individuals. This intervention suggests that mobile phones could be an effective aid to improve patient adherence and health outcomes in resource-limited settings

					The number needed to treat (NNT) to achieve greater than 95% adherence was nine (95% CI 5.0–29.5) and the NNT to achieve viral load suppression was 11 (5.8–227.3).		
<p><b>18. Bilingual Text Messaging Translation: Translating Text Messages from English into Spanish for the Text4Walking Program</b>  <b>Buccholz et al (2015)</b>  <b>USA</b></p>	<p>Qualitative approach                  Focus group interviews</p>	<p>Consent was gained and study documents were provided to participants that were translated from English to Spanish by a native English speaker fluent in Spanish. Columbian Spanish was used for translation; all study documentation was reviewed and approved by a certified translator. 8 Spanish speaking adults were included; eligibility criteria for this study included: Spanish speaking adults; adults of between ages 30-65 years old not engaging in regular physical activity, with no health issues that prohibited them from increasing physical activity, and those able to use mobile phone for texting. The group was recruited from a church site in an urban city with a large</p>	<p>To translate a database of English motivational physical activity messages into Spanish and review these text messages with a group of Hispanic adults to inform the use of these text messages in an intervention study to help reduce risks of diabetes and hypertension</p>	<p>Text 4Walking text messaging Program                  The 1.5-hour session was conducted by bilingual researchers. An English-speaking doctoral level experienced focus group researcher was also present. A general introduction was first provided; participants were then placed into smaller groups of two or three. Each group was asked to review a segment of the 246 translated text messages for accuracy and meaningfulness. The translated text messages were placed into PowerPoint along with a set of 44 culturally appropriate photos depicting barriers to walking and walking scenarios.</p>	<p>Interviews were transcribed and translated into English by bilingual group leaders along with an experienced researcher. They reviewed participants hand written notes on the handouts. They then reviewed the flip chart notes with group reflections. A consensus was reached by three researchers as to when and how to edit the translated text messages as well as determining which text messages should be added accordingly with participant suggestions and popular themes that came up. Participants were well engaged in the group and thought that the messages could motivate them to walk more and suggested that receiving two text messages a day would be motivational for them. 22 text messages were added to the</p>	<p>Strengths- This study demonstrated a method whereby English motivational physical activity text messages could be successfully translated into Spanish which imposes the use of these text messages in a future intervention study                  Focus groups were used which enabled participants to provide feedback of the text messaging intervention. Group discussions enable the opportunity for participants to respond to the findings and offer explanations or alternative interpretations (Gerrish &amp; Lacey, 2009).                  Limitations- The sample size was very small, also from one geographic location making it difficult to generalise findings. Participants self-selected to leading to selection bias                  Focus groups impose limitations on study design such as individual participants dominating the discussions and excluding others from the topic. Also, the nature of some topics</p>	<p>To develop text messages that are culturally appropriate, it is important to incorporate bilingual and bicultural facilitators and materials to facilitate the development of tailored text messaging. By assuring cultural appropriateness, this study demonstrated an effective method to translate and review physical activity text Messages. This suggests future interventions to utilise similar methods giving opportunity for text messaging programs to improve health outcomes amongst other populations</p>

		<p>population of Hispanics                  Purposive sampling methods                  Participants were given handouts with specific translated text messages upon which they were asked to write their comments.</p>			<p>original database of 246 translated text messages, which resulted in a total of 268 text messages. Minor editions were made to four of the text messages to make the well suited to the participants. Text messages were Understood and seen as culturally appropriate, specific word preferences were seen related to personal preference, dialect, and level of formality.</p>	<p>maybe sensitive to discuss within a group; participants may feel uncomfortable sharing experiences or views openly</p>	
<p><b>19. Tailored, Interactive Text Messages for Enhancing Weight Loss Among African American Adults: The TRIMM Randomized Controlled Trial</b>                  Lin et al (2012)                  USA</p>	<p>Quantitative approach                  Randomized controlled trial                  Questionnaires</p>	<p>124 African-Americans participants were randomized to standard care which included counselling sessions with dieticians and physicians or standard care plus daily text messages that were tailored to participants' messages for 6 months Text messages were delivered in phases: preparation, reinforcement of participant-selected diet and exercise goals, reflection, goal integration, weight loss methods, and maintenance. There were follow-up visits</p>	<p>To examine whether behavioural theory-based mobile health intervention would enhance weight-loss when added to standard care amongst overweight/obese African American adults</p>	<p>This study conducted a randomized control trial in which participants were randomized to the standard care group or the group receiving standard care along with tailored text messages. Randomization of participants took place using a web-based programme for achieving equal allocation                  Standard Care Intervention consisted of an initial clinical assessment in which participants received a 20-minute session with a dietician, a visit with a study physician to review their health</p>	<p>63 participants were randomized to the mobile health intervention and the remaining 61 to standard care control. Weights were collected in-window for 45 (36.3%) at 3 months and 51 (41.1%) at 6 months. Mean weight loss at 3 months was 2.5 kg greater in the intervention group compared with standard care (<math>P &lt; 0.001</math>) and 3.4 kg greater (<math>P = 0.001</math>) at 6 months. Results show positive correlation between weight-loss and participants engagement with messages</p>	<p>Strength- RCT was used useful in assessing the effectiveness of the intervention within this particular ethnic minority (African-Americans) which demonstrates feasibility and efficacy within other ethnic minorities                  Randomized sampling method used via web-based programme, reduces bias and allows equal opportunity of selection. The control group also received a robust intervention with efficient resources for obese patients seeking to lose weight through the provision of medical assistance. The intervention attempts mimic real human interaction from practitioners; first names of</p>	<p>Further research is required to validate findings, current findings suggest tailored text messaging to be a promising approach to weight control amongst underserved, urban African American Adults. Interventions using tailored text messages have the potential to aid internal health care practitioners in reducing persistent health inequalities</p>

		<p>at 3, 6, and 12 months and hand-written feedback surveys were completed. Participants were paid \$200 for taking part Random sample</p>		<p>status, educational materials on diet and physical activity, and a digital pedometer. The intervention group received same assessment and recommendations as the standard care control group, but also received an automated, tailored text messages for 6 months covering relevant goals among 8 options (Figure 1A)</p>		<p>participants were used to make it personal. The type and timing of messages was tailored to each participant’s educational needs and schedule, and feedback was tailored via interactive messages. The intervention allowed participants to engage and to promote self-efficacy, self-monitoring, accountability, problem-solving, and barrier reduction. Study also included feedback allowing participants comments and views. Limitations- The duration of the intervention was short as it was only 6-months, perhaps a longitudinal study may be considered to assess the intervention over a longer period of time The study population was limited to African American adults recruited via Baltimore area churches, making results less transferrable to populations from other areas, countries and ethnicities Survey designs were used for feedback which led to participants missing follow-up sessions leading to low response rates. Risk of ‘Hawthorne effect’ physicians and researchers were taking part in the</p>
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						study, which could cause the participants to change their behaviours, resulting in inaccurate findings	
<p><b>20. Daily Text Messaging for Weight Control Among Racial and Ethnic Minority Women: Randomized Controlled Pilot Study</b> Steinberg et al (2013) USA</p>	<p>Quantitative approach Randomized controlled trial Surveys</p>	<p>At participant enrolment, informed consent was obtained and collected baseline data by administering survey measures. 50 obese women were randomized to either an intervention group, which used a fully automated system including daily text messages for self-monitoring tailored behavioural goals along with feedback (n=26) or to an educational control group (n=24). The inclusion criteria were to recruit women between ages of 25-50, BMI greater than or equal to 25. Weight was objectively measured at baseline and at 6 months. Adherence was defined as the proportion of text messages received in response to self-monitoring prompts. Stratified random sampling Questionnaires used to collect data regarding demographic</p>	<p>This pilot study aimed to evaluate the feasibility of a text messaging intervention for weight loss amongst predominantly black women</p>	<p>RCT conducted in which demographic data and self-monitoring adherence was studied Behavioural goals were set. Intervention group-automated tailored text messaging system Educational control group- Patient information sheets about behavioural goals, a pedometer, 2 face-to-face group sessions, and a skills training DVD</p>	<p>Various tests were used including the chi-square tests and <i>t</i> tests to examine differences in baseline characteristics between study arms. The <i>t</i> tests were used to examine absolute weight change, percentage of weight loss, and BMI change between study arms. The ANOVA was conducted to examine goal attainment and weight change across tertiles of self-monitoring adherence. Pearson correlation tests were performed to examine the overall association between text messaging adherence and goal attainment and weight loss. In the intervention group the average daily text messaging adherence rate was 49% (SD 27.9) with 85% (22/26) texting self-monitored behavioural goals. 70% strongly agreed that daily texting was easy and helpful; 76% found texting was appropriate. At 6 months, the intervention arm lost a mean of 1.27</p>	<p>Strength- RCT design used to assess intervention This study effectively assessed the feasibility of a text messaging intervention used in weight-loss amongst an understudied population Study isolated the use of the intervention within the control group to receive comparable results Limitations- Sample predominantly Black-African women, findings may not generalize to other population settings.</p>	<p>Given the increasing use of mobile devices, text messaging may be a useful self-monitoring tool for weight control, particularly among populations most in need of intervention</p>



		characteristics and anthropometrics. Programme satisfaction was assessed using a-item online questionnaire to assess intervention satisfaction. Using a 4-point Likert scale with response options ranging from strongly agree (=4) to strongly disagree (=1), where participants reported and rated whether they found daily text messages regarding self-monitoring to be easy, helpful overall, helpful for increasing daily steps, and important			kg (SD 6.51), and the control arm gained a mean of 1.14 kg (SD 2.53; mean difference – 2.41 kg, 95% CI –5.22 to 0.39; $P=0.09$ )		
<b>21. Mobilizing Your Medications: An Automated Medication Reminder Application for Mobile Phones and Hypertension Medication Adherence in a High-Risk Urban Population</b> <b>Patel et al (2013)</b> <b>USA</b>	Quantitative approach Randomized controlled trial Surveys	After obtaining informed consent 50 high-risk urban patients with hypertension were recruited using a purposive sampling technique Of the 2 participants who failed to complete the study, one was admitted to a chronic care facility and 1 was lost to follow-up resulting in 48 patients depending on the inclusion criteria: (1) age 18 to 80 years, (2) established essential hypertension, (3)	The aims of this study were to: 1) assess the adherence to antihypertensive medications in the 3-month pre-intervention period compared to when using the Pill Phone provided on personal mobile phones; 2) To assess continued medication adherence in the post intervention period after using the Pill Phone; 3) To evaluate	The Pill Phone was used as a mobile health management application it was owned by VOCEL Inc. But is no longer available. It enabled medication adherence via reminder text messages and information exchange to help patients tackle healthcare issues related to medication adherence	Statistical analysis was conducted using Windows SPSS 19.0 software two-tailed <i>t</i> -test was used to MO risky assess differences between the pre-intervention and intervention time points. The power analysis, which assumed 80% power and an alpha level of 0.05, estimated that a total of 44 patients would be needed to detect the estimated intervention effect. Forty-eight patients were remaining by the end of the study, 96%	Strength: Automated telephone systems have been successful for appointments used in diabetic centres; text messages have been used to remind patients in a wide variety of health care issues e.g., asthma control, taking oral contraceptives, using sunscreen, patients suffering from HIV and malaria Limitations: The population was pre-dominantly African American, ignoring other ethnic minority groups Purposive sampling method only represents small samples compared to random sampling methods,	A mobile-phone-based automated medication reminder system shows promise in improving medication adherence and blood pressure in high-cardiovascular-risk individuals.

		<p>prescribed at least two antihypertensive medications, (4) fluency in English, and (5) DC Medicaid as primary medical insurance. Exclusion criteria were (1) patients with end-stage organ disease (kidney, liver, heart, lung, pancreas), (2) patients with a terminal</p> <p>Participants completed a pre- and post-Morisky medication adherence survey.</p>	<p>patient usage patterns and acceptance of the Pill Phone</p>		<p>of the patients were African-American and majority of the patients had diabetes mellitus. A significant difference was found between the activation and post-activation phases (<math>p = .001</math>). The increase in measured adherence between the pre-activation and activation phases approached significance (<math>p = .057</math>), it was also seen that average blood pressure and level of control during study period improved significantly. Participants reported a high level of satisfaction with the medication reminder application at the final study visit</p>	<p>making the sample unrepresentative of the population, For patients taking numerous medications, the number of reminders they received was perceived as an additional burden or nuisance. Participants likely became fatigued with indicating “taken” to each individual reminder for every pill taken at a certain time</p> <p>Baseline demographics did not appear to predict Pill Phone use, with the exception that women were more likely to use the mobile-phone-based medication</p>	
<p><b>22. Microenterprise intervention to reduce sexual risk behaviors and increase employment and HIV preventive practices in economically-vulnerable African-American young adults (EMERGE):</b></p>	<p>Quantitative study Randomized Controlled Trial Questionnaire/surveys</p>	<p>40 participants were randomly allocated to one of two groups (treatment and control groups) 20 participants in each group. A computer-generated system was used to randomly allocate participants. Inclusion criteria: African-American, aged 18–24, live in the local area of study, MD, have experienced at least one episode of</p>	<p>To examine the feasibility of conducting a larger trial of an HIV prevention microenterprise intervention for economically-vulnerable African-American young adults.</p>	<p>The Author has discussed behaviour changes through examples of the Asset theory (theory of choice). Therefore, text messages on healthy sexual practices were provided in the form of small nudges to motivate behaviour change</p>	<p>Descriptive statistics used for the primary and secondary outcomes for the specified time points for all participants and by study group. Frequencies and proportions were used to summarize binary and categorical data. Means and standard deviations (or medians and interquartile ranges) were used to summarize continuous data.</p>	<p>Strengths- The study design enabled the researchers to examine the uncertainties that would arise when planning for a larger trial, such as participant willingness to be randomized, the time needed to collect data, the tolerability of the intervention, and the response rates to outcome assessments. Text messages were adapted to explore mobile phone usages and health behaviours in an</p>	<p>First U.S.-based randomized clinical trial assessing HIV prevention through technology-based interventions amongst economically-vulnerable African-American young adults.</p>

<p><b>protocol for a feasibility randomized clinical trial (Mayo-Wilson et al, 2019) USA</b></p>		<p>homelessness in the last 12 months, are unemployed or employed for fewer than 10 hours per week, are not enrolled in school, own a cell phone with text messaging function, report at least one episode of unprotected or unsafe sex in the prior 12 months.</p>			<p>random-effects linear model was used to explore the variability in the participants' pre-exposure behaviours and to explore the variability of participant trajectories in behaviours over the exposure period. Individuals that were unemployed or not going to school were less likely to follow safe sex practices.</p>	<p>impoverished U.S. urban setting with a focus on both African-American women and men All study participants were masked to allocation and study design-reducing potential bias Limitation- The sample retrieved was small for a RCT study design. The recruitment of economically-vulnerable young adults who are receiving supportive residential services (i.e., emergency shelter and transitional housing) rather than recruiting more at-risk youth who are disconnected from supportive services.</p>	
<p><b>23. The Feasibility of a Using a Smart Button Mobile Health System to Self-Track Medication Adherence and Deliver Tailored Short Message Service Text Message Feedback Bartlett et al (2019) USA</b></p>	<p>Mixed Methods Interviews and Surveys-longitudinal study patients interviewed over 52 days.</p>	<p>Convenience sampling technique used to recruit 5 patients with CKD. Inclusion criteria: adults &lt;18 years, Mobile phone users, CKD patients.</p>	<p>To evaluate the feasibility and acceptability of using an mHealth system for medication adherence tracking and intervention delivery.</p>	<p>mHealth intervention used to enhance patients' health behaviours to improve medication adherence. No mention of a behaviour change model.</p>	<p>Data were analysed with descriptive statistics appropriate for level of measurement using IBM SPSS. Narrative analysis of comments made by participants was used to at least identify patient views on mHealth. Participants were motivated and willing to use it to self-track medication adherence, and found the mHealth system acceptable to use in most cases</p>	<p>Strengths-The study was useful in identifying the advantages of mHealth interventions and opportunities to improve the study for the future clinical trial Longitudinal study was useful to assess the effectiveness of this intervention over a longer period of time. Limitations- The intervention was assessed amongst a very small sample of 5 patients only, making it difficult to make generalisations across larger sample groups.</p>	<p>there is a need to consider individual user characteristics, including gender, race, ethnicity, income, number and types of medications taken, and different chronic conditions, to determine if using a smart button self-tracker and mHealth system is feasible and then subsequently determine if using a smart button self-tracker and mHealth system can improve medication adherence. Future research will also</p>

							need to further evaluate the content of tailored SMS text messages for content and face validity congruent with systems thinking and determine the best timing for delivering messages.
<p><b>24. Text message-based intervention to improve treatment adherence among rural patients with type 2 diabetes mellitus: a qualitative study</b></p> <p><b>Chen et al (2018)</b> <b>China</b></p>	<p>Qualitative study Focus group interviews</p>	<p>A purposive sample was selected. However, the number of participants is not stated. Six focus group discussions with T2DM patients, six with village doctors, and three with public health physicians took place. Semi-structured interview guides were employed to facilitate qualitative data collection.</p>	<p>To explore the perspectives of rural T2DM patients and health workers on a text message-based intervention (TMI) for increasing patients' adherence in rural China.</p>	<p>Patient adherence was found to improve. Positive behavioural outcomes resulted during the usage of text messages amongst diabetic patients. Individuals were taking medications on time, attending appointments on time and consulting with health care providers when required.</p>	<p>Audio recordings of the sessions were transcribed verbatim, and theme analysis was performed on NVIVO. Based on the participants' reports, Type 2DM patients had insufficient knowledge about diabetes and suboptimal adherence to treatment in rural China. Most participants had a positive attitude toward text messages to improve treatment adherence and knowledge. The perceived potential barriers to the utilization of TMI included poor eyesight, educational background or gradually losing interest during a long-term intervention. The suggestions for successfully implementing this strategy included family or social support, applicability of the text</p>	<p>Strengths- Study explores experience of ethnic groups of rural China; findings add to and correlate with findings from other studies conducted in different regions of China (Lin et al, 2012; Xiao et al, 2014). Investigates the use of text message-based interventions amongst both healthcare providers and patients, to explore the full effects of the system used in healthcare settings. Limitations- Sample may not be generalizable to larger samples from different regions and ethnic groups. Method of data collection (focus groups), may affect true patient views. Patients may not be candid or may find it difficult to fully express their experiences due to influences by other participants. Limited information regarding sampling techniques and recruitment of participants.</p>	<p>A Text messaging-based intervention is promising for improving T2DM patients' adherence to treatment in rural China. The findings of the present study can contribute knowledge to the application of such interventions in similar settings.</p>

					message content, adequate frequency and timing of sending the messages, and combining of messages with other educational formats.		
<p><b>25. Effectiveness of text message based, diabetes self-management support programme (SMS4BG): two arm, parallel randomised controlled trial</b></p> <p><b>Dobson et al (2018)</b> <b>New Zealand</b></p>	<p>Quantitative Study A nine month, two arms, parallel, randomised controlled trial was conducted in adults with poorly controlled diabetes between June 2015 and August 2017.</p>	<p>366 Participants were randomly allocated to the control group (n=183) or the Intervention group (n=183). Eligible participants were English speaking adults aged &gt;16 years with poorly controlled type 1 or 2 diabetes; and those using a mobile phone.</p>	<p>To determine the effectiveness of a theoretically based and individually tailored text messaging system for the support of diabetes self-support intervention amongst adults with poorly controlled diabetes.</p>	<p>The text messaging intervention was designed to alter negative health behaviours to positive adherent behaviours. Supporting the self-management of diabetes. The intervention group received a tailored text messages for 9 months in addition to usual care; whilst, the control group only received only usual care. Text messages provided information, support, motivation and reminders related to diabetes self-management and lifestyle behaviours.</p>	<p>Statistical analyses were performed by SAS version 9.4 (SAS Institute). All statistical tests were two sided at a 5% significance level. Amongst the intervention participants, 169 (92%) completed questions at follow-up about satisfaction and acceptability of the intervention. Primary outcome- Changes in glycaemic (HbA1c) control from baseline to 9 months; Secondary outcomes- Changes in HbA1c at three and six months, self-efficacy, diabetes self-care behaviours, perceptions and beliefs about diabetes, health related quality of life, perceived support, intervention engagement and satisfaction at nine months. Participants reported high levels of satisfaction with Intervention, and that messages were a good way to deliver this type</p>	<p>Strengths- Large sample obtained including diverse population; the use of pragmatic design. The study contributes valuable evidence on the use of text messages in diabetes particularly for individuals with poor control. Considering poorer outcomes are experienced by ethnic minority groups, strength of this study was its high proportion of participants representing these groups. The intervention delivered tailored messages to meet the health needs and goals of each individual. Limitations- There was difficulty with recruitment, which resulted in a sample size smaller than initially planned Alternative methods of recruitment could be explored, such as through laboratory test facilities to ensure access to the intervention regardless of clinician availability. Due to messages being in English, some participants were not able to take part due to language barriers.</p>	<p>This study showed that a tailored and automated SMS self-management support programme has potential for improving glycaemic control in adults with poorly controlled diabetes. This study shows the potential of using a text messaging intervention as a low cost, scalable solution for increasing the reach of diabetes self-management support. It showed that a text messaging programme can increase a patient's feelings of support without the need for personal contact from a healthcare professional.</p>

					of support. Ten participants reported technical issues while receiving the intervention, most commonly issues replying to the messages (n=4), issues accessing graphs (n=2), and mobile reception issues (n=2). The reduction in Hb1Ac was significantly greater in the intervention group than the control group.		
<p><b>26. Mobile phone messaging to promote uptake of HIV testing among migrant African communities in the UK</b> Evans et al (2018) UK</p>	Quantitative study Questionnaire surveys	<p>169 patients were enrolled onto the study within the city of Nottingham by a team of community researchers. The eligibility criteria were: Adults &lt;18 years, from the African community, owning a mobile phone, understand and read English. They were sent two text messages per week (one on HIV and one on general health) for 12 weeks. Baseline and follow-up questionnaires were completed to measure HIV testing behaviour, HIV-related knowledge and attitudes and general health. Participants' views on the intervention were</p>	To investigate the use of a text messaging intervention to encourage HIV testing among migrant African communities.	The intervention was aimed at improving health behaviours and attitudes in relation to HIV screening. The intervention was called "Health4U"	Data was analysed by an external researcher; statistical analyses was performed using IBM SPSS Version 21.0.	<p>Strengths- Study was successful to assess the effectiveness of mHealth intervention amongst African ethnic minorities within the UK. Recruitment was successful in terms of participant numbers. A fairly large sample was recruited. An external researcher for data analyses reduced possibility of potential biases.</p> <p>Limitations- Data collection using online, text and email methods were not successful in this population group. Face-to-face interactions or telephone follow up were preferred.</p>	This study demonstrates the feasibility and potential health benefits of mobile phone-based interventions for African migrant communities. Furthermore, the study indicates mHealth interventions to be an acceptable and wide-reaching mechanism for health promotion more generally among African migrant communities. However, the effectiveness of text messaging interventions in changing screening behaviour, health and quality of life

		solicited through questionnaires also.					outcomes needs to be assessed in a well-designed RCT with longer follow-up periods.
<p><b>27. Perceptions and Acceptability of Text Messaging for Diabetes Care in Primary Care in Argentina: Exploratory Study</b>  <b>Moyano et al (2019)</b>  <b>Argentina</b></p>	Qualitative study Semi-structured interviews	<p>In total 24 individuals were interviewed via telephone. Semi-structured interview guide was used.</p> <p>Inclusion criterion was: Adults &lt;18 years, with type 2 Diabetes receiving care from selected clinics, had access to a mobile phone, and received texts during the implementation of the program, owner of a mobile phone.</p> <p>A combination of convenience and saturation sampling was used to enrol participants between ages 39 and 66 years.</p>	To explore perceptions and acceptability of a short message service (SMS) text messaging intervention for diabetes care in underserved people with diabetes in Argentina.	<p>The text messaging intervention was designed to enhance self-management behaviours and optimize diabetes care for patients with diabetes.</p> <p>Intervention does tend to focus on elements of the HBM for example, risk perception, Educational messages and reminders to address issues related with adherence to diabetic treatment regimens, lifestyle modification, diabetes education, and facilitation of clinical encounters with the primary care team were included.</p>	<p>Data collection stopped when data saturation was reached.</p> <p>Written transcripts were classified and then codified according to the study objectives and the dimensions addressed, the written transcripts were entered into ATLAS.ti version 7 combined with the manual technique of information coding.</p> <p>Finally, data were abstracted and interpreted through content analysis. As part of the analysis, direct quotations representative of the participants' opinions was selected and included.</p> <p>Majority of participants found text messages an acceptable and adequate method to aid self-management of diabetes. Patients considered messages as educational reminders that that can help bring about changes in risk perception and care practices and to function as psychosocial support.</p>	<p>Strength- The study design allowed for the exploration of subjective elements in persons with diabetes, to better understand the experiential processes of this type of intervention. Interviewing techniques to reduce biases were used such as using indirect or generic questions.</p> <p>Limitations- the nature of study and recruitment of a small sample may lack generalizability across other populations.</p>	The study findings provide evidence on the acceptability and value of text messages for diabetes care, and reinforce the importance of adding an mHealth component for diabetes management, implemented in low-income settings.

					There was also a strong association between receiving text messages and having a better patient-physician relationship. Additionally, social barriers that affect diabetes care such as socioeconomic and psychosocial vulnerability were identified for example, age, employability, education level, gender etc.		
<p><b>28. Exploring Perceived Barriers to Medication Adherence and the Use of Mobile Technology in Underserved Patients with Chronic Conditions.</b>  <b>Hincapie et al (2017)</b>  <b>USA</b></p>	<p>Qualitative study                  Focus group</p>	<p>Seventeen patients were purposively selected participated in 4 focus groups. interviews explored the barriers patients faced with medication adherence and their perceptions of using mobile phones and text messages. Eligibility criteria; Adults &lt;18 years, living with an LTC, can read and understand English, using/owning mobile phone. Interviews were framed and guided using theoretical concepts of the HBM.</p>	<p>To explore barriers to medication adherence and identify opportunities and challenges for the potential use of mHealth adherence interventions in an underserved population.</p>	<p>The aim of the text messaging intervention was to improve adherence and self-management behaviours amongst patients with LTCs. The Health Belief Model was used as theoretical framework.</p>	<p>Audio-recorded data were transcribed and thematically analysed to identify common themes across the data set. The following themes were identified: (1) perceived barriers to medication adherence, (2) everyday practices used to improve medication adherence, and (3) perceived benefits and barriers to technology use. The use of text messages seemed beneficial. Some individuals expressed willingness to try smartphone applications instead but stated that they would not be able to afford them. Changes in daily routine and complexity of</p>	<p>Strength- Exploratory design adds to the findings and literature based on mHealth interventions designed for self-managing LTCs                  Limitations- Very small sample leading to issues to generalize findings.</p>	<p>Findings highlight the importance of considering diverse experiences when engaging patients in mHealth for medication adherence. Providing patient-centred approaches to assist patients construct their individualized medication adherence strategies may lead to better outcomes.</p>



					medication regimens were seen as other barriers to medication adherence.		
<p><b>29. Effects of a Short Message Service (SMS) Intervention on Reduction of HIV Risk Behaviours and Improving HIV Testing Rates Among Populations Located near Roadside Wellness Clinics: A Cluster Randomised Controlled Trial in South Africa, Zimbabwe and Mozambique</b></p> <p><b>Govender et al (2019) Africa</b></p>	Quantitative study RCT	<p>Sample was selected across three southern African countries. Individuals randomised into the control arm or the SMS arm using a computer-generated system. Follow-up questionnaires were completed at a 6-month follow-up.</p>	<p>To assess the effectiveness of a SMS intervention in reducing HIV risk behaviours and improving HIV testing behaviours among truck drivers, sex workers and community residents located near Roadside Wellness.</p>	<p>The intervention was used to enhance safe sex behaviours and promote screening for HIV testing. The SMS arm received 35 HIV risk reduction and HIV testing SMSs over a 6-month period.</p>	<p>Data analysed using SPSS software. The SMS intervention had no significant impact on sexual risk behaviours. However, participants in the SMS arm were more likely to have tested for HIV in the previous 6 months.</p>	<p>Strengths- The intervention was assessed amongst a large sample selected across three different regions, allowing generalisations to be made. Limitations- Insufficient details provided regarding methods of recruitment, data collection and analyses.</p>	<p>Results indicate that the SMS intervention providing health promoting information, improved HIV testing rates in key and vulnerable populations in southern Africa.</p>
<p><b>30. Acceptability and feasibility of short message service to improve ART medication adherence among</b></p>	Mixed methods Cross-sectional-Survey administration and focus groups used for data collection.	<p>422 participants were randomly selected from a patient list, including those who had an appointment during the study period. Structured interviews and translated questionnaires were administered to</p>	<p>To examine the feasibility and acceptability of a short message service to improve medication adherence among people living with HIV/AIDS receiving</p>	<p>Text messages were to be designed to support adherence to ART for those with HIV/AIDS. This included educational, informative and reminder messages.</p>	<p>Quantitative data from questionnaires was analysed on SPSS 21.0. Qualitative findings from focus group discussions were processed using thematic analyses. Selective coding of the transcript was</p>	<p>Strength- Mixed method conducted increasing confidence and reliability of findings. Large sample used to assist with generalisability across similar samples. Limitations- Ethics regarding data protection were highlighted, which appears to be an issue in</p>	<p>Suggestions are made for the need of interventions that could be better suited for those less likely to uptake text messages for example, translated text messages to address those not being able to speak</p>

<p><b>people living with HIV/AIDS receiving antiretroviral treatment at Adama hospital medical college, Central Ethiopia</b> Endebu et al (2019)</p>		<p>explore and assess the feasibility and acceptability of SMS on adherence to ART.</p>	<p>Antiretroviral Treatment.</p>		<p>performed based on the major themes. Triangulation of different data sources was performed to verify the findings.</p>	<p>less developed countries, which could affect recruitment and people not wanting to take part due to confidentiality issues.</p>	<p>or understand English.</p>
<p><b>31. Mobile Health Technologies May Be Acceptable Tools for Providing Social Support to Tuberculosis Patients in Rural Uganda: A Parallel Mixed-Method Study</b> Musimanta et al (2020)</p>	<p>Mixed methods Demographic surveys and interviews.</p>	<p>Purposively selected patients receiving TB treatment In-depth interviews conducted with patients who had TB. Surveys collated to elicit information about socio-demographics, health status, social support, and general preferences for wireless intervention.</p>	<p>To explore TB patients' current access to social support and perceptions of utilising real-time adherence monitoring interventions to support medication adherence.</p>	<p>Intervention was aimed to deliver messages to offer social and educational support for patient with TB.</p>	<p>Quantitative data input into STATA 13, included participants socio-demographic and social support characteristics. Qualitative data were analysed using content analysis to derive categories describing accessibility and perceptions.</p>	<p>Strengths- The study has utilised a mixed methods approach strengthening rigour. Has highlighted needs of interventions offering support for conditions such as TB. Limitations- Insufficient details number of participants recruited. Chosen sampling technique may impose issues to determine generalisability across samples with varied characteristics. This study is also based on self-reported responses about sensitive topics, which may be vulnerable to social desirability bias. Also conducted amongst those who use mobile phone. Non-user view not considered.</p>	<p>Mobile phone interventions have the potential to provide social support for TB medication adherence. However, further research needed to focus on optimising mHealth interventions to provide social support to TB patients and training of TB patients and social supporters to match their expectations.</p>
<p><b>32. British South Asian Patients' Perspectives on the Relevance</b></p>	<p>Qualitative Focus group interviews</p>	<p>Sample was purposively selected. 67 participants recruited and interviewed.</p>	<p>To explore the perceptions and views of British South Asian patients with T2D on mobile health</p>	<p>Text messages were delivered to support patients with type 2 diabetes. Therefore, messages were sent containing information</p>	<p>Focus group discussions took place in SA languages. They were audio-recorded, and translated and transcribed verbatim,</p>	<p>Strengths- Study was insightful to SA patient experiences of text messages they preferred to receive to support their self-management</p>	<p>Results outline and present the importance of a culturally appropriate intervention to</p>

<p><b>and Acceptability of Mobile Health Text Messaging to Support Medication Adherence for Type 2 Diabetes: Qualitative Study</b> Prinjha et al (2020)</p>		<p>Data collected via 8 focus group interviews in Leicester, UK.</p>	<p>SMS text messaging to support medication adherence, aimed at the general UK population.</p>	<p>to support self-management.</p>	<p>and then thematically analysed by qualitative researcher.</p>	<p>Study very relevant to research topic of interest. Limitations- Study sample did not have an even spread of diverse participants. Majority of the subjects were of first generation, and fewer from second or third generations.</p>	<p>increase the uptake of text messaging in SA ethnic minorities, to help reduce health inequalities.</p>
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**Appendix 7. Table 13. Critical Appraisal Framework**

	<b>Adapted from CASP tool (2006)</b>	<b>NICE 2016</b>
<b>Clear Aims</b>	<ul style="list-style-type: none"> <li>• Did the trial address a clearly focused issue? In terms of</li> <li>• The population studied- ethnic minority</li> <li>• The intervention given- SMS text messaging intervention</li> <li>• The comparator given</li> <li>• The outcomes considered- positive behavioural outcomes/enhancements</li> </ul>	<p>Clear (+)</p> <p>Unclear (-)</p> <p>Mixed</p> <p>Not Addressed</p> <p>Not Reported</p> <p>Not Applicable</p>
<b>Research design- Methods</b>	<ul style="list-style-type: none"> <li>• Were the most rigorous methods used, given the nature of the research? Mobile phone intervention used? were SMS utilized?</li> <li>• Were appropriate comparisons made to interpret findings?</li> <li>• Were appropriate data collection points made?</li> <li>• Were biases minimized? Did the design help minimize threats to the internal construct and external validity of the study (e.g., was blinding procedure used in RCT)</li> <li>• Were quantitative or qualitative measures used to examine behaviour change?</li> </ul>	<p>Appropriate (+)</p> <p>Inappropriate (-)</p> <p>Not Addressed</p> <p>Not Reported</p> <p>Not Applicable</p>
<b>Population and sample selection</b>	<ul style="list-style-type: none"> <li>• Was the recruitment strategy appropriate for the aims of the research?</li> <li>• Was the appropriate population selected for the study? Were ethnic minority populations included or not? Or was study based solely on Caucasian samples</li> <li>• Was the appropriate sampling design used, best in terms of the study design to enhance representativeness of the sample? Were sample biases minimised?</li> <li>• Was sample size appropriate for study? Was power analysis used for sample size estimation?</li> </ul>	<p>Good (++)</p> <p>Adequately addressed (+)</p> <p>Poorly addressed (-)</p> <p>Not Addressed</p> <p>Not Reported</p> <p>Not Applicable</p>

<b>Data collection and measurement</b>	<ul style="list-style-type: none"> <li>• Has the researcher justified the methods chosen to conduct studies?</li> <li>• Were key variables obtained and addressed via the most appropriate data collection method e.g., interviews, observations, etc.</li> <li>• Are specific techniques adequately described and did the method benefit the researcher given the aims of the study and the selected sample population</li> <li>• Did the data collection method yield data achieving high reliability and validity?</li> <li>• Has the researcher made the methods explicit (e.g., for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)</li> <li>• How was behaviour change captured by researchers e.g., via in-depth interviews or cross-sectional surveys</li> </ul>	<p>Appropriate/Well covered (++)</p> <p>Adequately addressed (+)</p> <p>Inadequately reported (-)</p> <p>Not Addressed</p> <p>Not Reported</p> <p>Not Applicable</p>
<b>Procedures</b>	<ul style="list-style-type: none"> <li>• If an interventional study was conducted, is it described in well enough detail, was it implemented appropriately? Did participants allocated within the intervention group receiving it? If so, how many? Is there evidence of instrument fidelity?</li> <li>• Were biases due to be caused by data collection methods minimised? Were staff members adequately trained for data collection?</li> </ul>	<p>Appropriate/Well covered (++)</p> <p>Adequately addressed (+)</p> <p>Inadequately reported (-)</p> <p>Not Addressed</p> <p>Not Reported</p> <p>Not Applicable</p>
<b>Results/ Findings (data analysis)</b>	<ul style="list-style-type: none"> <li>• Were the statistical methods used appropriate?</li> <li>• Was the best analytical method used? (e.g., were confounding variables controlled?)</li> <li>• Were type I and type II errors avoided in quantitative studies using RCT?</li> <li>• Was the data analysis sufficiently rigorous?</li> <li>• Is there is an in-depth description of the analysis process? If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data? Were results found to be statistically significant, was statistical significance presented?</li> </ul>	<p>Appropriate/Well covered (++)</p> <p>Adequately addressed (+)</p> <p>Inadequately reported (-)</p> <p>Not Addressed</p> <p>Not Reported</p> <p>Not Applicable</p>

	<ul style="list-style-type: none"> <li>• Was information about effect size and precision of estimates (confidence intervals) presented</li> <li>• Have the researchers discussed whether or how the findings can be transferred to other populations or considered other ways the text messaging intervention be used to enhance behavioural outcomes</li> </ul>	
<b>Generalisability</b>	<ul style="list-style-type: none"> <li>• Can the findings be applied of a SMS intervention be generalised and applied elsewhere</li> </ul>	<p>Good (++)</p> <p>Limited (+)</p> <p>Poor (-)</p> <p>Not Addressed</p> <p>Not Reported</p> <p>Not Applicable</p>
<b>Summary of assessment</b>	<ul style="list-style-type: none"> <li>• How valuable is the research? Regardless of limitations do findings appear to be valid?</li> <li>• Does the study contribute meaningful evidence to be used in practice?</li> <li>• Does the researcher discuss the contribution the study makes to existing knowledge or understanding e.g., do they consider the findings in relation to current practice or policy? or relevant research-based literature?</li> </ul>	<p>Clear (+)</p> <p>Unclear (-)</p> <p>Mixed</p> <p>Not Addressed</p> <p>Not Reported</p> <p>Not Applicable</p>

### Appendix 8. Table 14. *Quality Summary*

Sample judgement based on sampling framework, methods of participant selection, recruitment methods, number of participants recruited and representativeness of target population. Method judgement based on methodology, description of fieldwork, data collection methods and analysis framework.

In line with NICE (2016), quality assessment indicators, each of the sections was given a judgement of good (++), appropriate/adequate/average (+), or poor (-) dependent upon the quality of the paper and description provided. The positive and negative aspects of each research paper have been stated along with the relevance to the developing study identified. Papers are not in chronological order, but are numbered in correspondence to those presented in the data extraction sheet (Appendix 6, Table 12).

**High Quality= 25 (++)**

Author	Sample rating	Method rating	Positive	Negative	Relevance to study and review aims
4. Leon et al (2015)	Good (++)	Good (++)	<ul style="list-style-type: none"> <li>• Clear methods used to fulfil aims of study.</li> <li>• Combined sampling methods- convenience and purposive sampling.</li> <li>• Clear thematic analysis method- verified by external researchers.</li> <li>• Ethical Approval obtained.</li> </ul>	<ul style="list-style-type: none"> <li>• Quantitative researchers may argue sample to be small, however, findings reflect larger studies.</li> <li>• No mention of analysis with respect to age or gender.</li> </ul>	<ul style="list-style-type: none"> <li>• Various factors identified influencing patient behaviours.</li> <li>• Improvements in medication adherence through an SMS intervention.</li> </ul>
5. Mbuagbaw et al (2012)	Good (++)	Good (++)	<ul style="list-style-type: none"> <li>• Mixed methods used to strengthen rigor of data collected.</li> <li>• Good explanation of randomization explained.</li> <li>• Service providers and outcome assessors were blinded to allocation reducing possibilities of bias.</li> <li>• Appropriate analysis techniques used to compare variables.</li> <li>• Translation of intervention considered.</li> <li>• Ethical Approval attained.</li> </ul>	<ul style="list-style-type: none"> <li>• Insufficient details provided regarding interviews. No clarity on how they were conducted and analysed. No mention of particular themes that may have risen.</li> <li>• Although a computer-generated program assisted with randomization, no clarity on sampling techniques.</li> </ul>	<ul style="list-style-type: none"> <li>• Good explanation of methods used to attain data.</li> <li>• The use of translation and preference of language was useful for intervention group.</li> <li>• focus group discussions insightful to capture patient health belief behaviours</li> <li>• Improvements in medication adherence through an SMS intervention.</li> </ul>

6. Xiao et al (2014)	Good (++)	Good (++)	<ul style="list-style-type: none"> <li>• Surveys administered to assess adherence to ART</li> <li>• Aims of the study fulfilled by survey questions to outline and assess patients' willingness to accept SMS.</li> <li>• Participants given choices to self-administer the survey or have the survey administered by trained interviewer reducing bias and Hawthorne effect</li> <li>• Large and representative multi-site sample</li> <li>• Good description of sample variables</li> <li>• Stratified sample obtained from local Centres for Disease Control and Prevention (CDC) and rural clinics within 6 different cities in China. This gives a wide spread of varied demographical factors that may associate with mobile phone use.</li> </ul>	<ul style="list-style-type: none"> <li>• No mention of ethical approval</li> <li>• More details regarding analysis methods could be provided</li> </ul>	<ul style="list-style-type: none"> <li>• Data collection method useful to obtain information regarding participants' willingness to accept SMS</li> <li>• Wide range of variables of sample to consider (age, gender, education, marital status, occupation, income, family size, drinking and ART dosing habits (daily frequency, time, and methods of reminder)</li> <li>• Provides an understanding the acceptability of short message service (SMS) as a reminder for improving medication adherence.</li> </ul>
9. Lin et al (2014)	Good (++)	Good (++)	<ul style="list-style-type: none"> <li>• Clear explanation of methods used, sampling technique (random sample attained), randomisation procedure and the participants recruited within the intervention and control group.</li> <li>• Development of validated instruments to measure self-efficacy to change a series of behaviours associated with weight management.</li> <li>• Quantitative analysis techniques used to assess and compare variables.</li> </ul>	<ul style="list-style-type: none"> <li>• Ethical approval not stated</li> </ul>	<ul style="list-style-type: none"> <li>• Good description of methods and instruments used to assess the impact of a text messaging intervention to assist with weight loss.</li> <li>• Validated surveys adapted to Chinese culture to avoid cultural barriers that may hinder recruitment rate and adherence</li> <li>• Enhancement of positive behavioural outcomes and improvement in weight management through SMS intervention</li> </ul>



10 Bobrow et al (2014)	Good (++)	Good (++)	<ul style="list-style-type: none"> <li>• Randomised controlled trial-randomised three-arm parallel group.</li> <li>• Random sampling technique used.</li> <li>• Research staff and participants were blinded to trial allocation reducing biases.</li> <li>• Three different instruments utilised to assess adherence to medication and knowledge regarding hypertension.</li> <li>• Clear description of content and format of the surveys included.</li> <li>• Ethical approval obtained.</li> </ul>	<ul style="list-style-type: none"> <li>• Insufficient details about analysis included.</li> </ul>	<ul style="list-style-type: none"> <li>• Varied instruments and descriptions of tools- aspects to consider and explore further by interviews.</li> <li>• Improvements in medication adherence through an SMS intervention providing clinic appointment information, medication pick-up reminders, medication adherence support and hypertension-related education.</li> </ul>
20. Steinberg et al (2013)	Good (++)	Good (++)	<ul style="list-style-type: none"> <li>• Good description of methods.</li> <li>• Random sample selected.</li> <li>• Clear description of intervention and behaviour goals.</li> <li>• Surveys useful for data regarding demographic characteristics and anthropometrics.</li> <li>• Good description of the various analyses' technique utilised to analyse different variables</li> <li>• Ethical approval obtained.</li> </ul>	<ul style="list-style-type: none"> <li>• Only 50 subjects recruited for this RCT, could have been a larger sample</li> <li>• Sample pre-dominantly black-African women, making it ethno/androcentric-and difficult for generalisations to be made.</li> </ul>	<ul style="list-style-type: none"> <li>• Theory-based approach where participants are assigned individualized lifestyle and behaviour change goals.</li> <li>• Implications for patient education described.</li> <li>• Enhancement of positive behavioural outcomes promoting weight-loss amongst obese individuals via SMS.</li> </ul>
21. Patel et al (2013)	Good (++)	Good (++)	<ul style="list-style-type: none"> <li>• Randomised controlled trial, study methods explained in detail.</li> <li>• Validated surveys used to assess medication adherence.</li> <li>• Purposive sampling method used to achieve study aims.</li> <li>• Analyses techniques described adequately.</li> <li>• Ethical approval obtained.</li> </ul>	<ul style="list-style-type: none"> <li>• Inappropriate sampling method used, could have made a random selection.</li> <li>• Small sample obtained; a larger randomised sample would be more suited for this study design.</li> </ul>	<ul style="list-style-type: none"> <li>• Good findings, showing acceptance and usage of an automated medication reminder.</li> <li>• Improvements in medication adherence through an SMS intervention.</li> </ul>

22. Mayo-Wilson (2019)	Good (++)	(Good (++))	<ul style="list-style-type: none"> <li>• Randomised controlled trial-adequate information of methods.</li> <li>• Random sample obtained-appropriate method of recruitment for study design.</li> <li>• Clear description of participants allocated to treatment and control group.</li> <li>• Sample attained to meet the aims of the study.</li> </ul>	<ul style="list-style-type: none"> <li>• Small sample recruited for the nature of study, and only including participants between ages of 18-24, which may impose issues with generalisability.</li> </ul>	<ul style="list-style-type: none"> <li>• Messages benefitted individuals with HIV, as they felt texts nudged them to engage in safer-sex behaviours, for example condom use.</li> <li>• The findings inform whether and how to conduct a larger efficacy trial for HIV risk reduction in this population.</li> </ul>
26. Evans et al (2018)	Good (++)	Good (++)	<ul style="list-style-type: none"> <li>• Detailed information on study methodology and sample selection.</li> <li>• Quantitative study-RCT performed.</li> <li>• Adequate description of follow-up phase and participant drop-out.</li> <li>• Patient views of SMS intervention taken into account even though quantitative study.</li> <li>• Fairly large sample of 163 subjects attained.</li> <li>• Validated questionnaires used to measure HIV-related behaviour.</li> </ul>	<ul style="list-style-type: none"> <li>• Patient experiences collated from surveys. Qualitative interviews would be better to elicit patient views on text messaging interventions.</li> </ul>	<ul style="list-style-type: none"> <li>• Findings report intervention to be a feasible and acceptable intervention to promote both HIV testing and lifestyle behaviours among African migrant communities in the UK.</li> </ul>
23. Bartlett et al (2019)	Average (+)	Good (++)	<ul style="list-style-type: none"> <li>• Detailed description of study conducted- Mixed methods employed to fully explore patient perceptions of text messaging interventions to aid in self-management of CKD.</li> <li>• Convenience sample attained to achieve aims of study and the qualitative element of study.</li> <li>• Intervention explained in detail.</li> <li>• Ethical approval obtained; process discussed.</li> </ul>	<ul style="list-style-type: none"> <li>• Very small sample of 5 participants, findings may not apply to wider samples with CKD.</li> </ul>	<ul style="list-style-type: none"> <li>• Acceptability and feasibility of mobile phone use and text messages explored amongst CKD patients.</li> <li>• Patient views reveal technology-based interventions to be beneficial to aid with adherence but at the same time can be disruptive.</li> <li>• Although the sample size limits generalizability, Findings are useful in identifying opportunities to improve future iterations of the mHealth system components.</li> </ul>

24. Chen et al (2018)	Good (++)	Good (++)	<ul style="list-style-type: none"> <li>• Good description of study design and sample selection methods</li> <li>• Qualitative study- Six focus groups conducted to explore the perspectives of patients with type 2 diabetes and their health carers on a text messaging intervention.</li> <li>• Details on interview guide provided along with analyses of interviews (thematic interviews)</li> <li>• Aims of study clearly defined and addressed through study design.</li> <li>• Format and content of text messages discussed.</li> </ul>	<ul style="list-style-type: none"> <li>• No clarity on number of participants recruited.</li> <li>• Perhaps a quantitative study can be conducted with a larger sample to produce results that can be generalisable.</li> </ul>	<ul style="list-style-type: none"> <li>• Findings support SMS for self-managing diabetes and are applicable to similar settings employing similar interventions.</li> </ul>
25. Dobson et al (2018)	(Good ++)	(Good ++)	<ul style="list-style-type: none"> <li>• Study design thoroughly described.</li> <li>• RCT conducted to assess effectiveness of text messaging interventions.</li> <li>• Fairly large sample of 366 participants selected, with equal allocation in treatment and control group.</li> <li>• This study contributes to the evidence around the use of SMS to support diabetes management.</li> </ul>	<ul style="list-style-type: none"> <li>• Issues with identifying and recruiting sample led to a much smaller sample than planned by researchers of the study.</li> </ul>	<ul style="list-style-type: none"> <li>• A tailored, text messaging intervention to aid self-management resulted in improvements in glycaemic control in adults with poorly controlled diabetes.</li> </ul>
28. Hincapie et al (2017)	Good (++)	Good (++)	<ul style="list-style-type: none"> <li>• Qualitative study conducted- appropriate methods utilised to achieve aims of study.</li> <li>• Focus groups conducted from which patient experiences of using SMS intervention for medication adherence obtained.</li> <li>• Acceptable sample size for study design.</li> </ul>	<ul style="list-style-type: none"> <li>• A larger can be conducted to determine whether findings apply upon wider population.</li> </ul>	<ul style="list-style-type: none"> <li>• Patients had mixed views in relation to mobile phone use.</li> <li>• Relevant themes to study of interest identified (1) perceived barriers to medication adherence, (2) everyday practices used to improve medication adherence, and (3) perceived benefits and barriers to technology use. Use of text messages seemed beneficial.</li> </ul>

			<ul style="list-style-type: none"> <li>• The Health Belief Model was used as theoretical framework to develop the focus group guide.</li> <li>• Appropriate analyses technique outlined.</li> </ul>		
29. Govender et al (2019)	Average (+)	Good (++)	<ul style="list-style-type: none"> <li>• RCT conducted.</li> <li>• Good description of methods-study design, sample detail.</li> <li>• Discusses issues related to HIV testing in low-income countries.</li> </ul>	<ul style="list-style-type: none"> <li>• Not enough clarity on recruitment methods or analyses techniques.</li> </ul>	<ul style="list-style-type: none"> <li>• Findings support the use of SMS interventions, and reveal educational texts to have improved HIV testing rates in key and vulnerable populations in southern Africa.</li> </ul>
30. Endebu et al (2019)	Good (++)	Good (++)	<ul style="list-style-type: none"> <li>• Mixed methods approach</li> <li>• Surveys translated into local language, increasing response rate.</li> <li>• Good description of methods and, analyses techniques and sample recruitment.</li> <li>• Presents feasibility and acceptance to text. messages in low-income countries.</li> </ul>	<ul style="list-style-type: none"> <li>• Limited information about the type of text messaging intervention delivered.</li> </ul>	<ul style="list-style-type: none"> <li>• Findings prove text messaging interventions to be an acceptable and feasible intervention amongst those with HIV/AIDS.</li> </ul>
31. Musiimenta et al (2020)	Average (+)	Good (++)	<ul style="list-style-type: none"> <li>• Mixed methods approach- detail provided on data collection and analyses methods.</li> <li>• Instruments and interviews translated into local languages to address language barriers.</li> <li>• Useful findings supporting use of text messaging in patients with TB.</li> </ul>	<ul style="list-style-type: none"> <li>• Insufficient details on sample recruitment methods.</li> <li>• Data collection methods may impose biases.</li> </ul>	<ul style="list-style-type: none"> <li>• Findings contribute to the use of text messages offering social support for LTCs such as TB within low-income countries.</li> </ul>
32. Prinjha et al (2020)	Good (++)	Good (++)	<ul style="list-style-type: none"> <li>• Detailed information provided on study methods, including data collection and analyses.</li> <li>• Study aims addressed to investigate SA patient experiences of using text messages.</li> </ul>	<ul style="list-style-type: none"> <li>• Study conducted amongst small sample, was not able to obtain an even spread of diverse participants imposing issues related to generalisability.</li> </ul>	<ul style="list-style-type: none"> <li>• Findings address similar issues to the research topic of interest; and has been conducted across similar SA sample.</li> <li>• Results support the use of text messages being an acceptable intervention for SA patients if culturally adapted.</li> </ul>

**Medium Quality= 5 (+)**

<b>Author</b>	<b>Sample Rating</b>	<b>Method Rating</b>	<b>Positive</b>	<b>Negative</b>	<b>Relevance to study</b>
3. Shetty et al (2011)	Average (+)	Average (+)	<ul style="list-style-type: none"> <li>• Methods have been described- RCT conducted.</li> <li>• Validated surveys used for data collection of baseline variables.</li> <li>• Random sample selected appropriately for study.</li> <li>• Ethical approval attained.</li> </ul>	<ul style="list-style-type: none"> <li>• Not enough information provided on data collection methods.</li> <li>• No clarity on the type of questions asked regarding diet habits and adherence to drug prescriptions.</li> <li>• Brief description of data analysis methods stated.</li> <li>• Blinding procedures not stated during randomisation.</li> </ul>	<ul style="list-style-type: none"> <li>• Good findings, indicating SMS intervention to be acceptable to diabetic patients and helped improve the health outcomes, through adherence to advised behavioural modifications.</li> <li>• Improvements in medication adherence for management of diabetes through an SMS intervention.</li> </ul>
7. Osborn and Mulvaney (2013)	Average (+)	Poor (-)	<ul style="list-style-type: none"> <li>• Small sample obtained. However, findings reflect upon larger studies.</li> <li>• Purposive sampling technique performed to help achieve study aims.</li> <li>• Interviews described in detail.</li> <li>• Interviews performed by external research assistant, reducing potentials for bias.</li> <li>• Validated questionnaires combined and used to assess adherence and self-management in diabetic patients.</li> </ul>	<ul style="list-style-type: none"> <li>• Inadequate information regarding data analysis techniques- Procedures not explained in sequential order, appears rather scattered and unclear.</li> <li>• No clarity on the study design.</li> <li>• Only recruited 22 subjects, could perform this interventional study using larger sample.</li> </ul>	<ul style="list-style-type: none"> <li>• Identifies factors impacting adherence within patients with long-term conditions i.e., diabetes.</li> <li>• Recognises the benefits of the intervention for comparable patient groups.</li> <li>• Improvements in medication adherence for management of diabetes through an SMS intervention.</li> </ul>
8. DeSouza et al (2014)	Poor (-)	Average (+)	<ul style="list-style-type: none"> <li>• Data collection techniques outlined and described.</li> </ul>	<ul style="list-style-type: none"> <li>• No clarity on sample selection techniques.</li> <li>• Healthcare personnel were responsible for data</li> </ul>	<ul style="list-style-type: none"> <li>• Researchers identify aspects such as social desirability to avoid biases (DeSouza et al 2014).</li> </ul>

			<ul style="list-style-type: none"> <li>• Large sample obtained allowing generalisations to be made to similar settings.</li> <li>• Development of validated instruments to explore mobile phone usage in people living infectious diseases.</li> <li>• Data analysis techniques stated and described.</li> </ul>	<ul style="list-style-type: none"> <li>• collection, imposing possibility of biases.</li> <li>• Ethical approval not stated.</li> </ul>	<ul style="list-style-type: none"> <li>• Development of a new tool, adapted from the HIVIND study questionnaire to promote the management of chronic illnesses.</li> <li>• Management of long-term conditions using an SMS intervention.</li> </ul>
17. Lester et al (2010)	Average (+)	Poor (-)	<ul style="list-style-type: none"> <li>• Methods have been stated (RCT).</li> <li>• Multi-site sample recruited across three clinics in Kenya.</li> <li>• Random sample selected- large sample obtained.</li> <li>• Participants and clinical staff were not masked to treatment-reducing potentials of biases.</li> <li>• Time scale of study included.</li> </ul>	<ul style="list-style-type: none"> <li>• No clarity on randomisation procedures.</li> <li>• Not explained how many participants allocated within the control and intervention group. Also, very brief description of what each group offered.</li> <li>• Inadequate details regarding demographic variables.</li> <li>• Insufficient information regarding data analysis techniques</li> <li>• Ethical approval not stated</li> </ul>	<ul style="list-style-type: none"> <li>• Good findings-demonstrate that patients allocated receiving SMS support had significantly improved ART adherence compared to the control group.</li> <li>• Focuses on both patients and healthcare workers to identify factors associated with adherence to ART.</li> <li>• Improvements in medication adherence and suppression of HIV.</li> </ul>
18. Buccholz et al (2015)	Poor (-)	Good (++)	<ul style="list-style-type: none"> <li>• Good description of methods- data collection and sampling techniques.</li> <li>• Purposive sampling method recruited to fulfil study aims.</li> <li>• Translation was considered as English was not first language- to overcome communication barriers.</li> <li>• Detailed description of analytical techniques used for interviews given.</li> </ul>	<ul style="list-style-type: none"> <li>• Very small sample size (8 patients) prevents findings being generalised.</li> <li>• Unable to explore variables across samples with different characteristics.</li> </ul>	<ul style="list-style-type: none"> <li>• The development of culturally appropriate text messages enhances positive behaviour and increase physical activities. Factors and concerns identified.</li> </ul>

			<ul style="list-style-type: none"> <li>• Interviews analysed by external bilingual researchers, reducing potentials for bias.</li> <li>• Ethical approval obtained.</li> </ul>		
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**Poor Quality= 1 (-)**

Author	Sample Rating	Method Rating	Positive	Negative	Relevance to study
I. Lin et al (2012)	Poor (-)	Poor (-)	<ul style="list-style-type: none"> <li>• Useful theoretical ideas regarding behaviour changes and management of LTCs.</li> <li>• Data collection methods stated.</li> <li>• Sampling method stated-purposive sampling method used.</li> <li>• Good Large sample obtained, representing Taiwanese population.</li> <li>• Analysis techniques stated</li> </ul>	<ul style="list-style-type: none"> <li>• Mobile phone intervention not used, however, relevant findings obtained reflecting upon other studies included in review regarding barriers related to LTCs.</li> <li>• Data collection and analysis techniques were briefly described. Insufficient information, more detail needed.</li> <li>• Sampling technique does not seem appropriate for recruiting such a large sample of 317</li> <li>• Ethical approval not obtained.</li> </ul>	<ul style="list-style-type: none"> <li>• Findings identify useful information, and the need for tailored services to improve self-management of type 2 diabetes.</li> <li>• Explores the gaps between perception and performance of health management strategies for type 2 diabetes within Taiwanese ethnic minority group.</li> </ul>

**Appendix 9. Patient Activation Measure**

*Are you a user of the FLO text messaging system? Please circle the answer that applies*

*Yes/No*

1.	When all is said and done, I am the person who is responsible for take care of my health	Disagree Strongly, Disagree, Agree, Agree Strongly, N/A
2.	Taking an active role in my own health care which is the most important thing that affects my health	Disagree Strongly, Disagree, Agree, Agree Strongly, N/A
3.	I am confident I can help prevent or reduce problems associated with my health	Disagree Strongly, Disagree, Agree, Agree Strongly, N/A
4.	I know what each of my prescribed medications do	Disagree Strongly, Disagree, Agree, Agree Strongly, N/A
5.	I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself	Disagree Strongly, Disagree, Agree, Agree Strongly, N/A
6.	I am confident that I can tell a doctor my concerns I have even when he or she does not ask	Disagree Strongly, Disagree, Agree, Agree Strongly, N/A
7.	I am confident that I can follow through on medical treatments I may need to do at home	Disagree Strongly, Disagree, Agree, Agree Strongly, N/A
8.	I understand my health problems and what causes them	Disagree Strongly, Disagree, Agree, Agree Strongly, N/A
9.	I know what treatments are available for my health problems	Disagree Strongly, Disagree, Agree, Agree Strongly, N/A
10.	I have been able to maintain (keep up with) lifestyle changes, like eating right or exercising	Disagree Strongly, Disagree, Agree, Agree Strongly, N/A
11.	I know how to prevent problems with my health	Disagree Strongly, Disagree, Agree, Agree Strongly, N/A
12.	I am confident I can figure out solutions when new problems arise with my health	Disagree Strongly, Disagree, Agree, Agree Strongly, N/A
13.	I am confident that I can maintain lifestyle changes, like eating right and exercising, even during times of stress	Disagree Strongly, Disagree, Agree, Agree Strongly, N/A



## Appendix 10. Urdu PAM Tool

مریض

ایکٹوشن پیمائش

کیا آپ ایف ایل او ٹیکسٹ میسجنگ سسٹم کے صارف ہیں؟ براہ کرم جو جواب لاگو ہوتا ہے اسے دائرہ میں لائیں

جی ہاں

نہیں

1.	جب سب کچھ کہا جاتا ہے اور کیا ہوتا ہے، میں وہی شخص ہوں جو میری صحت کا خیال رکھنا ذمہ دار ہے	سختی سے متفق ہوں متفق نہیں متفق ہوں مضبوطی سے اتفاق کریں N / A
2.	اپنی اپنی صحت کی دیکھ بھال میں ایک اہم کردار ادا کرنا جو میری صحت کو متاثر کرتی ہے، سب سے اہم چیز ہے	سختی سے متفق ہوں متفق نہیں متفق ہوں مضبوطی سے اتفاق کریں N / A
3.	مجھے یقین ہے کہ میں اپنی صحت سے منسلک مسائل کو روکنے یا کم کرنے میں مدد کر سکتا ہوں	سختی سے متفق ہوں متفق نہیں متفق ہوں مضبوطی سے اتفاق کریں N / A
4.	میں جانتا ہوں کہ میرے مکلف کردہ دواؤں میں سے ہر ایک کیا کرتا ہے	سختی سے متفق ہوں متفق نہیں متفق ہوں مضبوطی سے اتفاق کریں N / A
5.	مجھے یقین ہے کہ میں یہ کہہ سکتا ہوں کہ مجھے ڈاکٹر جانے کی ضرورت ہے یا میں اپنے آپ کو ایک صحت کے مسئلہ کی دیکھ بھال کروں	سختی سے متفق ہوں متفق نہیں متفق ہوں مضبوطی سے اتفاق کریں N / A
6.	مجھے یقین ہے کہ میں ڈاکٹروں کو اپنے خدشات کو بتا سکتا ہوں میں بھی اس سے بھی پوچھتا ہوں جب وہ نہیں پوچھا	سختی سے متفق ہوں متفق نہیں متفق ہوں مضبوطی سے اتفاق کریں N / A
7.	مجھے یقین ہے کہ میں طبی علاج کے ذریعے پیروی کر سکتا ہوں جو گھر میں کرنے کی ضرورت ہو	سختی سے متفق ہوں متفق نہیں متفق ہوں مضبوطی سے اتفاق کریں N / A
8.	میں اپنی صحت کے مسائل کو سمجھتا ہوں اور ان کی کیا وجہ ہے	سختی سے متفق ہوں متفق نہیں متفق ہوں مضبوطی سے اتفاق کریں N / A
9.	میں جانتا ہوں کہ میری صحت کے مسائل کے لئے علاج کیا دستیاب ہے	سختی سے متفق ہوں متفق نہیں متفق ہوں مضبوطی سے اتفاق کریں N / A

10.	میں طرز زندگی میں تبدیلیوں کو برقرار رکھنے کے قابل ہو گیا ہوں، جیسا کہ صحیح یا مشق کھانے میں	سختی سے متفق ہوں متفق نہیں متفق ہوں مضبوطی سے اتفاق کریں N / A
11.	میں جانتا ہوں کہ میری صحت کے ساتھ مسائل کو کیسے روکنا ہے	سختی سے متفق ہوں متفق نہیں متفق ہوں مضبوطی سے اتفاق کریں N / A
12.	مجھے یقین ہے کہ جب میں نئی صحت پیدا کروں گا تو میں حل نکال سکتا ہوں	سختی سے متفق ہوں متفق نہیں متفق ہوں مضبوطی سے اتفاق کریں N / A
13.	میں یقین رکھتا ہوں کہ میں طرز زندگی میں تبدیلیوں کو برقرار رکھ سکتا ہوں، بشمول حق اور کھانے کی طرح، کشیدگی کے وقت بھی	سختی سے متفق ہوں متفق نہیں متفق ہوں مضبوطی سے اتفاق کریں N / A

### Appendix 11. Gujrati PAM Tool

#### દર્દી સક્રિયકરણ માપ

શું તમે FLO ટેક્સ્ટ મેસેજિંગ સિસ્ટમના વપરાશકર્તા છો? કૃપા કરીને લાગુ થતા જવાબને વર્તુળ કરો

હા

ના

1.	જ્યારે બધું કહેવા અને કરવામાં આવે ત્યારે, હું તે વ્યક્તિ છું જે મારી સ્વાસ્થ્યની કાળજી લેવા માટે જવાબદાર છે	ભારપૂર્વક અસંમત અસંમત સંમત થાઓ સંમતિપૂર્વક એન / એ N/A
2.	મારી પોતાની સ્વાસ્થ્ય કાળજીમાં સક્રિય ભૂમિકા લેવી એ મારી સ્વાસ્થ્યને અસર કરતી સૌથી અગત્યની વસ્તુ છે	ભારપૂર્વક અસંમત અસંમત સંમત થાઓ સંમતિપૂર્વક એન / એ N / A
3.	મને વિશ્વાસ છે કે હું મારા સ્વાસ્થ્ય સાથે સંકળાયેલી સમસ્યાઓ રોકવા અથવા ઘટાડવા માટે મદદ કરી શકું છું	ભારપૂર્વક અસંમત અસંમત સંમત થાઓ સંમતિપૂર્વક એન / એ N/A
4.	મને ખબર છે કે મારી દરેક સૂચિત દવાઓ શું કરે છે	ભારપૂર્વક અસંમત અસંમત સંમત થાઓ સંમતિપૂર્વક એન / એ N/A
5.	મને વિશ્વાસ છે કે હું કહી શકું કે મારે ડોક્ટર પાસે જવાની જરૂર છે અથવા હું સ્વાસ્થ્ય સમસ્યાની કાળજી લઈ શકું છું કે નહીં	ભારપૂર્વક અસંમત અસંમત સંમત થાઓ સંમતિપૂર્વક એન / એ N/A
6.	હું વિશ્વાસ કરું છું કે જ્યારે હું અથવા તેણી પૂછતો નથી ત્યારે પણ હું મારી ચિંતાઓ ડોક્ટરને કહી શકું છું	ભારપૂર્વક અસંમત અસંમત સંમત થાઓ સંમતિપૂર્વક એન / એ N/A
7.	હું વિશ્વાસ કરું છું કે હું તબીબી સારવારો પર ધ્યાન આપી શકું છું જે મને ઘર પર કરવાની જરૂર પડી શકે છે	ભારપૂર્વક અસંમત અસંમત સંમત થાઓ સંમતિપૂર્વક એન / એ N/A
8.	હું મારી સ્વાસ્થ્ય સમસ્યાઓ સમજું છું અને તેનાથી શું થાય છે	ભારપૂર્વક અસંમત અસંમત સંમત થાઓ સંમતિપૂર્વક એન / એ N/A
9.	હું જાણું છું કે મારી સ્વાસ્થ્ય સમસ્યાઓ માટે કઈ સારવાર ઉપલબ્ધ છે	ભારપૂર્વક અસંમત અસંમત સંમત થાઓ સંમતિપૂર્વક એન / એ N/A

10.	હું જીવનશૈલીના ફેરફારોને જાળવી રાખવા (ચાલુ રાખવું) સાચવી રાખું છું, જેમ કે યોગ્ય ખાવું અથવા કસરત કરવી	ભારપૂર્વક અસંમત અસંમત સંમત થાઓ સંમતિપૂર્વક એન / એ N/A
11.	હું જાણું છું કે કેવી રીતે મારા સ્વાસ્થ્ય સાથે સમસ્યાઓ રોકવી	ભારપૂર્વક અસંમત અસંમત સંમત થાઓ સંમતિપૂર્વક એન / એ N/A
12.	મને વિશ્વાસ છે કે જ્યારે હું મારી સ્વાસ્થ્ય સાથે નવી સમસ્યાઓ ઊભી કરીશ ત્યારે હું ઉકેલો શોધી શકું છું	ભારપૂર્વક અસંમત અસંમત સંમત થાઓ સંમતિપૂર્વક એન / એ N/A
13.	મને વિશ્વાસ છે કે હું જીવનશૈલીમાં પરિવર્તન જાળવી શકું છું, જેમ કે તંદુરસ્ત સમયે ખાવું અને કસરત કરવી, પણ	ભારપૂર્વક અસંમત અસંમત સંમત થાઓ સંમતિપૂર્વક એન / એ N/A

## Appendix 12. Hindi PAM tool

### रोगी सक्रियण उपाय

क्या आप FLO टेक्स्ट मैसेजिंग सिस्टम के उपयोगकर्ता हैं? कृपया उस उत्तर को सर्कल करें जो लागू होता है

हाँ

नहीं

1.	जब सब कहा और किया जाता है, तो मैं वह व्यक्ति हूँ जो मेरे स्वास्थ्य की देखभाल करने के लिए जिम्मेदार है	दृढ़ता से असहमत असहमत इस बात से सहमत दृढ़ता से सहमत एन / ए N/A
2.	मेरे स्वयं के स्वास्थ्य देखभाल में एक सक्रिय भूमिका लेना जो सबसे महत्वपूर्ण बात है जो मेरे स्वास्थ्य को प्रभावित करती है	दृढ़ता से असहमत असहमत इस बात से सहमत दृढ़ता से सहमत एन / ए N/A
3.	मुझे विश्वास है कि मैं अपने स्वास्थ्य से जुड़ी समस्याओं को रोकने या कम करने में मदद कर सकता हूँ	दृढ़ता से असहमत असहमत इस बात से सहमत दृढ़ता से सहमत एन / ए N/A
4.	मुझे पता है कि मेरी प्रत्येक निर्धारित दवा क्या करती है	दृढ़ता से असहमत असहमत इस बात से सहमत दृढ़ता से सहमत एन / ए N/A
5.	मुझे पूरा विश्वास है कि मैं बता सकता हूँ कि मुझे डॉक्टर के पास जाने की जरूरत है या नहीं और मैं खुद एक स्वास्थ्य समस्या का ध्यान रख सकता हूँ या नहीं	दृढ़ता से असहमत असहमत इस बात से सहमत दृढ़ता से सहमत एन / ए N/A
6.	मुझे पूरा विश्वास है कि मैं एक डॉक्टर को अपनी चिंताओं को बता सकता हूँ, तब भी जब वह पूछता है या नहीं	दृढ़ता से असहमत असहमत इस बात से सहमत दृढ़ता से सहमत एन / ए N/A
7.	मुझे विश्वास है कि मैं चिकित्सा उपचार के माध्यम से पालन कर सकता हूँ जो मुझे घर पर करना पड़ सकता है	दृढ़ता से असहमत असहमत इस बात से सहमत दृढ़ता से सहमत एन / ए N/A
8.	मैं अपनी स्वास्थ्य समस्याओं को समझता हूँ और उनके क्या कारण हैं	दृढ़ता से असहमत असहमत इस बात से सहमत दृढ़ता से सहमत एन / ए N/A
9.	मुझे पता है कि मेरी स्वास्थ्य समस्याओं के लिए क्या उपचार उपलब्ध हैं	दृढ़ता से असहमत असहमत इस बात से सहमत दृढ़ता से सहमत एन / ए N/A
10.	मैं जीवनशैली में बदलाव, जैसे कि सही खाना या व्यायाम करना, बनाये रखने में सक्षम रहा हूँ	दृढ़ता से असहमत असहमत

		इस बात से सहमत दृढ़ता से सहमत एन / ए N/A
11.	मुझे पता है कि अपने स्वास्थ्य के साथ समस्याओं को कैसे रोका जाए	दृढ़ता से असहमत असहमत इस बात से सहमत दृढ़ता से सहमत एन / ए N/A
12.	मुझे विश्वास है कि मैं अपने स्वास्थ्य के साथ नई समस्याएँ आने पर समाधान निकाल सकता हूँ	दृढ़ता से असहमत असहमत इस बात से सहमत दृढ़ता से सहमत एन / ए N/A
13.	मुझे विश्वास है कि मैं जीवनशैली में बदलाव ला सकता हूँ, जैसे कि सही समय पर खाना और व्यायाम करना, यहां तक कि तनाव के समय भी	दृढ़ता से असहमत असहमत इस बात से सहमत दृढ़ता से सहमत एन / ए N/A

### Appendix 13. Bengali PAM tool

#### रोगीर सक्रियकरण परिमाप

आपनि कि एफएलओ टेक्नॉट मेसेजिंग सिस्टेमेर ब्यवहारकारी? प्रयोज्य उतुरटि वृत्ताकार करून ह्यँ

ना

1.	जब सब कहा और किया जाता है, तो मैं वह व्यक्ति हूँ जो मेरे स्वास्थ्य की देखभाल करने के लिए जिम्मेदार है	दृ॒भावे असम्प्रति असम्प्रत राजि दृ॒भावे एन / ए सम्प्रत हन N/A
2.	मेरे स्वयं के स्वास्थ्य देखभाल में एक सक्रिय भूमिका लेना जो सबसे महत्वपूर्ण बात है जो मेरे स्वास्थ्य को प्रभावित करती है	दृ॒भावे असम्प्रति असम्प्रत राजि दृ॒भावे एन / ए सम्प्रत हन N/A
3.	मुझे विश्वास है कि मैं अपने स्वास्थ्य से जुड़ी समस्याओं को रोकने या कम करने में मदद कर सकता हूँ	दृ॒भावे असम्प्रति असम्प्रत राजि दृ॒भावे एन / ए सम्प्रत हन N/A
4.	मुझे पता है कि मेरी प्रत्येक निर्धारित दवा क्या करती है	दृ॒भावे असम्प्रति असम्प्रत राजि दृ॒भावे एन / ए सम्प्रत हन N/A
5.	मुझे पूरा विश्वास है कि मैं बता सकता हूँ कि मुझे डॉक्टर के पास जाने की जरूरत है या नहीं और मैं खुद एक स्वास्थ्य समस्या का ध्यान रख सकता हूँ या नहीं	दृ॒भावे असम्प्रति असम्प्रत राजि दृ॒भावे एन / ए सम्प्रत हन N/A
6.	मुझे पूरा विश्वास है कि मैं एक डॉक्टर को अपनी चिंताओं को बता सकता हूँ, तब भी जब वह पूछता है या नहीं	दृ॒भावे असम्प्रति असम्प्रत राजि दृ॒भावे एन / ए सम्प्रत हन N/A
7.	मुझे विश्वास है कि मैं चिकित्सा उपचार के माध्यम से पालन कर सकता हूँ जो मुझे घर पर करना पड़ सकता है	दृ॒भावे असम्प्रति असम्प्रत राजि दृ॒भावे एन / ए सम्प्रत हन N/A
8.	मैं अपनी स्वास्थ्य समस्याओं को समझता हूँ और उनके क्या कारण हैं	दृ॒भावे असम्प्रति असम्प्रत राजि दृ॒भावे एन / ए सम्प्रत हन N/A
9.	मुझे पता है कि मेरी स्वास्थ्य समस्याओं के लिए क्या उपचार उपलब्ध हैं	दृ॒भावे असम्प्रति

		असम्मत राजि दृ N्भावे एन / ए सम्मत इन N/A
10.	मैं जीवनशैली में बदलाव, जैसे कि सही खाना या व्यायाम करना, बनाये रखने में सक्षम रहा हूँ	दृ N्भावे असम्मति असम्मत राजि दृ N्भावे एन / ए सम्मत इन N/A
11.	मुझे पता है कि अपने स्वास्थ्य के साथ समस्याओं को कैसे रोका जाए	दृ N्भावे असम्मति असम्मत राजि दृ N्भावे एन / ए सम्मत इन N/A
12.	मुझे विश्वास है कि मैं अपने स्वास्थ्य के साथ नई समस्याएँ आने पर समाधान निकाल सकता हूँ	दृ N्भावे असम्मति असम्मत राजि दृ N्भावे एन / ए सम्मत इन N/A
13.	मुझे विश्वास है कि मैं जीवनशैली में बदलाव ला सकता हूँ, जैसे कि सही समय पर खाना और व्यायाम करना, यहां तक कि तनाव के समय भी	दृ N्भावे असम्मति असम्मत राजि दृ N्भावे एन / ए सम्मत इन N/A



### Appendix 14. Punjabi PAM tool

#### ਰੋਗੀ ਸਰਗਰਮੀ ਦੇ ਉਪਾਅ

ਕੀ ਤੁਸੀਂ ਐੱਫ.ਐੱਲ.ਓ ਟੈਕਸਟ ਮੈਸੇਜਿੰਗ ਸਿਸਟਮ ਦੇ ਉਪਭੋਗਤਾ ਹੋ? ਕਿਰਪਾ ਕਰਕੇ ਜਵਾਬ ਲਾਗੂ ਕਰੋ ਜੇ ਲਾਗੂ ਹੁੰਦਾ ਹੈ

ਹਾਂ

ਨਹੀਂ

1.	ਜਦੋਂ ਸਭ ਕੁਝ ਕਿਹਾ ਜਾਂਦਾ ਹੈ ਅਤੇ ਕੀਤਾ ਜਾਂਦਾ ਹੈ, ਮੈਂ ਉਹ ਵਿਅਕਤੀ ਹਾਂ ਜੋ ਆਪਣੀ ਸਿਹਤ ਦੀ ਸੰਭਾਲ ਕਰਨ ਲਈ ਜ਼ਿੰਮੇਵਾਰ ਹੈ	ਜ਼ੋਰਦਾਰ ਅਸਹਿਮਤ ਅਸਹਿਮਤ ਸਹਿਮਤ ਸਹਿਮਤ ਹੋਵੇ ਪੂਰੀ ਤਰਾਂ ਨਾਲ ਐਨ / ਏ N/A
2.	ਮੇਰੀ ਆਪਣੀ ਸਿਹਤ ਸੰਭਾਲ ਵਿਚ ਇਕ ਸਰਗਰਮ ਭੂਮਿਕਾ ਨਿਭਾਓ ਜੋ ਕਿ ਮੇਰੀ ਸਿਹਤ 'ਤੇ ਅਸਰ ਪਾਉਣ ਵਾਲੀ ਸਭ ਤੋਂ ਮਹੱਤਵਪੂਰਣ ਚੀਜ਼ ਹੈ	ਜ਼ੋਰਦਾਰ ਅਸਹਿਮਤ ਅਸਹਿਮਤ ਸਹਿਮਤ ਸਹਿਮਤ ਹੋਵੇ ਪੂਰੀ ਤਰਾਂ ਨਾਲ ਐਨ / ਏ N/A
3.	ਮੈਨੂੰ ਭਰੋਸਾ ਹੈ ਕਿ ਮੈਂ ਆਪਣੀ ਸਿਹਤ ਨਾਲ ਜੁੜੀਆਂ ਸਮੱਸਿਆਵਾਂ ਨੂੰ ਰੋਕਣ ਜਾਂ ਘਟਾਉਣ ਵਿੱਚ ਮਦਦ ਕਰ ਸਕਦਾ ਹਾਂ	ਜ਼ੋਰਦਾਰ ਅਸਹਿਮਤ ਅਸਹਿਮਤ ਸਹਿਮਤ ਸਹਿਮਤ ਹੋਵੇ ਪੂਰੀ ਤਰਾਂ ਨਾਲ ਐਨ / ਏ N/A
4.	ਮੈਨੂੰ ਪਤਾ ਹੈ ਕਿ ਮੇਨ ਦੀਆਂ ਸਾਰੀਆਂ ਦਵਾਈਆਂ ਕੀ ਕਰਦੀਆਂ ਹਨ	ਜ਼ੋਰਦਾਰ ਅਸਹਿਮਤ ਅਸਹਿਮਤ ਸਹਿਮਤ ਸਹਿਮਤ ਹੋਵੇ ਪੂਰੀ ਤਰਾਂ ਨਾਲ ਐਨ / ਏ N/A
5.	ਮੈਨੂੰ ਪੂਰਾ ਵਿਸ਼ਵਾਸ ਹੈ ਕਿ ਮੈਂ ਇਹ ਦੱਸ ਸਕਦਾ ਹਾਂ ਕਿ ਮੈਨੂੰ ਡਾਕਟਰ ਕੋਲ ਜਾਣ ਦੀ ਜ਼ਰੂਰਤ ਹੈ ਜਾਂ ਨਹੀਂ ਕਿ ਮੈਂ ਆਪਣੀ ਸਿਹਤ ਸਮੱਸਿਆ ਦੀ ਸੰਭਾਲ ਕਰ ਸਕਦਾ ਹਾਂ	ਜ਼ੋਰਦਾਰ ਅਸਹਿਮਤ ਅਸਹਿਮਤ ਸਹਿਮਤ ਸਹਿਮਤ ਹੋਵੇ ਪੂਰੀ ਤਰਾਂ ਨਾਲ ਐਨ / ਏ N/A
6.	ਮੈਨੂੰ ਵਿਸ਼ਵਾਸ ਹੈ ਕਿ ਮੈਂ ਡਾਕਟਰ ਨੂੰ ਆਪਣੀਆਂ ਚਿੰਤਾਵਾਂ ਬਾਰੇ ਦੱਸ ਸਕਦਾ ਹਾਂ ਜਦੋਂ ਉਹ ਪੁੱਛਦਾ ਨਹੀਂ ਹੈ	ਜ਼ੋਰਦਾਰ ਅਸਹਿਮਤ ਅਸਹਿਮਤ ਸਹਿਮਤ ਸਹਿਮਤ ਹੋਵੇ ਪੂਰੀ ਤਰਾਂ ਨਾਲ ਐਨ / ਏ N/A
7.	ਮੈਨੂੰ ਪੂਰਾ ਵਿਸ਼ਵਾਸ ਹੈ ਕਿ ਘਰ ਵਿਚ ਮੈਨੂੰ ਲੋੜੀਂਦੇ ਡਾਕਟਰੀ ਇਲਾਜਾਂ 'ਤੇ ਧਿਆਨ ਦੇਣਾ ਚਾਹੀਦਾ ਹੈ	ਜ਼ੋਰਦਾਰ ਅਸਹਿਮਤ ਅਸਹਿਮਤ ਸਹਿਮਤ ਸਹਿਮਤ ਹੋਵੇ ਪੂਰੀ ਤਰਾਂ ਨਾਲ ਐਨ / ਏ N/A
8.	ਮੈਂ ਆਪਣੀਆਂ ਸਿਹਤ ਸਮੱਸਿਆਵਾਂ ਅਤੇ ਉਨ੍ਹਾਂ ਦੇ ਕਾਰਨਾਂ ਨੂੰ ਸਮਝਦਾ ਹਾਂ	ਜ਼ੋਰਦਾਰ ਅਸਹਿਮਤ ਅਸਹਿਮਤ ਸਹਿਮਤ ਸਹਿਮਤ ਹੋਵੇ ਪੂਰੀ ਤਰਾਂ ਨਾਲ ਐਨ / ਏ N/A
9.	ਮੈਨੂੰ ਪਤਾ ਹੈ ਕਿ ਮੇਰੀ ਸਿਹਤ ਸਮੱਸਿਆਵਾਂ ਲਈ ਕਿਹੜੇ ਇਲਾਜ ਉਪਲਬਧ ਹਨ	ਜ਼ੋਰਦਾਰ ਅਸਹਿਮਤ ਅਸਹਿਮਤ ਸਹਿਮਤ

		ਸਹਿਮਤ ਹੋਵੇ ਪੂਰੀ ਤਰਾਂ ਨਾਲ ਐਨ / ਏ N/A
10.	ਮੈਂ ਜੀਵਨ ਢੰਗ ਵਿਚ ਤਬਦੀਲੀਆਂ (ਜਿਵੇਂ ਕਿ ਖਾਣਾ ਖਾਣ ਜਾਂ ਕਸਰਤ ਕਰਨਾ) ਨੂੰ ਸਾਂਭਣ ਵਿਚ ਕਾਮਯਾਬ ਰਿਹਾ ਹਾਂ	ਜ਼ੋਰਦਾਰ ਅਸਹਿਮਤ ਅਸਹਿਮਤ ਸਹਿਮਤ ਸਹਿਮਤ ਹੋਵੇ ਪੂਰੀ ਤਰਾਂ ਨਾਲ ਐਨ / ਏ N/A
11.	ਮੈਨੂੰ ਪਤਾ ਹੈ ਕਿ ਮੇਰੀ ਸਿਹਤ ਨਾਲ ਸਮੱਸਿਆਵਾਂ ਨੂੰ ਕਿਵੇਂ ਰੋਕਿਆ ਜਾਵੇ	ਜ਼ੋਰਦਾਰ ਅਸਹਿਮਤ ਅਸਹਿਮਤ ਸਹਿਮਤ ਸਹਿਮਤ ਹੋਵੇ ਪੂਰੀ ਤਰਾਂ ਨਾਲ ਐਨ / ਏ N/A
12.	ਮੈਨੂੰ ਭਰੋਸਾ ਹੈ ਕਿ ਮੇਰੀ ਸਿਹਤ ਦੇ ਨਾਲ ਨਵੀਆਂ ਸਮੱਸਿਆਵਾਂ ਪੈਦਾ ਹੋਣ ਵੇਲੇ ਮੈਂ ਹੱਲ ਲੱਭ ਸਕਦਾ ਹਾਂ	ਜ਼ੋਰਦਾਰ ਅਸਹਿਮਤ ਅਸਹਿਮਤ ਸਹਿਮਤ ਸਹਿਮਤ ਹੋਵੇ ਪੂਰੀ ਤਰਾਂ ਨਾਲ ਐਨ / ਏ N/A
13.	ਮੈਨੂੰ ਵਿਸ਼ਵਾਸ ਹੈ ਕਿ ਮੈਂ ਜੀਵਨ ਵਿਚ ਤਬਦੀਲੀਆਂ ਨੂੰ ਸਹੀ ਤਰ੍ਹਾਂ ਖਾਣਾ ਬਣਾਉਣਾ ਅਤੇ ਕਸਰਤ ਕਰਨਾ, ਜਿਵੇਂ ਕਿ ਤਣਾਅ ਦੇ ਸਮੇਂ ਵੀ ਕਰ ਸਕਦਾ ਹਾਂ	ਜ਼ੋਰਦਾਰ ਅਸਹਿਮਤ ਅਸਹਿਮਤ ਸਹਿਮਤ ਸਹਿਮਤ ਹੋਵੇ ਪੂਰੀ ਤਰਾਂ ਨਾਲ ਐਨ / ਏ N/A

**Appendix 15. Tamil PAM tool**

நோயாளி செயல்படுத்தும் நடவடிக்கை

நீங்கள் FLO உரை செய்தி அமைப்பின் பயனரா? பொருந்தும் பதிவை வட்டமிடுங்கள்

ஆம்

இல்லை

1.	எல்லோரும் சொன்னதும் செய்து முடித்ததும், என் உடல் நலத்தை கவனித்துக்கொள்பவர் நான்தான்	கடுமையாக உடன்படவில்லை கருத்து வேறுபாடு ஒப்புக்கொள்கிறேன் கடுமையாக ஒப்புக்கொள் ந / அ N/A
2.	என் உடல்நலத்தை பாதிக்கும் மிக முக்கியமான விஷயம் இது என் சொந்த சுகாதார ஒரு செயலில் எடுத்து	கடுமையாக உடன்படவில்லை கருத்து வேறுபாடு ஒப்புக்கொள்கிறேன் கடுமையாக ஒப்புக்கொள் ந / அ N/A
3.	என் உடல்நலம் சம்பந்தப்பட்ட பிரச்சனைகளைத் தடுக்க அல்லது குறைக்க உதவ முடியும் என நான் நம்புகிறேன்	கடுமையாக உடன்படவில்லை கருத்து வேறுபாடு ஒப்புக்கொள்கிறேன் கடுமையாக ஒப்புக்கொள் ந / அ N/A
4.	நான் என் பரிந்துரைக்கப்பட்ட மருந்துகள் ஒவ்வொரு என்ன தெரியும்	கடுமையாக உடன்படவில்லை கருத்து வேறுபாடு ஒப்புக்கொள்கிறேன் கடுமையாக ஒப்புக்கொள் ந / அ N/A
5.	நான் டாக்டரிடம் செல்ல வேண்டுமா அல்லது ஒரு உடல்நலப் பிரச்சினையை நான் கவனித்துக் கொள்ளலாமா என்று எனக்குத் தெரியுமா என்று எனக்குத் தெரியும்	கடுமையாக உடன்படவில்லை கருத்து வேறுபாடு ஒப்புக்கொள்கிறேன் கடுமையாக ஒப்புக்கொள் ந / அ N/A
6.	ஒரு மருத்துவர் என் கவலையை என்னால் கேட்க முடியவில்லையே என்று கூட எனக்குத் தெரியும் என்று நான் நம்புகிறேன்	கடுமையாக உடன்படவில்லை கருத்து வேறுபாடு ஒப்புக்கொள்கிறேன்

		கடுமையாக ஒப்புக்கொள் ந / அ N/A
7.	நான் வீட்டுக்குச் செய்ய வேண்டிய மருத்துவ சிகிச்சைகள் மூலம் நான் பின்பற்ற முடியும் என்பதில் எனக்கு நம்பிக்கை இருக்கிறது	கடுமையாக உடன்படவில்லை கருத்து வேறுபாடு ஒப்புக்கொள்கிறேன் கடுமையாக ஒப்புக்கொள் ந / அ N/A
8.	என் உடல்நலப் பிரச்சனைகளை நான் புரிந்துகொள்கிறேன்	கடுமையாக உடன்படவில்லை கருத்து வேறுபாடு ஒப்புக்கொள்கிறேன் கடுமையாக ஒப்புக்கொள் ந / அ N/A
9.	என் உடல்நலப் பிரச்சனைகளுக்கு என்ன சிகிச்சைகள் இருக்கின்றன என்று எனக்குத் தெரியும்	கடுமையாக உடன்படவில்லை கருத்து வேறுபாடு ஒப்புக்கொள்கிறேன் கடுமையாக ஒப்புக்கொள் ந / அ N/A
10.	நான் சரியான முறையில் அல்லது உடற்பயிற்சி செய்வது போல, வாழ்க்கை முறை மாற்றங்களைப் பராமரிக்க முடிந்தது	கடுமையாக உடன்படவில்லை கருத்து வேறுபாடு ஒப்புக்கொள்கிறேன் கடுமையாக ஒப்புக்கொள் ந / அ N/A
11.	என் உடல் நலத்துடன் பிரச்சனைகளை எப்படித் தடுப்பது என்று எனக்குத் தெரியும்	கடுமையாக உடன்படவில்லை கருத்து வேறுபாடு ஒப்புக்கொள்கிறேன் கடுமையாக ஒப்புக்கொள் ந / அ N/A
12.	புதிய பிரச்சனைகள் எனது ஆரோக்கியத்துடன் எழும் போது தீர்வுகளை கண்டுபிடிக்க முடியும் என நான் நம்புகிறேன்	கடுமையாக உடன்படவில்லை கருத்து வேறுபாடு ஒப்புக்கொள்கிறேன் கடுமையாக ஒப்புக்கொள் ந / அ N/A
13.	மன அழுத்தம் நேரங்களில் கூட சரியான மற்றும் உடற்பயிற்சி சாப்பிடுவது போல, வாழ்க்கை முறை மாற்றங்களை பராமரிக்க முடியும் என்று எனக்கு நம்பிக்கை இருக்கிறது	கடுமையாக உடன்படவில்லை கருத்து வேறுபாடு ஒப்புக்கொள்கிறேன் கடுமையாக ஒப்புக்கொள்

		ந / அ	N/A
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**Appendix 16.** *Interview guide for Users of FLO text messaging System*

<b>Concepts and Domains</b>	<b>Discussion</b>
<b>Personal and socio-demographic characteristics</b>	Factors such as education level and gender, and how this affects their adherence regime and whether these factors affect their views of intervention
<b>Technology</b>	For how long have you been using FLO? How do you find the system? Have you experienced any challenges with the system? What will you improve/change?
<b>Self-management</b>	Are your symptoms of the disease well-controlled? How do you feel about your condition? Do you feel supported, are there any emotional consequences such as depression, anxiety? Do you understand the actual cause of your illness? the number of symptoms you see as part of your illness and experiences of it, whether text messages provided any support of identifying symptoms of certain conditions What do you understand about your treatment regime? Do you feel that medications help, or are you dependent on alternative therapies? Has the text messaging intervention help prompt you to take medications on time, exercising frequently and/or promoting healthy eating? Do you feel supported from text messages? Do the messages provide relevant information required to manage disease effectively? Do text-messages prompt you regarding when to visit your health care providers? Do you face difficulties/barriers with the medication regime/self-management regime?
<b>Health beliefs and Behavioural outcomes</b>	Is the intervention beneficial to your health? Do you have any negative views towards the text messaging system? Do you feel that text messages help changes behaviour in positive ways or negative way? Do the messages promote healthy behaviours e.g., healthy eating, exercising? How interested do you feel about your condition and the management? Do text messages make you feel motivated about their management? Do you have any fears about the consequences of their condition? Do you show poor self-management measures? If so, why?
<b>Religious and fatalistic factors</b>	Does religion play a part in the management of your condition? Do you feel that a 'higher power' helps to deal with the condition rather than medications? Do you feel that God helps get through it? In general, would you say that your health condition results from God and believe that God is the only cure? Does text messaging intervene with God and religion? Do you feel that your faith is a stronghold even during hard times they face in relation to your disease? Do cultural traditions and customs play a part in self-management? (Such as different roles/responsibilities between men and women in terms of cultural norms) Do you prefer traditional medications rather than 'western medications'?

**Appendix 17. Interview guide for Non-users of FLO text messaging System**

<b>Concepts and Domains</b>	<b>Discussion</b>
<b>Personal and socio-demographic characteristics</b>	Factors such as education level and gender, and how this affects their adherence regime and whether these factors affect their views of intervention
<b>Technology</b>	<p>Have you used FLO or any other text messaging intervention in the past?</p> <p>If you have,</p> <ul style="list-style-type: none"> <li>• What was your experience of using the system?</li> <li>• Have you experienced any barriers and challenges?</li> <li>• Why have you decided not to use anymore?</li> </ul> <p>If you haven't</p> <ul style="list-style-type: none"> <li>• Why you have not engaged with the technology?</li> <li>• What were the key challenges?</li> </ul> <p>How do you envisage a text intervention to be to meet your needs?</p>
<b>Self-management</b>	<p>Are your symptoms of the disease well-controlled?</p> <p>How do you feel about your condition?</p> <p>Do you feel supported, are there any emotional consequences such as depression, anxiety?</p> <p>Do you understand the actual cause of your illness? the number of symptoms you see as part of your illness and experiences of it</p> <p>Do you feel that you would be better supported if using interventions/ systems such as text messages of identifying symptoms of certain conditions?</p> <p>What do you understand about your treatment regime?</p> <p>Do you feel that medications help, or are you dependent on alternative therapies?</p> <p>Are you taking medications on time, exercising frequently and/or promoting healthy eating?</p> <p>Do you feel supported from your health care provider?</p> <p>Do you have the relevant information required to manage disease effectively from your health care providers?</p> <p>Do you visit your health care providers, when required?</p> <p>Do you face difficulties/barriers with the medication regime/self-management regime?</p> <p>Do the messages provide relevant information required to manage disease effectively?</p> <p>Do you visit your health care providers, when required?</p>
<b>Health beliefs and Behavioural outcomes</b>	<p>Does your current treatment regimen show to have any benefits to your health outcomes?</p> <p>How interested do you feel about your condition and the management?</p> <p>Do you feel that a text messaging intervention would aid in self-management if you were to engage with such systems?</p> <p>Do you feel that using a text-messaging intervention will have a positive or a negative impact on health behaviour outcomes?</p> <p>Do you have any fears about the consequences of condition?</p> <p>Do you show poor self-management measures? If so, why?</p>
<b>Religious and fatalistic factors</b>	<p>Does religion play a part in the management of your condition?</p> <p>Do you feel that a 'higher power' helps to deal with the condition rather than medications?</p> <p>Do you feel that God helps get through it?</p>

	<p>In general, would you say that your health condition results from God and believe that God is the only cure?</p> <p>Do you feel that a text messaging intervention intervene with God and religion? Is this your reason for not engaging within such interventions?</p> <p>Do you feel that your faith is a stronghold even during hard times they face in relation to your disease?</p> <p>Do cultural traditions and customs play a part in self-management? (Such as different roles/responsibilities between men and women in terms of cultural norms)</p> <p>Do you prefer traditional medications rather than ‘western medications?</p>
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**Appendix 18. Eligibility Criterion**

Please select from the following options provided below, to help determine whether you are an eligible participant for the study. Please tick your answers below.

What is your age?

Under 18

18-24 years old

25-34 years old

35-44 years old

45-54 years old

55-64 years old

65 plus

What is your gender?

Male

Female

Rather not say

Are you of South-Asian Origin?

Yes

No

If so, how would you best describe your ethnic background?

Pakistani

Afghanistan

Indian

Nepalese

Bengali

Sri-Lankan

If any other, please state: \_\_\_\_\_

Are you currently living with a long-term illness or condition?

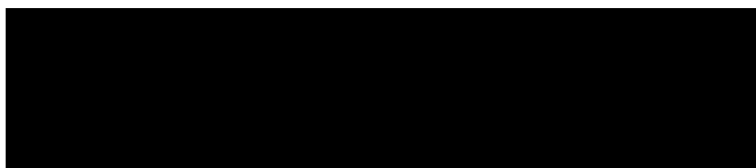
Yes

No

Are you a current user or have been a previous user of the FLO?

Yes

No

**Appendix 19. Letter of Confirmation from Clinician and Study Site**

[www.swbh.nhs.uk](http://www.swbh.nhs.uk)

23<sup>rd</sup> August, 2018

TO WHOM IT MAY CONCERN

Dear Sir/Madam,

This is to let you know that I am happy to be involved and allow access to my SWBH Trust FLORENCE data (subject to local RND approval) for this research project entitled:

Explaining the Experiences and Use of Text Messages to Enhance Health Behaviours and Self-Management in South Asian Patients

I believe this is a request by NRES and the research supervisor.

Please let me know if you need any further information.

Yours faithfully,

Dr  

Consultant in Diabetes and Endocrinology

**Appendix 20. University Ethical Approval Letter**

**Research, Enterprise and Engagement  
Ethical Approval Panel**

**Doctoral & Research Support  
Research and Knowledge Exchange,  
Maxwell Building, Room 827  
University of Salford, Manchester**

**M5 4WT  
T +44(0)161 295 2280  
[www.salford.ac.uk](http://www.salford.ac.uk)**

**5 June 2018**

Dear Tahreem,

**RE: ETHICS APPLICATION HSR1718-075 – ‘Exploring the experiences and use of text messages to enhance health behaviours and self-management in South Asian patients.’**

Based on the information that you have provided; I am pleased to inform you that your application HSR1718-075 has been approved to go forward to NRES.

Once you have received it, please submit a copy of the NRES approval letter to [HealthResearchEthics@salford.ac.uk](mailto:HealthResearchEthics@salford.ac.uk) so that it can be placed on your application file.

If there are any changes to the project and/or its methodology, then please inform the Health Research Ethics Support team as soon as possible.

Yours sincerely,

*A Clark*

Dr. Andrew Clark

**Deputy Chair of the Research Ethics Panel**

## Appendix 21. NRES/IRAS Approval Letter



Professor Paula Ormandy  
 University of Salford,  
 School of Health & Society  
 MS 2.78,  
 Mary Seacole Building  
 Frederick Road Campus  
 M6 6PU

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

[Research-permissions@wales.nhs.uk](mailto:Research-permissions@wales.nhs.uk)

13 February 2019

Dear Professor Ormandy

**Study title: Exploring the experiences and use of text messages to enhance health behaviours and self-management in South Asian patients**

**IRAS project ID: 246915**

**REC reference: 18/YH/0436 Sponsor:**

**University of Salford**

I am pleased to confirm that [HRA and Health and Care Research Wales \(HCRW\) Approval](#) has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

**How should I continue to work with participating NHS organisations in England and Wales?**

You should now provide a copy of this letter to all participating NHS organisations in England and Wales, as well as any documentation that has been updated as a result of the assessment.

Participating NHS organisations in England and Wales **will not** be required to formally confirm capacity and capability before you may commence research activity at site. As such, you may commence the research at each organisation 35 days following sponsor provision to the site of the local information pack, so long as:

- You have contacted participating NHS organisations (see below for details)

- The NHS organisation has not provided a reason as to why they cannot participate
- The NHS organisation has not requested additional time to confirm.

You may start the research prior to the above deadline if the site positively confirms that the research may proceed.

If not already done so, you should now provide the [local information pack](#) for your study to your participating NHS organisations. A current list of R&D contacts is accessible at the [NHS RD Forum website](#)

HRA and Health and Care Research Wales (HCRW) Approval Letter

IRAS project ID 246915

website and these contacts **MUST** be used for this purpose. After entering your IRAS ID you will be able to access a password protected document (password: Redhouse1). The password is updated on a monthly basis so please obtain the relevant contact information as soon as possible; please do not hesitate to contact me should you encounter any issues.

Commencing research activities at any NHS organisation before providing them with the full local information pack and allowing them the agreed duration to opt-out, or to request additional time (unless you have received from their R&D department notification that you may commence), is a breach of the terms of HRA and HCRW Approval. Further information is provided in the “summary of assessment” section towards the end of this document.

It is important that you involve both the research management function (e.g., R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details of the research management function for each organisation can be accessed [here](#).

### **How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?**

HRA and HCRW Approval does not apply to NHS/HSC organisations within the devolved administrations of Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) has been sent to the coordinating centre of each participating nation. You should work with the relevant national coordinating functions to ensure any nation specific checks are complete, and with each site so that they are able to give management permission for the study to begin.

Please see [IRAS Help](#) for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

### **How should I work with participating non-NHS organisations?**

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to [obtain local agreement](#) in accordance with their procedures.

### **What are my notification responsibilities during the study?**

The document “After Ethical Review – guidance for sponsors and investigators”, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments

- Notifying the end of the study

The [HRA website](#) also provides guidance on these topics, and is updated in the light of changes in

**I am a participating NHS organisation in England or Wales. What should I do once I receive this letter?**

You should work with the applicant and sponsor to complete any outstanding arrangements so you are able to confirm capacity and capability in line with the information provided in this letter.

**The sponsor contact for this application is as follows:**

IRAS project ID 246915

Name: Professor Ben Light

Tel: 01612950159

Email: [b.light@salford.ac.uk](mailto:b.light@salford.ac.uk)

**Who should I contact for further information?**

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **246915**. Please quote this on all correspondence.

Yours sincerely

Maeve Ip Groot Bluemink Assessor

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

*Copy to: Professor Ben Light, University of Salford –*

*Sponsor Contact [REDACTED] – Lead R&D Contact*

*Ms Tahreem Chaudhry, University of Salford - Student*

## **Appendix 22. Original Patient Information Sheet (PIS)**

### **PARTICIPANT INFORMATION SHEET**

**Title of study:** Exploring the experiences and use of text messages to enhance health behaviours and self-management in South Asian patients

**Name of Researcher:** Ms Tahreem Chaudhry

#### **Invitation paragraph**

I am currently studying for my PhD, which seeks to explore the use of text messaging in the South Asian population to promote positive health behaviour and increase and support self-management of a Long-Term Condition. If you are interested to participate, please see details below regarding further information about the study.

#### **What is the purpose of the study?**

The main over-arching aim of this research is to explore the experiences of South Asian people and examine whether factors such as health beliefs, cultural and religious customs contribute to patient activation and engagement of text messaging. I hope that this study will generate a better understanding of who is using the intervention, what the intervention delivers and the effects it has in the management of long-term diseases or conditions within an ethnic minority group.

#### **Why have I been invited to take part?**

We are inviting you to take part in this research because you are of South-Asian ethnic origin, living with a long-term condition. We are looking to talk to people who have

- Used the FLO text messaging system to help self-manage their condition
- Have used the Flo text messaging system previously, but are no longer using it
- Or those people who have chosen not to or do not wish to use the system.

Talking to people from these different groups will help us understand whether text messaging is useful, to whom, how and when, or whether there are other ways to help people manage their illness.

#### **Do I have to take part?**

You DO NOT have to participate if you do not wish to, your involvement is voluntary. If you decide that this is not for you it will not affect your involvement with FLO or your access to any other healthcare services. If you do decide to participate, a consent form will be provided for you to sign. If you take part, you can still choose to withdraw at any time, however, any information up to the point of withdrawal you have already given will be used as part of the research.

#### **What will happen to me if I take part?**

If you agree to participate in this study here is a summary of what you can expect to happen:

1. Discuss with the researcher any questions and sign the consent form.
2. Identify with the researcher a location that is convenient to you where the interview could

take place (for example your home or a local community centre, or the hospital).

3. Discuss your need for a translator and agree a plan, there are different options you could consider. All study questionnaires and interviews can be translated in the preferred language of the participants. The researcher can speak different languages (XXX) and will be able to conduct interviews in some of the native language if preferred to English. If you may prefer, you can ask a member of your family to sit with you in the interview in case you don't understand, acting as your interpreter. If you don't wish to have a family member with you an alternative option is that we could conduct the interview using an external translator (such as the hospitals Language Line).
4. You will be first asked to complete a short questionnaire this should take you approximately 10 minutes and asks questions about how you manage yourself and your illness.
5. After completing the questionnaire, you will be invited to take part in an interview, which can be conducted face-to-face or via telephone, depending on patient preferences. This interview will ask you questions about your experiences of living with a long-term condition, how you manage and what support you receive. Additional questions will be asked to those who use text messaging services about how it helps or doesn't help manage their condition. All interviews will be digitally recorded.

#### **Expenses and payments?**

There are no direct payment costs associated with your involvement in the study. However, you will be reimbursed any travel costs incurred when attending an interview.

#### **What are the possible disadvantages and risks of taking part?**

It is unlikely that there will be any disadvantages of participating within the study and there will be no risk to the physical health. However, in the event that you become distressed by the content of the survey/interview, the researcher can signpost you to easily accessible services, such as mental health charity services across various sites in UK providing counselling for psychological support.

Psychological support can be sought through helplines such as 'Samaritans' or 'Saneline' which offer confidential emotional support via telephone, email, letter and face to face for people in distress.

If you do not wish to respond to certain questions asked during survey/interviews or feel uncomfortable, the interview can be stopped and postponed to another date and time. You are free to withdraw and exit the survey/interview at any time. Confidentiality of information will be respected at all times.

#### **What are the possible benefits of taking part?**

There are no personal benefits from participating; however, this study can aid to facilitate culturally tailored interventions for you and other ethnic minority groups. Your input will be highly appreciated, and the result of the study could inform changes to how text messages are delivered to you and others. Your participation will encourage engagement with other patients with similar experiences, collaborating with other service users and/ or carers, interacting with local patient support groups, and the participation of future patients and members of the community who may be interested in getting involved.

#### **What if there is a problem?**

If you have a concern about any aspect of this study, you should ask to speak to the researcher: **(Ms T Chaudhry contact details below)** who will do their best to answer your questions. If you remain



unhappy and wish to complain formally you can do this by contacting the Research Supervisor (Professor Paula Ormandy or Dr Cristina Vasilica, contact details below).

If the matter is still not resolved, please forward your concerns to Professor Susan McAndrew, Chair of the Health Research Ethical Approval Panel, Room MS1.91, Mary Seacole Building, Frederick Road Campus, University of Salford, Salford, M6 6PU. Tel: 0161 295-2778. E: [s.mcandrew@salford.ac.uk](mailto:s.mcandrew@salford.ac.uk)

### **Will my data be kept confidential?**

Your anonymity will be respected throughout the study and the information you provide will be kept confidential at all times. Hard copy questionnaires will be kept securely in a locked filing cabinet in a locked office. As soon after as possible the questionnaire data will be entered onto an electronic database and the paper questionnaire securely destroyed. Similarly, the interview digital recording will be removed from the recording device straight after the interview and placed on a password protected computer, then typed out into a research coded word file.

Your data will be anonymised and allocated a research code, any interviews and questionnaires will not be identifiable to you. A master list of names and research codes, as well as the research data files, will be stored in a password protected computer, the password known only to the research team, within the University of Salford. The University has a legal responsibility to confidentially store your data after research for 5 years then the information will be securely destroyed. It is important to keep information this long to make sure there is an opportunity for regulatory bodies to check that the research reporting is accurate, and the study conducted appropriately.

### **What will happen if I don't carry on with the study?**

All participants are eligible to withdraw at any point during the interview if they wish to, but all data collected up to that point would be used in the study. Contact details of all researchers are provided below.

### **What will happen to the results of the research study?**

Findings of the study will be published in national and international journals in the hope to influence and change nursing practice, supporting practitioners looking after individuals with similar experiences. If you are interested, a summary of research findings will be available and disseminated to you, via post to your home address. However, if you do not wish to disclose your address result summary can be presented to you at your appointment, after the study.

### **Who is organizing or sponsoring the research?**

The study is being organized by myself and my supervisors from within the University of Salford, we will be collaborating with FLO Providers at the Sandwell and West Birmingham Hospital NHS Trust.

Further information and contact details:

If you are interested in participating in the research, please contact myself **Ms Tahreem Chaudhry** – Email: [t.chaudhry@edu.salford.ac.uk](mailto:t.chaudhry@edu.salford.ac.uk) Tel: XXXXXXXXXXX

Or contact supervisors:

**Professor Paula Ormandy (supervisor):** [p.ormandy@salford.ac.uk](mailto:p.ormandy@salford.ac.uk) Tel: 0161 295-0453

**Dr Cristina Vasilica (supervisor):** [c.m.vasilica1@salford.ac.uk](mailto:c.m.vasilica1@salford.ac.uk)

## Appendix 23. Urdu PIS

**مطالعہ کا عنوان:** تجربے کی تلاش اور ٹیکسٹ پیغامات کا استعمال جنوبی ایشیا کے مریضوں میں صحت کے روپے اور خود مینجمنٹ بڑھانے کے لئے

محقق کا نام

مدعو پیراگراف

میں فی الحال اپنے پی ایچ ڈی کے لئے مطالعہ کر رہا ہوں، جو جنوبی ایشیا میں ٹیکسٹ پیغام رسانی کے استعمال کو مثبت صحت کے روپے کو فروغ دینے اور طویل مدتی حالت کی خود مختاری کو فروغ دینے اور مدد کرنے کے لئے تلاش کرنا چاہتا ہے۔ اگر آپ شرکت کرنے میں دلچسپی رکھتے ہیں تو، براہ کرم مطالعہ کے بارے میں مزید معلومات کے بارے میں ذیل تفصیلات دیکھیں

مطالعہ کا مقصد کیا ہے؟

اس ریسرچ کا بنیادی مقصد زیادہ سے زیادہ جنوبی ایشیا کے لوگوں کے تجربات کو دریافت کرنا ہے اور یہ جانچنے کے لئے ہے کہ آیا صحت کے عقائد، ثقافتی اور مذہبی روایات جیسے عوامل ٹیکسٹ پیغام رسانی کے مریض کو چالو کرنے اور مصروفیت میں حصہ لیتے ہیں۔ مجھے امید ہے کہ یہ مطالعہ مداخلت کا استعمال کرتے ہوئے بہتر سمجھا جائے گا، جس مداخلت کو نجات دیتا ہے اور اس کے اثرات میں طویل مدتی بیماریوں یا نسلی اقلیت گروپ کے اندر حالات کے انتظام میں ہے

حصہ لینے کے لئے مجھے کیوں مدعو کیا گیا ہے؟

ہم آپ کو اس تحقیق میں حصہ لینے کے لئے دعوت دے رہے ہیں کیونکہ آپ جنوبی-ایشیائی نسل پرست ہیں، ایک طویل مدتی حالت میں رہتے ہیں، ہم ایسے لوگوں سے بات کر رہے ہیں جو لوگ ہیں

- اپنی حالت خود کو منظم کرنے میں مدد کے لئے ٹیکسٹ پیغام رسانی کا نظام استعمال کیا
- پہلے ٹیکسٹ پیغام رسانی کا نظام استعمال کیا ہے، لیکن اب اس کا استعمال نہیں کر رہے ہیں
- یا وہ لوگ جنہوں نے منتخب نہیں کیا ہے یا نہیں نظام کا استعمال کرنا چاہتے ہیں

ان مختلف گروپوں کے لوگوں سے گفتگو کرتے ہوئے ہمیں یہ سمجھنے میں مدد ملتی ہے کہ ٹیکسٹ پیغام رسانی مفید ہے، کس طرح، کس طرح اور جب، یا لوگوں کو اپنی بیماری کا انتظام کرنے میں مدد کرنے کے دیگر طریقے موجود ہیں

کیا مجھے حصہ لینے کی ضرورت ہے؟

اگر آپ چاہیں تو آپ کو حصہ لینے کی ضرورت نہیں ہے، آپ کی شراکت رضاکارانہ ہے۔ اگر آپ فیصلہ کرتے ہیں کہ یہ آپ کے لئے نہیں ہے تو یہ ٹیکسٹ پیغام رسانی کا نظام یا کسی دوسرے صحت کی دیکھ بھال کی خدمات تک رسائی کے ساتھ آپ کی شراکت کو متاثر نہیں کرے گا۔ اگر آپ شرکت کرنے کا فیصلہ کرتے ہیں، تو آپ کو دستخط کرنے کے لئے ایک رضاکارانہ شکل فراہم کی جائے گی

اگر آپ حصہ لینے کے لئے آپ اب بھی کسی بھی وقت واپس لینے کا انتخاب کر سکتے ہیں، تاہم، آپ کو پہلے سے ہی واپس جانے کے لئے کسی بھی معلومات کو تحقیق کے حصے کے طور پر استعمال کیا جائے گا

اگر میں حصہ لے تو میرے ساتھ کیا ہوگا؟

1. محققین سے کوئی سوالات پر غور کریں اور رضاکارانہ فارم پر دستخط کریں۔
2. محققین کے ساتھ ایک شناخت کی شناخت کریں جو آپ کے لئے آسان ہے جہاں انٹرویو ہو سکتا ہے (مثال کے طور پر آپ (کے گھر یا ایک مقامی کمیونٹی سینٹر، یا ہسپتال
3. ایک مترجم کے لئے آپ کی ضرورت پر تبادلہ خیال کریں اور ایک منصوبہ پر اتفاق کریں، آپ مختلف خیالات پر غور کر سکتے ہیں۔ شرکاء کی ترجیحی زبان میں تمام مطالعہ کے سوالات اور انٹرویو کا ترجمہ کیا جا سکتا ہے۔ محقق مختلف زبانیں بول سکتے ہیں اور انگریزی میں ترجیح دیتے ہیں تو کچھ زبانی زبان میں انٹرویو کرنے کے قابل ہو جائے گا۔ اگر آپ ترجیح دیتے (XXX) سکتے ہیں

ہیں تو، آپ اپنے خاندان کے کسی فرد سے انٹرویو میں آپ کے ساتھ بیٹھ سکتے ہیں، اگر آپ سمجھتے نہیں ہیں، تو اپنے مترجم کے طور پر کام کرتے ہیں

آپ سب سے پہلے ایک مختصر سوالنامہ کو مکمل کرنے کے لئے کہا جائے گا، یہ آپ کو تقریباً 10 منٹ لے جانا چاہئے اور آپ 4. اپنے آپ کو اور آپ کی بیماری کا نظم کرنے کے بارے میں سوالات پوچھنے کے لئے مدعو کیا جائے گا۔ یہ انٹرویو آپ کو طویل مدتی حالت کے ساتھ رہنے کے اپنے تجربات کے بارے میں سوالات سے پوچھتا ہے، آپ کس طرح انتظام کرتے ہیں اور آپ کی کونسی مدد کرتے ہیں۔ اضافی سوالات ان سے پوچھے جائیں گے جو ٹیکسٹ پیغام رسانی خدمات استعمال کرتے ہیں اس کے بارے میں اس کی مدد کرتا ہے یا ان کی حالت کا انتظام کرنے میں مدد نہیں کرتا۔ تمام انٹرویو ڈیجیٹل ریکارڈ کیے جائیں گے

سوالنامہ مکمل کرنے کے بعد آپ کو ایک انٹرویو میں حصہ لینے کے لئے مدعو کیا جائے گا۔ یہ انٹرویو آپ کو طویل مدتی 5. حالت کے ساتھ رہنے کے اپنے تجربات کے بارے میں سوالات سے پوچھتا ہے، آپ کس طرح انتظام کرتے ہیں اور آپ کی کونسی مدد کرتے ہیں۔ اضافی سوالات ان سے پوچھے جائیں گے جو ٹیکسٹ پیغام رسانی خدمات استعمال کرتے ہیں اس کے بارے میں اس کی مدد کرتا ہے یا ان کی حالت کا انتظام کرنے میں مدد نہیں کرتا۔ تمام انٹرویو ڈیجیٹل ریکارڈ کیے جائیں گے

اخراجات اور ادائیگی؟

مطالعہ میں آپ کی شمولیت سے متعلق کوئی براہ راست ادائیگی کے اخراجات موجود نہیں ہیں۔ تاہم، انٹرویو میں شرکت کرنے وقت آپ کو کسی بھی سفر کے اخراجات کی ادائیگی کی جائے گی

حصہ لینے کے ممکنہ نقصانات اور خطرات کیا ہیں؟

یہ امکان نہیں ہے کہ مطالعہ کے اندر حصہ لینے میں کوئی نقصان ہو گا اور جسمانی صحت کے لئے کوئی خطرہ نہیں ہوگا۔ تاہم اس صورت میں جب آپ سروے / انٹرویو کے مواد سے پریشان ہو جاتے ہیں تو، محققین کو آپ آسانی سے قابل رسائی سروسز پر دستخط کرسکتے ہیں، جیسے کہ برطانیہ میں مختلف سائٹس میں دماغی صحت کی صدقہ خدمات نفسیاتی معاونت کے لئے 'مشاورت فراہم کرتی ہیں۔ نفسیات کی مدد سے ہتھیاروں جیسے 'سامریوں' یا 'سنیل

جس میں ٹیلی فون، ای میل، خط اور چہرہ کے ذریعے مصیبت میں لوگوں کے ساتھ خفیہ جذباتی تعاون پیش کی جاتی ہے

اگر آپ سروے / انٹرویو کے دوران پوچھے گئے مخصوص سوالات کا جواب نہیں دینا چاہتے ہیں یا ناجائز محسوس کرتے ہیں، تو انٹرویو کو کسی اور تاریخ اور وقت تک ملتوی کر دیا جا سکتا ہے۔ آپ کسی بھی وقت سروے / انٹرویو کو نکالنے اور باہر جانے کے لئے آزاد ہیں۔ معلومات کی رازداری ہر وقت احترام کی جائے گی

حصہ لینے کے ممکنہ فوائد کیا ہیں؟

حصہ لینے سے کوئی ذاتی فوائد نہیں ہیں۔ تاہم، یہ مطالعہ آپ اور دیگر نسلی اقلیتی گروہوں کے لئے ثقافتی طور پر موزوں مداخلت کو سہولت فراہم کرنے میں مدد کرسکتا ہے۔ آپ کا ان پٹ انتہائی تعریف کی جائے گی اور مطالعہ کا نتیجہ آپ کو اور دوسروں کو ٹیکسٹ پیغامات کو کیسے پہنچایا جاسکتا ہے کہ وہ تبدیلیوں کو مطلع کر سکتا ہے

پ کی شرکت دیگر مریضوں کو اسی طرح کی تجربات، دوسرے سروس کے صارفین اور / یا نگران کے ساتھ تعاون، مقامی مریضوں کے معاون گروہوں کے ساتھ بات چیت، اور مستقبل کے مریضوں اور کمیونٹی کے ممبروں کی شمولیت کے ساتھ مشغول ہونے کی حوصلہ افزائی کرے گی

کیا مسئلہ ہے اگر

اگر آپ اس مطالعہ کے کسی بھی پہلو کے بارے میں تشویش رکھتے ہیں تو، آپ کو محققین سے بات کرنے کے لئے پوچھنا چاہئے، جو آپ کے سوالات کا جواب دینے کے لئے اپنی پوری کوشش کریں گے۔ اگر آپ ناخوش رہیں اور رسمی طور پر شکایت کرنا چاہتے ہیں تو آپ ریسرچ سپروائزر (پروفیسر پاولا آرنلڈیڈی یا ڈاکٹر کرسٹینا ویسیلا، رابطہ رابطے کی تفصیلات کے ساتھ رابطہ کر سکتے ہیں

اگر معاملہ ابھی تک حل نہیں ہوا ہے تو، برائے مہربانی پروفیسر سوسن میک اینڈرو، ہیلتھ ریسرچ اخلاقی منظوری پینل، کمرہ مریم سییکول بلڈنگ، فریڈیک روڈ کیمپس، سلفور یونیورسٹی یونیورسٹی کی اپنی تشویشوں کو آگے بڑھیں، MS1.91

ٹیلی فون: 0161 295-2778

ای میل: [s.mcandrew@salford.ac.uk](mailto:s.mcandrew@salford.ac.uk)

کیا میرا ڈیٹا خفیہ رکھا جائے گا؟

آپ کے نام نہاد پورے مطالعے کا احترام کیا جائے گا اور آپ فراہم کردہ معلومات کو ہر وقت خفیہ رکھا جائے گا۔ ایک کاپی آفس میں ایک بند شدہ فلنگ کابینہ میں ہارڈ کاپی سوالناموں کو محفوظ طریقے سے رکھا جائے گا۔ جتنا جلد ممکن ہو، سوالنامہ کے اعداد و شمار کو ایک الیکٹرانک ڈیٹا بیس میں داخل کیا جائے گا اور کاغذ کا سوالنامہ محفوظ طریقے سے تباہ ہو جائے گا۔

اسی طرح انٹرویو ڈیجیٹل ریکارڈنگ انٹرویو کے بعد براہ راست ریکارڈنگ کے آلے سے ہٹا دیا جائے گا اور ایک پاس ورڈ محفوظ کمپیوٹر پر رکھا جائے گا، پھر ایک تحقیق شدہ کوڈڈ ورڈ فائل میں ٹائپ کیا جائے گا۔

آپ کے اعداد و شمار کو نامزد کیا جائے گا اور ایک تحقیقی کوڈ مختص کیا جائے گا، کسی بھی انٹرویو اور سوالنامے آپ کے لئے شناخت نہیں ہوسکتی۔ نام اور ریسرچ کوڈز کے ساتھ ریسرچ ڈیٹا فائلوں کی ماسٹر فہرست، پاسورڈ محفوظ کمپیوٹر میں ذخیرہ کیا جائے گا، صرف سلف فورڈ یونیورسٹی کے اندر ریسرچ ٹیم کے لئے جانا جاتا پاس ورڈ۔

یونیورسٹی میں 5 سال تک تحقیق کے بعد آپ کے ڈیٹا کو خفیہ طور پر ذخیرہ کرنے کی قانونی ذمہ داری ہے تو معلومات کو محفوظ طریقے سے تباہ کر دیا جائے گا۔ اس بات کا یقین کرنے کے لئے یہ معلومات برقرار رکھنا اہم ہے کہ انتظامی اداروں کے لئے یہ موقع معلوم ہو کہ تحقیقاتی رپورٹنگ درست ہے، اور اس کا مطالعہ مناسب طریقے سے ہوتا ہے۔

اگر میں مطالعہ کے ساتھ نہیں چلتا تو کیا ہوگا؟

تمام شرکاء انٹرویو کے دوران کسی بھی وقت واپس لینے کے اہل ہیں اگر وہ چاہتے ہیں، لیکن اس وقت تک تمام اعداد و شمار کو اس مطالعہ میں استعمال کیا جائے گا۔ تمام محققین کے رابطے کی تفصیلات ذیل میں فراہم کی جاتی ہیں۔

تحقیق کے مطالعہ کے نتائج کیا ہوگا؟

مطالعہ کے نتائج قومی اور بین الاقوامی جرنلوں میں شائع کی جائیں گی تاکہ وہ نرسنگ کے عمل کو اثر انداز کرنے اور انفرادی تجربات کے ساتھ افراد کی دیکھ بھال کرنے والوں کی مدد کرنے والے افراد کی مدد کریں۔

گر آپ دلچسپی رکھتے ہیں تو، تحقیقاتی نتائج کا خلاصہ آپ کے گھر کے ایڈریس پر پوسٹ کے ذریعہ دستیاب اور آپ کو تقسیم کیا جائے گا۔ تاہم، اگر آپ اپنے ایڈریس کے نتیجہ کا خلاصہ ظاہر نہیں کرنا چاہتے ہیں تو مطالعہ کے بعد، آپ کے تقرری میں پیش کی جا سکتی ہے۔

تحقیق کو منظم کرنے یا سپانسر کرنے والا کون کون ہے؟

یہ مطالعہ اپنے اور اپنے سپروائزرز کے ذریعہ سلفورڈ یونیورسٹی کے اندر اندر منعقد کیا جا رہا ہے، ہم سینڈیل و وسٹ برمنگھم ہسپتال این ایچ ایس ٹرسٹ کے ساتھ تعاون کریں گے۔

مزید معلومات اور رابطے کی تفصیلا

اگر آپ تحقیق میں شرکت کرنے میں دلچسپی رکھتے ہیں تو براہ مہربانی اپنے آپ سے رابطہ کریں۔

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ٹیلی فون: 0161 295-0453 یا سپروائزرز سے رابطہ کریں: پروفیسر پاولا آندھیڈی [P.Ormandy@salford.ac.uk](mailto:P.Ormandy@salford.ac.uk) ڈاکٹر کرستینا ویسلیکا [C.M.Vasilica1@salford.ac.uk](mailto:C.M.Vasilica1@salford.ac.uk)۔

## Appendix 24. Gujarati PIS

ભાગીદાર માહિતી શીટ

અભ્યાસનું શીર્ષક: દક્ષિણ એશિયન દર્દીઓમાં સ્વાસ્થ્ય વર્તન અને સ્વ-વ્યવસ્થાપન વધારવા માટે અનુભવો અને ટેકસ્ટ સંદેશાઓનો ઉપયોગ

સંશોધકનું નામ: મિસ તાહરેમ ચૌધરી

આમંત્રણ ફરો

હું હાલમાં મારા પીએચડી માટે અભ્યાસ કરી રહ્યો છું, જે દક્ષિણ એશિયાની વસતીમાં હકારાત્મક આરોગ્ય વર્તનને પ્રોત્સાહન આપવા અને લાંબા ગાળાની સ્થિતિના સ્વ-વ્યવસ્થાપનને વધારવા અને સમર્થન આપવા માટે ટેક્સ્ટ મેસેજિંગનો ઉપયોગ શોધવાનો પ્રયાસ કરે છે. જો તમે ભાગ લેવા રસ ધરાવો છો, તો અભ્યાસ વિશે વધુ માહિતીને સંબંધિત નીચે વિગતો જુઓ.

અભ્યાસનો હેતુ શું છે?

આ સંશોધનની મુખ્ય ઓવર-આર્કીંગનો ઉદ્દેશ એ દક્ષિણ એશિયન લોકોના અનુભવોનું અન્વેષણ કરવાનો છે અને આરોગ્ય માન્યતાઓ, સાંસ્કૃતિક અને ધાર્મિક રિવાજો જેવા પરિબલો દર્દી સક્રિયકરણ અને ટેક્સ્ટ મેસેજિંગના જોડાણમાં ફાળો આપે છે કે કેમ તે તપાસવું છે. હું આશા રાખું છું કે આ અભ્યાસ દખલનો ઉપયોગ કોણ કરે છે, હસ્તક્ષેપ પ્રદાન કરે છે અને વંશીય લઘુમતી જૂથમાં લાંબા ગાળાના રોગો અથવા શરતોના સંચાલનમાં થતી અસરો વિશે સારી સમજણ ઉત્પન્ન કરશે.

શા માટે મને ભાગ લેવા માટે આમંત્રણ આપવામાં આવ્યું છે?

અમે આ સંશોધનમાં ભાગ લેવા માટે તમને આમંત્રણ આપી રહ્યાં છીએ કારણ કે તમે દક્ષિણ-એશિયન વંશીય મૂળના છો, જે લાંબા ગાળાની સ્થિતિ સાથે જીવે છે. અમે લોકો સાથે વાત કરવા માંગીએ છીએ

- તેમની સ્થિતિ સ્વતઃ-વ્યવસ્થા કરવામાં સહાય માટે એફએલઓ ટેક્સ્ટ મેસેજિંગ સિસ્ટમનો ઉપયોગ કર્યો
- અગાઉ ફ્લોબ ટેક્સ્ટ મેસેજિંગ સિસ્ટમનો ઉપયોગ કર્યો છે, પરંતુ હવે તેનો ઉપયોગ કરી રહ્યાં નથી
- અથવા તે લોકો કે જેમણે સિસ્ટમનો ઉપયોગ ન કરવો પસંદ કર્યો નથી અથવા પસંદ કર્યો નથી.

આ જુદા જુદા જૂથોના લોકો સાથે વાત કરવાથી ટેક્સ્ટ મેસેજિંગ ઉપયોગી છે કે કેમ, ક્યારે, કેવી રીતે અથવા ક્યારે અથવા લોકો તેમની બીમારીને સંચાલિત કરવામાં મદદ કરવા માટે અન્ય રસ્તાઓ છે કે નહીં તે સમજવામાં અમને સહાય કરશે.

મારે ભાગ લેવો પડશે?

જો તમારે ઇચ્છા ન હોય તો તમારે ભાગ લેવાની જરૂર નથી, તમારી સામેલગીરી સ્વૈચ્છિક છે. જો તમે નિર્ણય કરો કે આ તમારા માટે નથી, તો તે એફએલઓ સાથેની તમારી સામેલગીરી અથવા અન્ય કોઈપણ આરોગ્યસંભાળ સેવાઓની તમારી એક્સેસને અસર કરશે નહીં. જો તમે ભાગ લેવાનું નક્કી કરો છો, તો સાઇન ઇન કરવા માટે સંમતિ ફોર્મ પ્રદાન કરવામાં આવશે. જો તમે ભાગ લેતા હો તો પણ તમે કોઈપણ સમયે ઉપાડ કરવાનું પસંદ કરી શકો છો, જો કે, તમે અગાઉથી આપેલી ઉપાડની બિંદુ સુધીની કોઈપણ માહિતી સંશોધનના ભાગ રૂપે ઉપયોગમાં લેવામાં આવશે. જો હું ભાગ લઈશ તો મારી સાથે શું થશે?

જો તમે આ અભ્યાસમાં ભાગ લેવા માટે સંમત છો, તો અહીં તમે જે બનવાની અપેક્ષા રાખી શકો છો તેના સારાંશ છે:

1. સંશોધક સાથે કોઈપણ પ્રશ્નોની ચર્ચા કરો અને સંમતિ ફોર્મ પર સહી કરો.
2. સંશોધક સાથે ઓળખો કે જ્યાં ઇન્ટરવ્યૂ થઈ શકે છે ત્યાં તમારા માટે અનુકૂળ સ્થાન (ઉદાહરણ તરીકે તમારું ઘર અથવા સ્થાનિક સમુદાય કેન્દ્ર, અથવા હોસ્પિટલ).
3. અનુવાદકની તમારી જરૂરિયાત વિશે ચર્ચા કરો અને કોઈ યોજના સાથે સંમત થાઓ, ત્યાં વિવિધ વિકલ્પો છે જે તમે ધ્યાનમાં લઈ શકો છો. સહભાગીઓની પસંદગીની ભાષામાં બધા અભ્યાસ પ્રશ્નો અને ઇન્ટરવ્યૂનું ભાષાંતર કરી શકાય છે. સંશોધક વિવિધ ભાષાઓ (XXX) બોલી શકે છે અને જો અંગ્રેજીમાં પ્રાધાન્ય આપી હોય તો તે મૂળ ભાષામાં કેટલાક ઇન્ટરવ્યૂ લઈ શકશે. જો તમે પ્રાધાન્ય આપો, તો તમે તમારા ઇન્ટરવ્યૂ તરીકે અભિનય કરતી વખતે સમજતા ન હોવ તો ઇન્ટરવ્યૂમાં તમારા પરિવારના સભ્યને તમારી સાથે બેસવા માટે કહી શકો છો. જો તમે તમારી સાથે કોઈ પારિવારિક સભ્ય ન હોય તો હોવ તો વૈકલ્પિક વિકલ્પ એ છે કે અમે બાહ્ય અનુવાદક (જેમ કે હોસ્પિટલ્સ ભાષા રૂબા) નો ઉપયોગ કરીને ઇન્ટરવ્યૂ લઈ શકીએ છીએ.
4. તમને એક ટૂંકી પ્રશ્નાવલી પૂર્ણ કરવા માટે સૌ પ્રથમ પૂછવામાં આવશે જેમાં તમને આશરે 10 મિનિટનો સમય લાગશે અને તમે તમારી જાતને અને તમારી બીમારીને કેવી રીતે સંચાલિત કરો છો તેના વિશે પ્રશ્નો પૂછશે.
5. પ્રશ્નાવલી પૂર્ણ કર્યા પછી, તમને ઇન્ટરવ્યૂમાં ભાગ લેવા માટે આમંત્રિત કરવામાં આવશે, જે દર્દીની પસંદગીઓ પર આધાર રાખીને, સામ-સામે અથવા ટેલિફોન દ્વારા હાથ ધરવામાં આવે છે. આ ઇન્ટરવ્યૂ તમને લાંબા ગાળાની સ્થિતિ, તમે કેવી રીતે મેનેજ કરો છો અને તમને કઈ ટેકો મળે છે તે વિશેના તમારા અનુભવો વિશે પ્રશ્નો પૂછશે. વધારાના પ્રશ્નો પૂછવામાં આવશે જેઓ ટેક્સ્ટ મેસેજિંગ સેવાઓનો ઉપયોગ કેવી રીતે મદદ કરે છે અથવા તેમની સ્થિતિને સંચાલિત કરવામાં સહાય કરતાં નથી. બધા ઇન્ટરવ્યૂ ડિજિટલી રેકોર્ડ કરવામાં આવશે.

ખર્ચ અને ચૂકવણી?

અભ્યાસમાં તમારી સામેલગીરી સાથે સંકળાયેલ કોઈ સીધી ચુકવણી ખર્ચ નથી. જો કે, ઇન્ટરવ્યૂમાં હાજરી આપતી કોઈપણ મુસાફરી ખર્ચની તમને પરત કરવામાં આવશે.

ભાગ લેવાના સંભવિત ગેરલાભ અને જોખમો શું છે?

તે અસંભવિત છે કે અભ્યાસમાં ભાગ લેતા કોઈપણ ગેરફાયદા થશે અને શારીરિક સ્વાસ્થ્ય માટે કોઈ જોખમ નહીં રહે. જો કે, જો તમે મોજણી / ઇન્ટરવ્યૂની સામગ્રી દ્વારા તકલીફ અનુભવો છો, તો સંશોધક યુકેમાં વિવિધ સાઇટ્સમાં માનસિક આરોગ્ય ચેરિટી સેવાઓ જેવી કે માનસિક સહાય માટે સલાહ આપીને સરળતાથી એક્સેસિબલ સેવાઓ પર સાઇન-ઇન કરી શકે છે. 'સમરિટન્સ' અથવા 'સેનલાઇન' જેવા હેલ્પલાઇન્સ દ્વારા માનસિક સહાયની માંગ કરી શકાય છે જે હેલ્પલાઇન્સની સાથે ઇન્ટરવ્યૂના સમયગાળામાં અનુભવવામાં આવેલા કોઈપણ અસ્વસ્થતા અનુભવો છો, તો ઇન્ટરવ્યૂ રોકી શકાય છે અને બીજી તારીખ અને સમય પર મુકવામાં આવશે. તમે કોઈપણ સમયે સર્વેક્ષણ / ઇન્ટરવ્યૂમાંથી બહાર નીકળવા અને બહાર નીકળવા માટે સ્વતંત્ર છો. માહિતીની ગુપ્તતા હંમેશાં સન્માનિત કરવામાં આવશે.

ભાગ લેવાના સંભવિત ફાયદા શું છે?

ભાગ લેતા કોઈ અંગત ફાયદા નથી; જો કે, આ અભ્યાસ તમને અને અન્ય વંશીય લઘુમતી જૂથો માટે સાંસ્કૃતિક રૂપે અનુરૂપ હસ્તક્ષેપને સરળ બનાવવા માટે સહાય કરી શકે છે. તમારા ઇનપુટની ખૂબ પ્રશંસા થશે અને અભ્યાસના પરિણામ તમને અને અન્ય લોકોને ટેકસ્ટ સંદેશાઓ કેવી રીતે વિતરિત કરવામાં આવે છે તે કેરફારોની જાણ કરી શકે છે. તમારી સહભાગિતા બીજા દર્દીઓ સાથે સમાન અનુભવો સાથે સહભાગિતા, અન્ય સેવા વપરાશકર્તાઓ અને / અથવા સંભાળ રાખનારાઓ સાથે સહયોગ, સ્થાનિક દર્દી સહાય જૂથો સાથે વાર્તાલાપ, અને ભવિષ્યના દર્દીઓની ભાગીદારી અને સમાવિષ્ટ કરવામાં રસ ધરાવતા સમુદાયના સભ્યોની ભાગીદારીને પ્રોત્સાહિત કરશે

કોઈ સમસ્યા હોય તો શું?

જો તમને આ અભ્યાસના કોઈ પણ પાસાં વિશે ચિંતા હોય, તો તમારે સંશોધનકાર સાથે વાત કરવા માટે પૂછવું જોઈએ: (નીચે એમએસ ટી ચૌધરી સંપર્ક વિગતો) જે તમારા પ્રશ્નોના જવાબ આપવા માટે શ્રેષ્ઠ પ્રયાસ કરશે. જો તમે નાખુશ રહો અને ઔપચારિક રીતે ફરિયાદ કરવા માંગતા હો તો તમે સંશોધન સુપરવાઇઝર (પ્રોફેસર પૌલા ઓર્મેન્ડી અથવા ડૉ ડેવિડ બાપ્પાસિન્હો) પણ સંપર્ક કરી શકો છો. સંપર્ક કરીને તમારી ફરિયાદો પ્રોફેસર સુસાન મેકન્ડ્રુ, હેલ્થ રીસર્ચ એથિકલ એપ્રોવલ પેનલ, ચેર એમએસ 1.91, મેરી સીકોલ બિલ્ડિંગ, ફેડરિક રોડ કેમ્પસ, સેલફર્ડ યુનિવર્સિટી, સેલ્ફોર્ડ, એમ 6 6 પીયુ ને આગળ મોકલો. ટેલ: 0161 295 2778. ઇ: [s.mcandrew@salford.ac.uk](mailto:s.mcandrew@salford.ac.uk)

શું મારો ડેટા ગોપનીય રાખવામાં આવશે?

તમારું અનામિત્વ સમગ્ર અભ્યાસ દરમિયાન માન આપવામાં આવશે અને તમે જે માહિતી પ્રદાન કરો છો તે હંમેશાં ગોપનીય રાખવામાં આવશે. લોક ઓફિસમાં લોક ફાઇલિંગ કેબિનેટમાં હાર્ડ કોપિ પ્રશ્નાવલિ સુરક્ષિતપણે રાખવામાં આવશે. શક્ય તેટલા જલ્દી જ પ્રશ્નાવલિ ડેટાને ઇલેક્ટ્રોનિક ડેટાબેસ પર દાખલ કરવામાં આવશે અને કાગળના પ્રશ્નાવલિ સુરક્ષિતપણે નાશ પામશે. તેવી જ રીતે, ઇન્ટરવ્યૂ ડિજિટલ રેકોર્ડિંગ ઇન્ટરવ્યૂ પછી સીધી રેકોર્ડિંગ ડિવાઇસમાંથી દૂર કરવામાં આવશે અને પાસવર્ડ સુરક્ષિત કમ્પ્યુટર પર મૂકવામાં આવશે, પછી સંશોધન કોડેડ શબ્દ ફાઇલમાં ટાઇપ કરવામાં આવશે અને સંશોધન કોડ ફાઇલવામાં આવશે, કોઈપણ ઇન્ટરવ્યૂ અને પ્રશ્નાવલિ તમને ઓળખી શકશે નહીં. નામ અને સંશોધન કોડ્સની મુખ્ય સૂચિ તેમજ સંશોધન ડેટા ફાઇલો, પાસવર્ડ સંરક્ષિત કમ્પ્યુટરમાં સંગ્રહિત કરવામાં આવશે, જે ફક્ત સેલ્ફોર્ડ યુનિવર્સિટીની અંદર જ સંશોધન ટીમને ઓળખાય છે. 5 વર્ષ પછી સંશોધન પછી તમારા ડેટાને ગોપનીય રીતે સંગ્રહિત કરવા માટે યુનિવર્સિટીની કાયદેસરની જવાબદારી છે, પછી માહિતી સુરક્ષિત રીતે નાશ કરવામાં આવશે. સંશોધનની જાણ કરવી એ સચોટ છે કે નહીં તે તપાસવા માટે નિયમનકારી સંસ્થાઓ માટે એક તક છે તેની ખાતરી કરવા માટે આ માહિતીને લાંબા સમય સુધી રાખવી મહત્વપૂર્ણ છે અને આ અભ્યાસ યોગ્ય રીતે એ જુઓ છે.

બધા સહભાગીઓ ઇન્ટરવ્યૂ દરમિયાન કોઈપણ સમયે ઇન્ટરવ્યૂ લેવા માટે પાત્ર છે, પરંતુ તે મુદ્દા પર એકત્રિત કરવામાં આવેલા તમામ ડેટાનો અભ્યાસમાં ઉપયોગ કરવામાં આવશે. બધા સંશોધકોની સંપર્ક વિગતો નીચે આપેલ છે.

સંશોધન અભ્યાસના પરિણામોનું શું થશે?

અભ્યાસના તારણો રાષ્ટ્રીય અને આંતરરાષ્ટ્રીય સામયિકોમાં નર્સિંગ પ્રેક્ટિસને પ્રભાવિત કરવા અને બદલવાની આશામાં, સમાન અનુભવોવાળા વ્યક્તિઓની સંભાળ રાખતા પ્રેક્ટિશનર્સને સહાય કરવાની આશામાં પ્રકાશિત કરવામાં આવશે.

જો તમને રસ હોય, તો સંશોધનના તારણોનો સારાંશ તમારા ઘરના સરનામા પર પોસ્ટ દ્વારા તમને ઉપલબ્ધ કરાશે અને તમને પ્રચારિત કરવામાં આવશે. જો કે, જો તમે તમારા સરનામાંને જાહેર કરવા માંગતા ન હોવ તો પરિણામ અભ્યાસ સારાંશ પછી, તમારી મુલાકાતમાં તમને રજૂ કરી શકાય છે.

સંશોધનનું આયોજન કે પ્રાયોજક કોણ છે?

અભ્યાસ મારી જાતને અને મારા સુપરવાઇઝર દ્વારા સેલ્ફોર્ડ યુનિવર્સિટીની અંદરથી ગોઠવવામાં આવે છે, અમે સેન્ડવેલ અને વેસ્ટ બર્મિંગહામ હોસ્પિટલ એનએચએસ ટ્રસ્ટમાં એફએલઓ પ્રોવાઇડર્સ સાથે સહયોગ કરીશું.

વધુ માહિતી અને સંપર્ક વિગતો:

જો તમે સંશોધનમાં ભાગ લેવા રસ ધરાવો છો, તો કૃપા કરીને મારી જાતને મિસ તાહરેમ ચૌધરીનો સંપર્ક કરો - ઇમેઇલ:

[T.Chaudhry@edu.salford.ac.uk](mailto:T.Chaudhry@edu.salford.ac.uk) ટેલિફોન: XXXXXXXXXXXX

અથવા સંપર્ક સુપરવાઇઝર:

પ્રોફેસર પૌલા ઓર્મેન્ડી (સુપરવાઇઝર) : [P.Ormandy@salford.ac.uk](mailto:P.Ormandy@salford.ac.uk) ટેલ: 0161 295-0453

ક્રિસ્ટિના વાસિલિકા (સુપરવાઇઝર): [C.M.vasilical@salford.ac.uk](mailto:C.M.vasilical@salford.ac.uk)

## Appendix 25. Hindi PIS

### आंशिक सूचना शीट

अध्ययन का शीर्षक: दक्षिण एशियाई रोगियों में स्वास्थ्य व्यवहार और आत्म-प्रबंधन को बढ़ाने के लिए पाठ संदेशों के अनुभवों और उपयोग की खोज

शोधकर्ता का नाम: मिस तहरीम चौधरी

#### निमंत्रण अनुच्छेद

मैं वर्तमान में अपने पीएचडी के लिए अध्ययन कर रहा हूँ, जो सकारात्मक स्वास्थ्य व्यवहार को बढ़ावा देने और दीर्घकालिक स्थिति के आत्म-प्रबंधन को बढ़ाने और समर्थन करने के लिए दक्षिण एशियाई आबादी में पाठ संदेश के उपयोग का पता लगाने का प्रयास करता है। यदि आप भाग लेने के इच्छुक हैं, तो अध्ययन के बारे में अधिक जानकारी के लिए कृपया नीचे विवरण देखें।

#### अध्ययन का उद्देश्य क्या है?

इस शोध का मुख्य उद्देश्य है, दक्षिण एशियाई लोगों के अनुभवों का पता लगाना और यह जांचना कि क्या स्वास्थ्य विश्वास, सांस्कृतिक और धार्मिक रीति-रिवाजों जैसे कारक रोगी की सक्रियता और पाठ संदेश भेजने में योगदान करते हैं। मुझे आशा है कि यह अध्ययन इस बात की बेहतर समझ उत्पन्न करेगा कि हस्तक्षेप का उपयोग कौन कर रहा है, हस्तक्षेप क्या बचाता है और एक जातीय अल्पसंख्यक समूह के भीतर दीर्घकालिक बीमारियों या स्थितियों के प्रबंधन में इसके क्या प्रभाव हैं।

#### मुझे भाग लेने के लिए क्यों आमंत्रित किया गया है?

हम आपको इस शोध में भाग लेने के लिए आमंत्रित कर रहे हैं क्योंकि आप दक्षिण-एशियाई जातीय मूल के हैं, एक दीर्घकालिक स्थिति के साथ रह रहे हैं। हम उन लोगों से बात करना चाह रहे हैं जिनके पास है

- अपनी स्थिति को स्वयं प्रबंधित करने में मदद करने के लिए FLO पाठ संदेश प्रणाली का उपयोग किया
- पहले फ्ल पाठ संदेश प्रणाली का उपयोग किया है, लेकिन अब इसका उपयोग नहीं कर रहे हैं
- या उन लोगों को जिन्होंने प्रणाली का उपयोग करने के लिए नहीं चुना है या नहीं करना चाहते हैं।

इन विभिन्न समूहों के लोगों से बात करने से हमें यह समझने में मदद मिलेगी कि क्या टेक्स्ट मैसेजिंग उपयोगी है, किससे, कैसे और कब, या अन्य तरीके हैं जिससे लोगों को अपनी बीमारी का प्रबंधन करने में मदद मिल सके।

#### क्या मुझे भाग लेना है?

यदि आप नहीं चाहते हैं तो आपको इसमें भाग लेने की आवश्यकता नहीं है, आपकी भागीदारी स्वैच्छिक है। यदि आप तय करते हैं कि यह आपके लिए नहीं है, तो यह एफएलओ के साथ आपकी भागीदारी या किसी अन्य स्वास्थ्य सेवा के लिए आपकी पहुंच को प्रभावित नहीं करेगा। यदि आप भाग लेने का निर्णय लेते हैं, तो हस्ताक्षर करने के लिए एक सहमति प्रपत्र प्रदान किया जाएगा। यदि आप भाग लेते हैं, तब भी आप किसी भी समय वापस लेने का विकल्प चुन सकते हैं, हालाँकि, आपके द्वारा पहले ही दी गई वापसी की कोई भी जानकारी अनुसंधान के हिस्से के रूप में उपयोग की जाएगी।

#### अगर मैं भाग लेता हूँ तो मेरा क्या होगा?

यदि आप इस अध्ययन में भाग लेने के लिए सहमत हैं, तो इस बात का सारांश है कि आप क्या होने की उम्मीद कर सकते हैं:

1. शोधकर्ता के साथ किसी भी प्रश्न पर चर्चा करें और सहमति फॉर्म पर हस्ताक्षर करें।



2. शोधकर्ता के साथ उस स्थान को पहचानें जो आपके लिए सुविधाजनक हो, जहां साक्षात्कार हो सकता है (उदाहरण के लिए आपका घर या स्थानीय सामुदायिक केंद्र, या अस्पताल)।
3. एक अनुवादक के लिए अपनी आवश्यकता पर चर्चा करें और एक योजना से सहमत हों, ऐसे विभिन्न विकल्प हैं जिन पर आप विचार कर सकते हैं। सभी अध्ययन प्रश्नावली और साक्षात्कार प्रतिभागियों की पसंदीदा भाषा में अनुवादित किए जा सकते हैं। शोधकर्ता विभिन्न भाषाओं (एक्सएक्सएक्स) को बोल सकता है और अंग्रेजी के लिए पसंदीदा होने पर कुछ मूल भाषा में साक्षात्कार आयोजित करने में सक्षम होगा। यदि आप पसंद कर सकते हैं, तो आप अपने परिवार के किसी सदस्य को इंटरप्रेटर के रूप में कार्य करने के मामले में साक्षात्कार में आपके साथ बैठने के लिए कह सकते हैं। यदि आप अपने साथ परिवार का कोई सदस्य नहीं रखना चाहते हैं, तो एक वैकल्पिक विकल्प यह है कि हम एक बाहरी अनुवादक (जैसे अस्पताल भाषा लाइन) का उपयोग करके साक्षात्कार का संचालन कर सकते हैं।
4. आपको सबसे पहले एक लघु प्रश्नावली पूरी करने के लिए कहा जाएगा, इससे आपको लगभग 10 मिनट लगने चाहिए और आपके और आपकी बीमारी के प्रबंधन के बारे में सवाल पूछे जाएंगे।
5. प्रश्नावली पूरा करने के बाद, आपको एक साक्षात्कार में भाग लेने के लिए आमंत्रित किया जाएगा, जिसे रोगी की प्राथमिकताओं के आधार पर आमने-सामने या टेलीफोन के माध्यम से आयोजित किया जा सकता है। यह साक्षात्कार आपको दीर्घकालिक स्थिति के साथ रहने के आपके अनुभवों के बारे में प्रश्न पूछेगा कि आप कैसे प्रबंधन करते हैं और आपको क्या समर्थन मिलता है। अतिरिक्त संदेश उन लोगों से पूछे जाएंगे जो टेक्स्ट मैसेजिंग सेवाओं का उपयोग करते हैं कि यह कैसे मदद करता है या उनकी स्थिति को प्रबंधित करने में मदद नहीं करता है। सभी साक्षात्कार डिजिटल रूप से दर्ज किए जाएंगे।

#### व्यय और भुगतान?

अध्ययन में आपकी भागीदारी से जुड़ी कोई प्रत्यक्ष भुगतान लागत नहीं है। हालांकि, साक्षात्कार में भाग लेने पर आपको किसी भी यात्रा लागत की प्रतिपूर्ति की जाएगी।

#### भाग लेने के संभावित नुकसान और जोखिम क्या हैं?

यह संभावना नहीं है कि अध्ययन के भीतर भाग लेने का कोई नुकसान होगा और शारीरिक स्वास्थ्य के लिए कोई जोखिम नहीं होगा। हालांकि, इस घटना में कि आप सर्वेक्षण / साक्षात्कार की सामग्री से व्यथित हो जाते हैं, शोधकर्ता आपको आसानी से सुलभ सेवाओं पर हस्ताक्षर कर सकता है, जैसे कि ब्रिटेन में विभिन्न साइटों पर मानसिक स्वास्थ्य परोपकार सेवाएं मनोवैज्ञानिक समर्थन के लिए परामर्श प्रदान करती हैं। मनोवैज्ञानिक सहायता ar समरिटन्स 'या can सैनलाइन' के माध्यम से मांगी जा सकती है जो टेलीफोन, ईमेल, पत्र के माध्यम से गोपनीय भावनात्मक समर्थन की पेशकश करते हैं और संकट में लोगों के लिए सामना करते हैं।

यदि आप सर्वेक्षण / साक्षात्कार के दौरान पूछे गए कुछ सवालों के जवाब नहीं देना चाहते हैं या असहज महसूस कर रहे हैं, तो साक्षात्कार को रोका जा सकता है और किसी अन्य तिथि और समय के लिए स्थगित कर दिया जा सकता है। आप किसी भी समय सर्वेक्षण / साक्षात्कार को वापस लेने और बाहर निकलने के लिए स्वतंत्र हैं। सूचना की गोपनीयता का हर समय सम्मान किया जाएगा।

#### भाग लेने के संभावित लाभ क्या हैं?

भाग लेने से कोई व्यक्तिगत लाभ नहीं है; हालांकि, यह अध्ययन आपके और अन्य जातीय अल्पसंख्यक समूहों के लिए सांस्कृतिक रूप से अनुरूप हस्तक्षेप को सुविधाजनक बनाने में मदद कर सकता है। आपके इनपुट की बहुत सराहना की जाएगी और अध्ययन के परिणाम परिवर्तन को सूचित कर सकते हैं कि कैसे टेक्स्ट संदेश आपको और दूसरों को वितरित किए जाते हैं।

आपकी भागीदारी अन्य रोगियों के साथ समान अनुभव के साथ जुड़ाव को प्रोत्साहित करेगी, अन्य सेवा उपयोगकर्ताओं और / या देखभालकर्ताओं के साथ सहयोग करना, स्थानीय रोगी सहायता समूहों के साथ बातचीत करना, और भविष्य के रोगियों और समुदाय के सदस्यों की भागीदारी जो इसमें शामिल होने में रुचि रखते हैं।

अगर कोई समस्या है तो क्या होगा?

यदि आपको इस अध्ययन के किसी भी पहलू के बारे में चिंता है, तो आपको शोधकर्ता से बात करने के लिए कहना चाहिए: (नीचे मिस टी चौधरी संपर्क विवरण) जो आपके सवाल के जवाब देने की पूरी कोशिश करेंगे। यदि आप दुखी रहते हैं और औपचारिक रूप से शिकायत करने की इच्छा रखते हैं, तो आप अनुसंधान पर्यवेक्षक (प्रोफेसर पाउला ओरमंडी या डॉ। क्रिस्टीना वासिलिका, संपर्क विवरण नीचे संपर्क करके) कर सकते हैं।

यदि मामला अभी भी हल नहीं हुआ है, तो कृपया अपनी चिंताओं को प्रोफेसर सुसान मैकएन्ड्रू, हेल्थ रिसर्च एथिकल एप्रूवल पैनल के चेयरमैन, रूम MS1.91, मैरी सीकोल बिल्डिंग, फ्रेडरिक रोड कैंपस, यूनिवर्सिटी ऑफ सलफोर्ड, सलफोर्ड, M6 6PU के सामने रखें। दूरभाष: 0161 295 2778. ई: [s.mcandrew@salford.ac.uk](mailto:s.mcandrew@salford.ac.uk)

क्या मेरा डेटा गोपनीय रखा जाएगा?

पूरे अध्ययन में आपकी गुमनामी का सम्मान किया जाएगा और आपके द्वारा दी गई जानकारी को हर समय गोपनीय रखा जाएगा। हार्ड कॉपी प्रश्नावली को एक बंद कार्यालय में एक बंद फाइलिंग कैबिनेट में सुरक्षित रूप से रखा जाएगा। जितनी जल्दी हो सके प्रश्नावली डेटा को एक इलेक्ट्रॉनिक डेटाबेस पर दर्ज किया जाएगा और पेपर प्रश्नावली को सुरक्षित रूप से नष्ट कर दिया जाएगा। इसी तरह, साक्षात्कार डिजिटल रिकॉर्डिंग को साक्षात्कार के बाद सीधे रिकॉर्डिंग डिवाइस से हटा दिया जाएगा और एक पासवर्ड संरक्षित कंप्यूटर पर रखा जाएगा, फिर एक शोध कोड वर्ड फ़ाइल में टाइप किया जाएगा।

आपके डेटा को अज्ञात कोड दिया जाएगा और एक शोध कोड आवंटित किया जाएगा, कोई भी साक्षात्कार और प्रश्नावली आपके लिए पहचान योग्य नहीं होगी। नाम और अनुसंधान कोड की एक मास्टर सूची, साथ ही साथ अनुसंधान डेटा फ़ाइलों को एक पासवर्ड संरक्षित कंप्यूटर में संग्रहित किया जाएगा, जो पासवर्ड केवल रिसर्च टीम को ही जाना जाता है, सलफोर्ड विश्वविद्यालय के भीतर विश्वविद्यालय की कानूनी जिम्मेदारी है कि वह 5 वर्षों तक अनुसंधान के बाद आपके डेटा को गोपनीय रूप से संग्रहीत करे, तब सूचना सुरक्षित रूप से नष्ट हो जाएगी। यह सुनिश्चित करने के लिए इस जानकारी को लंबे समय तक रखना महत्वपूर्ण है कि नियामक निकायों के लिए यह जांचने का एक मौका है कि शोध रिपोर्टिंग सटीक है, और अध्ययन उचित रूप से आयोजित किया गया है।

यदि मैं अध्ययन के साथ नहीं चलूंगा तो क्या होगा?

सभी प्रतिभागी यदि चाहें तो साक्षात्कार के दौरान किसी भी बिंदु पर वापस लेने के लिए पात्र हैं, लेकिन उस बिंदु तक एकत्र सभी डेटा का उपयोग अध्ययन में किया जाएगा। सभी शोधकर्ताओं के संपर्क विवरण नीचे दिए गए हैं।

शोध अध्ययन के परिणामों का क्या होगा?

नर्सिंग अभ्यास को प्रभावित करने और बदलने की उम्मीद में राष्ट्रीय और अंतर्राष्ट्रीय पत्रिकाओं में अध्ययन के निष्कर्ष प्रकाशित किए जाएंगे, समान अनुभव वाले व्यक्तियों की देखभाल करने वाले चिकित्सकों का समर्थन करेंगे। यदि आप रुचि रखते हैं, तो शोध निष्कर्षों का एक सारांश आपके घर के पते पर पोस्ट के माध्यम से आपको उपलब्ध और प्रसारित किया जाएगा। हालांकि, यदि आप अध्ययन के बाद अपने पते के परिणाम सारांश का खुलासा नहीं करना चाहते हैं, तो आपको अपनी नियुक्ति के समय प्रस्तुत किया जा सकता है।

अनुसंधान का आयोजन या प्रायोजन कौन कर रहा है?

अध्ययन का आयोजन स्वयं और मेरे पर्यवेक्षकों द्वारा सलफोर्ड विश्वविद्यालय के भीतर से किया जा रहा है, हम सैंडवेल और वेस्ट बर्मिंघम अस्पताल एनएचएस ट्रस्ट में एफएलओ प्रदाताओं के साथ सहयोग करेंगे।

अधिक जानकारी और संपर्क विवरण:

आप अनुसंधान में भाग लेने में रुचि रखते हैं, तो कृपया खुद से संपर्क करें सुश्री तहरीम चौधरी -

[T.Chaudhry@edu.salford.ac.uk](mailto:T.Chaudhry@edu.salford.ac.uk) दूरभाष: XXXXXXXXXXXXXXXXXXXXXx

या पर्यवेक्षकों से संपर्क करें:

प्रोफेसर पाउला ओरमंडी (पर्यवेक्षक) : [P.Ormandy@salford.ac.uk](mailto:P.Ormandy@salford.ac.uk) दूरभाष:0161 295-0453

डॉ। क्रिस्टीना वासिलिका (पर्यवेक्षक): [C.M.vasilica1@salford.ac.uk](mailto:C.M.vasilica1@salford.ac.uk)

## Appendix 26. Bengali PIS

### পার্টনার ইনফরমেশন পত্রক

অধ্যয়ন শিরোনাম: দক্ষিণ এশিয়ার রোগীদের স্বাস্থ্যের আচরণ ও স্ব-ব্যবস্থাপনা উন্নত করার জন্য অভিজ্ঞতার অভিজ্ঞতা এবং পাঠ্য বার্তাগুলি ব্যবহার করা

গবেষক নামঃ মিস তাহেরেম চৌধুরী

#### আমন্ত্রণ অনুচ্ছেদ

আমি বর্তমানে আমার পি.এইচডি এর জন্য অধ্যয়নরত, যা দক্ষিণ এশিয়ার জনসংখ্যার ইতিবাচক স্বাস্থ্য আচরণকে বৃদ্ধি এবং দীর্ঘমেয়াদী অবস্থার স্বাবলম্বন বৃদ্ধিতে এবং সমর্থন করার জন্য পাঠ্য বার্তা প্রেরণের জন্য অনুসন্ধান করতে চায়। আপনি অংশগ্রহণ করতে আগ্রহী হলে, গবেষণা সম্পর্কে আরও তথ্যের জন্য নীচের বিবরণ দেখুন দয়া করে।

#### গবেষণা উদ্দেশ্য কি?

এই গবেষণার মূল লক্ষ্যটি দক্ষিণ এশিয়ার মানুষের অভিজ্ঞতার অন্বেষণ করা এবং স্বাস্থ্য বিশ্বাস, সাংস্কৃতিক ও ধর্মীয় প্রথার কারণগুলি রোগীর সক্রিয়করণ এবং পাঠ্য বার্তা প্রেরণের ক্ষেত্রে অবদান রাখতে কিনা তা পরীক্ষা করে দেখুন। আমি আশা করি এই গবেষণায় হস্তক্ষেপ ব্যবহার করা, হস্তক্ষেপ বিতরণ করা এবং জাতিগত সংখ্যালঘু গোষ্ঠীর দীর্ঘমেয়াদী রোগ বা অবস্থার পরিচালনার প্রভাবগুলি কীভাবে ব্যবহার করা হয় সে সম্পর্কে আরও ভালভাবে জেনে নেওয়া হবে।

#### আমাকে কেন অংশ নিতে আমন্ত্রণ জানানো হয়েছে?

আমরা এই গবেষণায় অংশ নেওয়ার জন্য আপনাকে আমন্ত্রণ জানাচ্ছি কারণ আপনি দক্ষিণ-এশীয় জাতিগত উত্স, দীর্ঘমেয়াদী অবস্থায় বসবাস করছেন। আমরা যারা আছে কথা বলতে খুঁজছেন

- তাদের অবস্থার স্ব-পরিচালনা করতে সহায়তা করার জন্য FLO টেক্সট মেসেজিং সিস্টেম ব্যবহার করে
- পূর্বে ফ্লো টেক্সট মেসেজিং সিস্টেম ব্যবহার করেছেন, কিন্তু এটি আর ব্যবহার করছেন না
- বা যারা যারা সিস্টেম বা সিস্টেম ব্যবহার করতে না চান না চয়ন করেছেন।

এই বিভিন্ন গোষ্ঠীর লোকেদের সাথে কথা বলার মাধ্যমে আমাদের পাঠ্য বার্তা প্রেরণ করা যায় কিনা তা বুঝতে সাহায্য করবে, কার কাছে, কখন এবং কখন, বা তাদের অসুস্থতা পরিচালনা করতে সহায়তা করার অন্য উপায় রয়েছে কিনা তাও আমাদের কাছে আছে।

#### আমি কি অংশ নিতে হবে?

আপনি যদি ইচ্ছুক না হন তবে আপনাকে অংশগ্রহণ করতে হবে না, আপনার অংশগ্রহণটি স্বেচ্ছাসেবক। আপনি যদি সিদ্ধান্ত করেন যে এটি আপনার জন্য নয় তবে এটি FLO এর সাথে আপনার জড়িততা বা অন্য কোন স্বাস্থ্যসেবা পরিষেবাগুলিতে আপনার অ্যাক্সেসকে প্রভাবিত করবে না। আপনি অংশগ্রহণ করার সিদ্ধান্ত নিলে, সাইন ইন করার জন্য একটি সম্মতি ফর্ম সরবরাহ করা হবে। যদি আপনি অংশ নেন তবে আপনি এখনও যে কোনও সময় প্রত্যাহার করতে পারেন তবে যাইহোক, ইতিমধ্যে আপনি যে পরিমাণ অর্থ প্রত্যাহার করেছেন তা অনুসন্ধানের অংশ হিসাবে ব্যবহার করা হবে।

#### আমি অংশ নিতে হলে আমার কি হবে?

আপনি যদি এই গবেষণায় অংশগ্রহণের জন্য সম্মত হন তবে আপনি কী ঘটতে আশা করতে পারেন তার সারাংশ এখানে রয়েছে:

1. গবেষক কোন প্রশ্ন নিয়ে আলোচনা করুন এবং সম্মতি ফর্ম সাইন ইন করুন।
2. গবেষকের সাথে সাক্ষাত্কার করুন যেখানে ইন্টারভিউটি আপনার পক্ষে সুবিধাজনক (উদাহরণস্বরূপ আপনার বাড়ি বা স্থানীয় কমিউনিটি সেন্টার, অথবা হাসপাতাল) হতে পারে।
3. একটি অনুবাদক আপনার প্রয়োজন আলোচনা এবং একটি পরিকল্পনা সম্মত হন, আপনি বিবেচনা করতে পারে বিভিন্ন অপশন আছে। সমস্ত গবেষণা প্রশ্নাবলী এবং সাক্ষাত্কার অংশগ্রহণকারীদের পছন্দসই ভাষা

অনুবাদ করা যেতে পারে। গবেষক বিভিন্ন ভাষা বলতে পারেন (XXX) এবং ইংরেজিতে পছন্দমত যদি কিছু স্থানীয় ভাষায় সাক্ষাত্কার পরিচালনা করতে পারবেন। আপনি যদি পছন্দ করতে পারেন তবে আপনার ইন্টারপ্রেটার হিসাবে অভিনয় না করলে আপনি সাক্ষাত্কারে আপনার সাথে বসতে আপনার পরিবারের সদস্যকে জিজ্ঞাসা করতে পারেন। আপনি যদি আপনার সাথে পরিবারের সদস্য হতে চান না তবে বিকল্প বিকল্পটি হল যে আমরা বাইরের অনুবাদক (যেমন হাসপাতাল ভাষা লাইন) ব্যবহার করে সাক্ষাত্কার পরিচালনা করতে পারি।

4. আপনাকে প্রথমে একটি সংক্ষিপ্ত প্রশ্নাবলী সম্পন্ন করতে বলা হবে যা আপনাকে প্রায় 10 মিনিট সময় নিতে এবং আপনার নিজের এবং আপনার অসুস্থতাকে পরিচালনা করার বিষয়ে প্রশ্ন করে।

5. প্রশ্নাবলী সম্পন্ন করার পরে, আপনাকে একটি সাক্ষাত্কারে অংশগ্রহণের জন্য আমন্ত্রণ জানানো হবে, যা রোগীর পছন্দগুলির উপর নির্ভর করে মুখোমুখি হতে পারে অথবা টেলিফোনের মাধ্যমে পরিচালিত হতে পারে। এই সাক্ষাত্কারটি আপনাকে দীর্ঘমেয়াদী অবস্থায় জীবিত থাকার অভিজ্ঞতার প্রশ্ন, আপনি কীভাবে পরিচালনা করবেন এবং আপনার কোন সহায়তা পাবেন তা সম্পর্কে প্রশ্ন জিজ্ঞাসা করবে। অতিরিক্ত প্রশ্ন জিজ্ঞাসা করা হবে যারা পাঠ্য বার্তা পরিষেবাগুলি কীভাবে এটি সহায়তা করে বা তাদের অবস্থা পরিচালনা করতে সহায়তা করে না সে সম্পর্কে এটি ব্যবহার করে। সমস্ত সাক্ষাত্কার ডিজিটালভাবে রেকর্ড করা হবে।

খরচ এবং পেমেন্ট?

গবেষণায় আপনার জড়িত সঙ্গে কোন সরাসরি পেমেন্ট খরচ আছে। যাইহোক, আপনি একটি সাক্ষাত্কারে অংশগ্রহণের সময় ব্যয় কোনো ভ্রমণ খরচ ফেরত দেওয়া হবে।

অংশ নিতে সম্ভাব্য অসুবিধা এবং ঝুঁকি কি কি?

গবেষণায় অংশগ্রহণের কোনো অসুবিধা হবে না এবং শারীরিক স্বাস্থ্যের কোনো ঝুঁকি থাকবে না এমন সম্ভাবনা নেই। যাইহোক, যদি আপনি জরিপ / সাক্ষাত্কারের বিষয়বস্তু দ্বারা বিরক্ত হন, তবে গবেষক আপনাকে মানসিক স্বাস্থ্য চ্যারিটি পরিষেবাদি যেমন মানসিক স্বাস্থ্য চ্যারিটি পরিষেবাদিগুলি মানসিক স্বাস্থ্যের জন্য পরামর্শ প্রদান করে সহজে অ্যাক্সেসযোগ্য পরিষেবায় সাইনপোস্ট করতে পারেন। 'সামারিটান' বা 'সানলাইন' হিসাবে হেল্পলাইনের মাধ্যমে মানসিক সহায়তা চাওয়া যেতে পারে যা দুর্দশাগ্রস্ত ব্যক্তিদের জন্য টেলিফোনে, ইমেল, চিঠি এবং মুখে মুখোমুখি গোপনীয় মানসিক সমর্থন প্রদান করে।

আপনি যদি জরিপ / সাক্ষাত্কারের সময় জিজ্ঞাসা করা নির্দিষ্ট প্রশ্নগুলিতে প্রতিক্রিয়া জানাতে না অস্বস্তি বোধ করেন তবে ইন্টারভিউটি বন্ধ এবং অন্য তারিখ এবং সময় স্থগিত করা যেতে পারে। আপনি যে কোন সময় সমীক্ষা / সাক্ষাত্কার প্রত্যাহার এবং প্রস্থান করতে পারেন। তথ্য গোপনীয়তা সর্বদা সম্মান করা হবে।

অংশ নিতে সম্ভাব্য সুবিধা কি কি?

অংশগ্রহণ থেকে কোন ব্যক্তিগত সুবিধা আছে; তবে, এই গবেষণায় আপনার এবং অন্যান্য জাতিগত সংখ্যালঘু গোষ্ঠীগুলির জন্য সাংস্কৃতিকভাবে পরিকল্পিত হস্তক্ষেপগুলি সহজতর করতে সহায়তা করতে পারে। আপনার ইনপুটটি অত্যন্ত প্রশংসা করা হবে এবং গবেষণার ফলাফল আপনাকে এবং অন্যদের কাছে কীভাবে পাঠ্য বার্তা বিতরণ করা হয় তা পরিবর্তনগুলি অবহিত করতে পারে।

আপনার অংশগ্রহণ অনুরূপ অভিজ্ঞতার সাথে অন্যান্য রোগীদের সাথে সহযোগিতা উত্সাহিত করবে, অন্যান্য পরিষেবা ব্যবহারকারী এবং / অথবা তত্ত্বাবধায়কদের সাথে সহযোগিতা করবে, স্থানীয় রোগীর সহায়তা গোষ্ঠীগুলির সাথে ইন্টারঅ্যাক্ট করবে এবং ভবিষ্যতে রোগীর অংশগ্রহণ এবং জড়িত থাকতে আগ্রহী সম্প্রদায়ের সদস্যদের অংশগ্রহণ করবে।

কোন সমস্যা হলে কি হবে?

যদি আপনার এই গবেষণার কোনও দিক সম্পর্কে উদ্বেগ থাকে, তবে আপনাকে গবেষককে কথা বলতে বলা উচিত: (নীচে টিএস চৌধুরী যোগাযোগের বিশদ) যারা আপনার প্রশ্নের উত্তর দিতে যথাসাধ্য চেষ্টা করবে। আপনি যদি অসুখী হন এবং আনুষ্ঠানিকভাবে অভিযোগ করতে চান তবে আপনি রিসার্চ সুপারভাইজার (অধ্যাপক পলা Professor Paula Ormandy বা Dr Cristina Vasilica, নীচের যোগাযোগের বিবরণ) -এর সাথে যোগাযোগ করে এটি করতে পারেন।

যদি বিষয়টি এখনও সমাধান না হয়, তবে আপনার উদ্বেগটি হেলথ রিসার্চ নৈতিক অনুমোদন প্যানেলের চেয়ার, রুম এমএস 1.91, মেরি সেকোল বিল্ডিং, ফ্রেডেরিক রোড ক্যাম্পাস, সালফোর্ড ইউনিভার্সিটি অফ সালফোর্ড, এম 6 6 পি ইউ এর চেয়ারম্যান প্রফেসর সুসান ম্যাক অ্যাড্রুকে নিয়ে যান। টেলিফোন: 0161 295 2778. ই:

আমার তথ্য গোপন রাখা হবে?

আপনার নামহীনতা অধ্যয়ন জুড়ে সম্মানিত করা হবে এবং আপনার দেওয়া তথ্য সর্বদা গোপনীয় রাখা হবে। হার্ড কপি প্রশ্নাবলী একটি লকড অফিসে একটি লক ফাইলিং মন্ত্রিসভা নিরাপদে রাখা হবে। যত তাড়াতাড়ি সম্ভব প্রশ্নপত্রের তথ্য একটি ইলেকট্রনিক ডাটাবেসে প্রবেশ করা হবে এবং কাগজ প্রশ্নাবলী নিরাপদে ধ্বংস করা হবে। একইভাবে, ইন্টারভিউ ডিজিটাল রেকর্ডিং সাক্ষাত্কারের পরে সরাসরি রেকর্ডিং ডিভাইস থেকে সরানো হবে এবং একটি পাসওয়ার্ড সুরক্ষিত কম্পিউটারে রাখা হবে, তারপর একটি গবেষণা কোডেড শব্দ ফাইলের মধ্যে টাইপ করা হবে।

আপনার তথ্য অনামী করা হবে এবং একটি গবেষণা কোড বরাদ্দ করা হবে, কোন সাক্ষাত্কার এবং প্রশ্নাবলী আপনার সনাক্ত করা যাবে না। নাম এবং গবেষণা কোডগুলির একটি মাস্টার তালিকা, পাশাপাশি গবেষণা তথ্য ফাইলগুলি, একটি পাসওয়ার্ড সুরক্ষিত কম্পিউটারে সংরক্ষণ করা হবে, যা শুধুমাত্র স্যালফোর্ড ইউনিভার্সিটির মধ্যে গবেষণা দলের পরিচিত পাসওয়ার্ড। পাঁচ বছরের জন্য গবেষণার পরে গোপনীয়ভাবে আপনার তথ্য সংরক্ষণের জন্য বিশ্ববিদ্যালয়টির বৈধ দায়িত্ব রয়েছে, তাহলে তথ্য নিরাপদে ধ্বংস হয়ে যাবে। গবেষণা রিপোর্ট সঠিক কিনা তা পরীক্ষা করার জন্য নিয়ন্ত্রক সংস্থাগুলির একটি সুযোগ আছে তা নিশ্চিত করার জন্য এই তথ্যটি দীর্ঘ রাখা গুরুত্বপূর্ণ, এবং গবেষণা যথাযথভাবে পরিচালিত হয়।

আমি যদি অধ্যয়ন চালিয়ে না যাই তবে কী হবে?

সমস্ত অংশগ্রহণকারী সাক্ষাত্কারে যে কোনও সময়ে সাক্ষাত্কারে প্রত্যাহারের যোগ্য হন তবে সেই বিন্দুতে সংগৃহীত সমস্ত তথ্য গবেষণাতে ব্যবহৃত হবে। সমস্ত গবেষক যোগাযোগের বিবরণ নিচে দেওয়া হয়।

গবেষণা গবেষণার ফলাফল কি হবে?

গবেষণার ফলাফলগুলি জাতীয় ও আন্তর্জাতিক জার্নালগুলিতে প্রকাশিত হবে, নার্সিং অনুশীলনকে প্রভাবিত ও পরিবর্তন করার আশা, একই ধরনের অভিজ্ঞতার ব্যক্তিদের তত্ত্বাবধানে অনুশীলনকারীদের সহায়তা করা। আপনি যদি আগ্রহী হন, গবেষণা ফলাফলের একটি সারাংশ আপনার বাড়ির ঠিকানায় পোস্টের মাধ্যমে উপলব্ধ এবং প্রচারিত হবে। যাইহোক, আপনি যদি আপনার ঠিকানা প্রকাশ করতে চান না তবে ফলাফলের সারসংক্ষেপটি আপনার অ্যাপয়েন্টমেন্ট আপনাকে পাঠানোর পরে উপস্থাপন করা যেতে পারে।

গবেষণা বা পৃষ্ঠপোষকতা কে?

স্যালফোর্ড বিশ্ববিদ্যালয় থেকে আমার এবং আমার সুপারভাইজাররা এই গবেষণাটি পরিচালনা করছেন, আমরা স্যান্ডওয়েল এবং ওয়েস্ট বার্মিংহাম হাসপাতাল এনএইচএস ট্রাস্ট FLO প্রোভাইডারদের সাথে সহযোগিতা করব।

আরও তথ্য এবং যোগাযোগের বিবরণ:

আপনি গবেষণা অংশগ্রহণ আগ্রহী হলে নিজেকে যোগাযোগ করুন: মিস তাহেরেম চৌধুরী মিস

ইমেইল: [T.Chaudhry@edu.salford.ac.uk](mailto:T.Chaudhry@edu.salford.ac.uk) টেলিফোন: XXXXXXXXXXXXX

অথবা যোগাযোগ সুপারভাইজার:

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ডাঃ ক্রিস্টিনা ভাসিলিকা (সুপারভাইজার): [C.M.Vasilica@salford.ac.uk](mailto:C.M.Vasilica@salford.ac.uk)

## Appendix 27. Punjabi PIS

### ਭਾਗ ਲੈਣ ਵਾਲੀ ਜਾਣਕਾਰੀ ਸੀਟ

ਅਧਿਐਨ ਦਾ ਸਿਰਲੇਖ: ਦੱਖਣੀ ਏਸ਼ੀਆਈ ਮਰੀਜ਼ਾਂ ਵਿਚ ਸਿਹਤ ਸੰਬੰਧੀ ਵਿਵਹਾਰ ਅਤੇ ਸਵੈ-ਪ੍ਰਬੰਧਨ ਨੂੰ ਵਧਾਉਣ ਲਈ ਤਜਰਬਿਆਂ ਦੀ ਜਾਣਕਾਰੀ ਅਤੇ ਟੈਕਸਟ ਮੈਸੇਜਾਂ ਦੀ ਵਰਤੋਂ ਕਰਨਾ

ਖੋਜਕਰਤਾ ਦਾ ਨਾਮ: ਮਿਸ ਤਹਿਰੀਮ ਚੌਧਰੀ  
ਸੱਦਾ ਪੈਰਾ

ਮੈਂ ਇਸ ਵੇਲੇ ਆਪਣੇ ਐੱਚ.ਡੀ.ਐੱਫ. ਲਈ ਪੜ੍ਹ ਰਿਹਾ ਹਾਂ ਜੋ ਸਾਊਥ ਏਸ਼ੀਅਨ ਜਨਸੰਖਿਆ ਵਿਚ ਸਕਾਰਾਤਮਕ ਸਿਹਤ ਵਿਹਾਰ ਨੂੰ ਉਤਸ਼ਾਹਿਤ ਕਰਨ ਅਤੇ ਲੰਮੀ ਮਿਆਦ ਦੀ ਸਥਿਤੀ ਦੇ ਸਵੈ-ਪ੍ਰਬੰਧਨ ਨੂੰ ਵਧਾਉਣ ਲਈ ਟੈਕਸਟ ਮੈਸੇਜਿੰਗ ਦੀ ਵਰਤੋਂ ਦੀ ਤਲਾਸ਼ ਕਰਨਾ ਚਾਹੁੰਦਾ ਹੈ. ਜੇ ਤੁਸੀਂ ਹਿੱਸਾ ਲੈਣ ਵਿਚ ਦਿਲਚਸਪੀ ਰੱਖਦੇ ਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਅਧਿਐਨ ਬਾਰੇ ਹੋਰ ਜਾਣਕਾਰੀ ਲੈਣ ਲਈ ਹੇਠਾਂ ਵੇਰਵੇ ਵੇਖੋ.

ਅਧਿਐਨ ਦਾ ਮਕਸਦ ਕੀ ਹੈ?

ਇਸ ਖੋਜ ਦਾ ਮੁੱਖ ਆਲਸਟਿੰਗ ਉਦੇਸ਼ ਦੱਖਣ ਏਸ਼ੀਆਈ ਲੋਕਾਂ ਦੇ ਤਜਰਬਿਆਂ ਦੀ ਖੋਜ ਕਰਨਾ ਅਤੇ ਇਹ ਤੈਅ ਕਰਨਾ ਹੈ ਕਿ ਜਿਵੇਂ ਕਿ ਸਿਹਤ ਵਿਸ਼ਵਾਸਾਂ, ਸੱਭਿਆਚਾਰਕ ਅਤੇ ਧਾਰਮਿਕ ਰੀਤੀ ਰਿਵਾਜ ਮੈਟਲ ਐਕਟੀਵੇਸ਼ਨ ਅਤੇ ਟੈਕਸਟ ਮੈਸੇਜਿੰਗ ਦੀ ਸ਼ਮੂਲੀਅਤ ਵਿੱਚ ਯੋਗਦਾਨ ਪਾਉਂਦੇ ਹਨ. ਮੈਂ ਉਮੀਦ ਕਰਦਾ ਹਾਂ ਕਿ ਇਹ ਅਧਿਐਨ ਕਿਸੇ ਦਰਮਿਆਨੀ ਘੱਟ ਗਿਣਤੀ ਸਮੂਹ ਦੇ ਅੰਦਰ ਲੰਮੇ ਸਮੇਂ ਦੀਆਂ ਬੀਮਾਰੀਆਂ ਜਾਂ ਹਾਲਤਾਂ ਦੇ ਪ੍ਰਬੰਧਾਂ ਵਿੱਚ ਦਖਲਅੰਦਾਜ਼ੀ ਦਾ ਇਸਤੇਮਾਲ ਕਰਨ ਵਾਲੇ, ਦਖਲਅੰਦਾਜ਼ੀ ਨੂੰ ਕਿੱਥੋਂ ਪਹੁੰਚਾਏਗਾ, ਅਤੇ ਇਸ ਦੇ ਪ੍ਰਭਾਵ ਨੂੰ ਕਿਸ ਤਰ੍ਹਾਂ ਸਮਝੇਗਾ

ਮੈਨੂੰ ਹਿੱਸਾ ਲੈਣ ਲਈ ਕਿਉਂ ਸੱਦਾ ਦਿੱਤਾ ਗਿਆ ਹੈ?

ਅਸੀਂ ਤੁਹਾਨੂੰ ਇਸ ਖੋਜ ਵਿੱਚ ਹਿੱਸਾ ਲੈਣ ਲਈ ਸੱਦਾ ਦੇ ਰਹੇ ਹਾਂ ਕਿਉਂਕਿ ਤੁਸੀਂ ਦੱਖਣ-ਏਸ਼ੀਅਨ ਨਸਲੀ ਮੂਲ ਦੇ ਹੋ, ਲੰਮੀ ਮਿਆਦ ਵਾਲੀ ਸਥਿਤੀ ਨਾਲ ਜੀ ਰਹੇ ਹੋ. ਅਸੀਂ ਉਨ੍ਹਾਂ ਲੋਕਾਂ ਨਾਲ ਗੱਲ ਕਰਨ ਦੀ ਕੋਸ਼ਿਸ਼ ਕਰ ਰਹੇ ਹਾਂ ਜਿਨ੍ਹਾਂ ਕੋਲ ਹੈ

- ਆਪਣੀ ਸਥਿਤੀ ਦੀ ਸਵੈ-ਸੰਭਾਲ ਕਰਨ ਲਈ FLO ਟੈਕਸਟ ਮੈਸੇਜਿੰਗ ਪ੍ਰਣਾਲੀ ਦਾ ਇਸਤੇਮਾਲ ਕੀਤਾ
- ਪਹਿਲਾਂ ਫਲੋ ਟੈਕ ਮੈਸੇਜਿੰਗ ਪ੍ਰਣਾਲੀ ਦਾ ਪ੍ਰਯੋਗ ਕੀਤਾ ਹੈ, ਪਰੰਤੂ ਹੁਣ ਇਸਦੀ ਵਰਤੋਂ ਨਹੀਂ ਕਰ ਰਹੇ ਹਨ
- ਜਾਂ ਉਹ ਲੋਕ ਜਿਨ੍ਹਾਂ ਨੇ ਸਿਸਟਮ ਦੀ ਵਰਤੋਂ ਨਹੀਂ ਕਰਨੀ ਚਾਹੁੰਦੇ ਜਾਂ ਨਹੀਂ ਕਰਨਾ ਚਾਹੁੰਦੇ

ਇਹਨਾਂ ਵੱਖ-ਵੱਖ ਸਮੂਹਾਂ ਦੇ ਲੋਕਾਂ ਨਾਲ ਗੱਲਬਾਤ ਕਰਨ ਨਾਲ ਇਹ ਸਮਝਣ ਵਿੱਚ ਸਾਡੀ ਮਦਦ ਹੋਵੇਗੀ ਕਿ ਕੀ ਟੈਕਸਟ ਮੈਸੇਜਿੰਗ ਉਪਯੋਗੀ ਹੈ, ਕਿਸ, ਕਿਸ ਅਤੇ ਕਦੋਂ, ਜਾਂ ਕੀ ਲੋਕਾਂ ਦੀ ਬਿਮਾਰੀ ਨੂੰ ਵਿਕਸਿਤ ਕਰਨ ਵਿੱਚ ਮਦਦ ਲਈ ਹੋਰ ਤਰੀਕੇ ਹਨ.

ਕੀ ਮੈਨੂੰ ਭਾਗ ਲੈਣ ਦੀ ਲੋੜ ਹੈ?

ਜੇ ਤੁਸੀਂ ਚਾਹੁੰਦੇ ਹੋ ਕਿ ਤੁਸੀਂ ਹਿੱਸਾ ਨਾ ਲਓ, ਤਾਂ ਤੁਹਾਡੀ ਸ਼ਮੂਲੀਅਤ ਸਵੈ-ਇੱਛਤ ਹੈ. ਜੇ ਤੁਸੀਂ ਇਹ ਫੈਸਲਾ ਕਰਦੇ ਹੋ ਕਿ ਇਹ ਤੁਹਾਡੇ ਲਈ ਨਹੀਂ ਹੈ ਤਾਂ ਇਹ FLO ਨਾਲ ਤੁਹਾਡੀ ਸ਼ਮੂਲੀਅਤ ਨੂੰ ਪ੍ਰਭਾਵਤ ਨਹੀਂ ਕਰੇਗਾ ਜਾਂ ਕਿਸੇ ਹੋਰ ਸਿਹਤ ਦੇਖਭਾਲ ਸੇਵਾਵਾਂ ਲਈ ਤੁਹਾਡੀ ਪਹੁੰਚ ਨੂੰ ਪ੍ਰਭਾਵਤ ਨਹੀਂ ਕਰੇਗਾ. ਜੇ ਤੁਸੀਂ ਹਿੱਸਾ ਲੈਣ ਦਾ ਫੈਸਲਾ ਕਰਦੇ ਹੋ, ਤਾਂ ਇਕ ਸਹਿਮਤੀ ਫਾਰਮ ਤੁਹਾਡੇ ਲਈ ਸਾਈਨ ਕਰਨ ਲਈ ਦਿੱਤਾ ਜਾਵੇਗਾ. ਜੇ ਤੁਸੀਂ ਹਿੱਸਾ ਲੈਂਦੇ ਹੋ ਤਾਂ ਤੁਸੀਂ ਕਿਸੇ ਵੀ ਸਮੇਂ ਕਢਵਾਉਣ ਦੀ ਚੋਣ ਕਰ ਸਕਦੇ ਹੋ, ਹਾਲਾਂਕਿ, ਤੁਹਾਡੇ ਵੱਲੋਂ ਪਹਿਲਾਂ ਤੋਂ ਦਿੱਤੇ ਗਏ ਕਢਵਾਉਣ ਦੀ ਕਿਸੇ ਵੀ ਜਾਣਕਾਰੀ ਨੂੰ ਖੋਜ ਦੇ ਹਿੱਸੇ ਵਜੋਂ ਵਰਤਿਆ ਜਾਵੇਗਾ.

ਜੇ ਮੈਂ ਭਾਗ ਲਵਾਂਗਾ ਤਾਂ ਮੇਰੇ ਨਾਲ ਕੀ ਹੋਵੇਗਾ?

ਜੇ ਤੁਸੀਂ ਇਸ ਅਧਿਐਨ ਵਿਚ ਹਿੱਸਾ ਲੈਣ ਲਈ ਸਹਿਮਤ ਹੁੰਦੇ ਹੋ ਤਾਂ ਇਸ ਬਾਰੇ ਸੰਖੇਪ ਜਾਣਕਾਰੀ ਹੈ ਕਿ ਤੁਸੀਂ ਕੀ ਕਰਨ ਦੀ ਉਮੀਦ ਕਰ ਸਕਦੇ ਹੋ:

1. ਖੋਜਕਰਤਾਵਾਂ ਨਾਲ ਕੋਈ ਸਵਾਲ ਕਰੋ ਅਤੇ ਸਹਿਮਤੀ ਫਾਰਮ ਤੇ ਦਸਤਖਤ ਕਰੋ.
2. ਖੋਜਕਰਤਾ ਨੂੰ ਉਸ ਜਗ੍ਹਾ ਦੀ ਪਛਾਣ ਕਰੋ ਜੋ ਤੁਹਾਡੇ ਲਈ ਸਹੂਲਤ ਹੈ ਜਿੱਥੋਂ ਇੰਟਰਵਿਊ ਕੀਤੀ ਜਾ ਸਕਦੀ ਹੈ (ਉਦਾਹਰਨ ਲਈ ਤੁਹਾਡਾ ਘਰ ਜਾਂ ਸਥਾਨਕ ਕਮਿਊਨਿਟੀ ਸੈਂਟਰ, ਜਾਂ ਹਸਪਤਾਲ).

3. ਇੱਕ ਅਨੁਵਾਦਕ ਲਈ ਤੁਹਾਡੀ ਲੋੜ ਬਾਰੇ ਚਰਚਾ ਕਰੋ ਅਤੇ ਇੱਕ ਯੋਜਨਾ 'ਤੇ ਸਹਿਮਤ ਹੋਵੋ, ਕਈ ਵਿਕਲਪ ਹਨ ਜਿਨ੍ਹਾਂ ਬਾਰੇ ਤੁਸੀਂ ਵਿਚਾਰ ਕਰ ਸਕਦੇ ਹੋ. ਸਾਰੇ ਅਧਿਐਨ ਪ੍ਰਸ਼ਨਾਂ ਅਤੇ ਇੰਟਰਵਿਊਆਂ ਦਾ ਭਾਗੀਦਾਰਾਂ ਦੀ ਤਰਜੀਹੀ ਭਾਸ਼ਾ ਵਿੱਚ ਅਨੁਵਾਦ ਕੀਤਾ ਜਾ ਸਕਦਾ ਹੈ. ਖੋਜਕਰਤਾ ਵੱਖ ਵੱਖ ਭਾਸ਼ਾਵਾਂ (XXX) ਬੋਲ ਸਕਦਾ ਹੈ ਅਤੇ ਜੇ ਉਹ ਅੰਗ੍ਰੇਜ਼ੀ ਨੂੰ ਤਰਜੀਹ ਦਿੰਦੇ ਹਨ ਤਾਂ ਕੁਝ ਮੂਲ ਭਾਸ਼ਾਵਾਂ ਵਿਚ ਇੰਟਰਵਿਊ ਕਰਨ ਦੇ ਯੋਗ ਹੋਣਗੇ. ਜੇ ਤੁਸੀਂ ਤਰਜੀਹ ਦਿੰਦੇ ਹੋ, ਤਾਂ ਤੁਸੀਂ ਆਪਣੇ ਪਰਿਵਾਰ ਦੇ ਕਿਸੇ ਮੈਂਬਰ ਨੂੰ ਇੰਟਰਵਿਊ ਵਿਚ ਬੈਠਣ ਲਈ ਕਹਿ ਸਕਦੇ ਹੋ ਜੇ ਤੁਸੀਂ ਸਮਝ ਨਹੀਂ ਸਕਦੇ, ਆਪਣੇ ਦੁਭਾਸ਼ੀਆ ਦੇ ਤੌਰ ਤੇ ਕੰਮ ਕਰਦੇ ਹੋ. ਜੇ ਤੁਸੀਂ ਆਪਣੇ ਨਾਲ ਇੱਕ ਪਰਿਵਾਰਕ ਮੈਂਬਰ ਨੂੰ ਭੇਜਣਾ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਸੁਝਾਵਾਂ ਲਈ ਇੱਕ ਸਲਾਹਕਾਰ ਨੂੰ ਸੰਪਰਕ ਕਰੋ (ਜਿਵੇਂ ਕਿ ਜਿਸ ਵਿੱਚ ਤੁਹਾਨੂੰ ਲਾਜ਼ਮੀ ਪੁੱਛੇ ਗਏ ਸਵਾਲਾਂ ਦੇ ਉੱਤਰਾਂ ਦੇ ਇੰਟਰਵਿਊ ਕਰ ਸਕਦੇ ਹੋ).

4. ਤੁਹਾਡੀ ਖੋਜ ਲਈ ਇੱਕ ਸੁਝਾਵਾਂ ਲਈ ਇੱਕ ਸਲਾਹਕਾਰ ਨੂੰ ਸੰਪਰਕ ਕਰੋ (ਜਿਵੇਂ ਕਿ ਜਿਸ ਵਿੱਚ ਤੁਹਾਨੂੰ ਲਾਜ਼ਮੀ ਪੁੱਛੇ ਗਏ ਸਵਾਲਾਂ ਦੇ ਉੱਤਰਾਂ ਦੇ ਇੰਟਰਵਿਊ ਕਰ ਸਕਦੇ ਹੋ).

5. ਪ੍ਰਸ਼ਨਾਵਲੀ ਨੂੰ ਭਰਨ ਤੋਂ ਬਾਅਦ, ਤੁਹਾਨੂੰ ਇੱਕ ਇੰਟਰਵਿਊ ਵਿੱਚ ਹਿੱਸਾ ਲੈਣ ਲਈ ਸੱਦਾ ਦਿੱਤਾ ਜਾਵੇਗਾ, ਜਿਸਨੂੰ ਮਰੀਜ਼ਾਂ ਦੇ ਤਰਜੀਹਾਂ ਦੇ ਆਧਾਰ ਤੇ, ਮੂੰਹ-ਜੁਬਾਨੀ ਜਾਂ ਟੈਲੀਫੋਨ ਦੁਆਰਾ ਆਯੋਜਿਤ ਕੀਤਾ ਜਾ ਸਕਦਾ ਹੈ. ਇਹ ਇੰਟਰਵਿਊ ਤੁਹਾਨੂੰ ਲੰਬੇ ਸਮੇਂ ਦੀਆਂ ਸਥਿਤੀਆਂ ਨਾਲ ਜੀਊਏ ਦੇ ਤੁਹਾਡੇ ਤਜਰਬਿਆਂ, ਤੁਸੀਂ ਕਿਵੇਂ ਪ੍ਰਬੰਧਿਤ ਕਰਦੇ ਹੋ ਅਤੇ ਤੁਹਾਨੂੰ ਕਿਹੋ ਜਿਹੀ ਸਹਾਇਤਾ ਪ੍ਰਾਪਤ ਕਰਦੇ ਹਨ ਬਾਰੇ ਪ੍ਰਸ਼ਨ ਪੁੱਛੇਗਾ. ਵਧੀਕ ਸਵਾਲ ਉਹਨਾਂ ਲੋਕਾਂ ਨੂੰ ਪੁੱਛੇ ਜਾਣਗੇ ਜੋ ਟੈਕਸਟ ਮੈਸੇਜਿੰਗ ਸੇਵਾਵਾਂ ਦੀ ਵਰਤੋਂ ਕਰਦੇ ਹਨ ਕਿ ਉਹ ਇਸਦੀ ਕਿਵੇਂ ਮਦਦ ਕਰਦੇ ਹਨ ਜਾਂ ਉਹਨਾਂ ਦੀ ਸਥਿਤੀ ਦਾ ਪ੍ਰਬੰਧਨ ਕਰਨ ਵਿੱਚ ਮਦਦ ਨਹੀਂ ਕਰਦੇ. ਸਾਰੇ ਇੰਟਰਵਿਊ ਡਿਜੀਟਲ ਰਿਕਾਰਡ ਕੀਤੇ ਜਾਣਗੇ. ਖਰਚੇ ਅਤੇ ਭੁਗਤਾਨ?

ਅਧਿਐਨ ਵਿਚ ਤੁਹਾਡੀ ਸ਼ਮੂਲੀਅਤ ਨਾਲ ਸੰਬੰਧਿਤ ਕੋਈ ਸਿੱਧਾ ਭੁਗਤਾਨ ਖਰਚ ਨਹੀਂ ਹੈ. ਹਾਲਾਂਕਿ, ਕਿਸੇ ਇੰਟਰਵਿਊ ਵਿੱਚ ਜਾਣ ਵੇਲੇ ਤੁਹਾਨੂੰ ਕਿਸੇ ਵੀ ਯਾਤਰਾ ਦੇ ਖਰਚੇ ਦੀ ਅਦਾਇਗੀ ਕੀਤੀ ਜਾਵੇਗੀ.

ਹਿੱਸਾ ਲੈਣ ਦੇ ਸੰਭਵ ਨੁਕਸਾਨ ਅਤੇ ਜੋਖਮ ਕੀ ਹਨ?

ਇਹ ਸੰਭਾਵਨਾ ਦੀ ਸੰਭਾਵਨਾ ਨਹੀਂ ਹੈ ਕਿ ਅਧਿਐਨ ਦੇ ਅੰਦਰ ਭਾਗ ਲੈਣ ਦੇ ਕੋਈ ਵੀ ਨੁਕਸਾਨ ਹੋਵੇਗੇ ਅਤੇ ਸਰੀਰਕ ਸਿਹਤ ਲਈ ਕੋਈ ਖਤਰਾ ਨਹੀਂ ਹੋਵੇਗਾ. ਹਾਲਾਂਕਿ, ਜੇਕਰ ਤੁਸੀਂ ਸਰਵੇਖਣ / ਇੰਟਰਵਿਊ ਦੀ ਸਮਗਰੀ ਦੁਆਰਾ ਪਰੇਸ਼ਾਨ ਹੋ ਜਾਂਦੇ ਹੋ ਤਾਂ, ਖੋਜਕਾਰ ਤੁਹਾਨੂੰ ਆਸਾਨੀ ਨਾਲ ਪਹੁੰਚਯੋਗ ਸੇਵਾਵਾਂ ਲਈ ਸਾਈਨ ਇਨ ਕਰ ਸਕਦਾ ਹੈ, ਜਿਵੇਂ ਕਿ ਯੂਕੇ ਦੀਆਂ ਵੱਖ-ਵੱਖ ਸਾਈਟਾਂ ਵਿਚ ਮਾਨਸਿਕ ਸਿਹਤ ਚੈਰਿਟੀ ਸੇਵਾਵਾਂ ਮਨੋਵਿਗਿਆਨਕ ਸਮਰਥਨ ਲਈ ਸਲਾਹ ਪ੍ਰਦਾਨ ਕਰਨਾ. 'ਸਮਾਰਟਨ' ਜਾਂ 'ਸੈਨਲੀਨ' ਜਿਹੀਆਂ ਹੈਲਪਲਾਈਨਾਂ ਰਾਹੀਂ ਮਨੋਵਿਗਿਆਨਕ ਸਹਾਇਤਾ ਮੰਗੀ ਜਾ ਸਕਦੀ ਹੈ ਜੇ ਸੰਕਟ ਸਮੇਂ ਲੋਕਾਂ ਨੂੰ ਟੈਲੀਫੋਨ, ਈਮੇਲ, ਪੱਤਰ ਅਤੇ ਉਨ੍ਹਾਂ ਦੇ ਚਿਹਰੇ ਤੋਂ ਗੁਪਤ ਭਾਵਨਾਤਮਕ ਸਹਾਇਤਾ ਪ੍ਰਦਾਨ ਕਰਨ ਦੀ ਸਹੂਲਤ ਹੈ. ਸਰਵੇਖਣ / ਇੰਟਰਵਿਊ ਦੌਰਾਨ ਪੁੱਛੇ ਗਏ ਕੁਝ ਸਵਾਲਾਂ ਦਾ ਜਵਾਬ ਨਹੀਂ ਦੇਣਾ ਚਾਹੁੰਦੇ ਹੋ ਜਾਂ ਬੇਅਰਾਮ ਮਹਿਸੂਸ ਕਰਦੇ ਹੋ, ਤਾਂ ਇੰਟਰਵਿਊ ਨੂੰ ਰੋਕਿਆ ਜਾ ਸਕਦਾ ਹੈ ਅਤੇ ਕਿਸੇ ਹੋਰ ਤਾਰੀਖ ਅਤੇ ਸਮੇਂ ਨੂੰ ਟਾਲਿਆ ਜਾ ਸਕਦਾ ਹੈ. ਤੁਸੀਂ ਕਿਸੇ ਵੀ ਸਮੇਂ ਵਾਪਿਸ ਲੈਣ ਅਤੇ ਸਰਵੇਖਣ / ਇੰਟਰਵਿਊ ਤੋਂ ਬਾਹਰ ਨਿਕਲਣ ਲਈ ਸੁਤੰਤਰ ਹੋ. ਜਾਣਕਾਰੀ ਦੀ ਗੁਪਤਤਾ ਨੂੰ ਹਰ ਸਮੇਂ ਆਦਰ ਕੀਤਾ ਜਾਵੇਗਾ.

ਹਿੱਸਾ ਲੈਣ ਦੇ ਸੰਭਵ ਲਾਭ ਕੀ ਹਨ?

ਹਿੱਸਾ ਲੈਣ ਤੋਂ ਕੋਈ ਨਿੱਜੀ ਲਾਭ ਨਹੀਂ ਹੈ; ਹਾਲਾਂਕਿ, ਇਹ ਅਧਿਐਨ ਤੁਹਾਡੇ ਅਤੇ ਹੋਰਨਾਂ ਨਸਲੀ ਘੱਟਗਿਣਤੀ ਸਮੂਹਾਂ ਲਈ ਸੱਭਿਆਚਾਰਕ ਤੌਰ ਤੇ ਤਿਆਰ ਕੀਤੀਆਂ ਗਈਆਂ ਦਖਲਅਤਾਂ ਨੂੰ ਸੁਖਾਲਾ ਬਣਾਉਣ ਲਈ ਸਹਾਇਤਾ ਕਰ ਸਕਦਾ ਹੈ. ਤੁਹਾਡੀ ਇੰਪੁੱਟ ਦੀ ਬਹੁਤ ਸ਼ਲਾਘਾ ਕੀਤੀ ਜਾਵੇਗੀ ਅਤੇ ਅਧਿਐਨ ਦੇ ਨਤੀਜਿਆਂ ਵਿੱਚ ਤਬਦੀਲੀਆਂ ਨੂੰ ਸੂਚਿਤ ਕੀਤਾ ਜਾ ਸਕਦਾ ਹੈ. ਤੁਹਾਡੀ ਖੋਜ ਅਤੇ ਦੁਸ਼ੀਆਂ ਦੁਆਰਾ ਟੈਕਸਟ ਮੈਸੇਜਿੰਗ ਵਿੱਚ ਮਦਦ ਕੀਤੇ ਜਾਂਦੇ ਹਨ ਅਤੇ / ਜਾਂ ਦੋਖਭਾਲ ਕਰਨ ਵਾਲਿਆਂ ਨਾਲ ਮਿਲਵਰਤਣ, ਸਥਾਨਕ ਰੋਗੀ ਸਹਾਇਤਾ ਸਮੂਹਾਂ ਦੇ ਨਾਲ ਤਾਲਮੇਲ ਕਰਨ ਅਤੇ ਭਵਿੱਖ ਦੇ ਮਰੀਜ਼ਾਂ ਅਤੇ ਭਾਈਚਾਰੇ ਦੇ ਮੈਂਬਰਾਂ ਦੀ ਸ਼ਮੂਲੀਅਤ ਨੂੰ ਉਤਸ਼ਾਹਿਤ ਕਰੇਗੀ ਜੇ ਸ਼ਾਮਲ ਹੋਣ ਵਿਚ ਦਿਲਚਸਪੀ ਲੈ ਸਕਦੇ ਹਨ.

ਜੇ ਕੋਈ ਸਮੱਸਿਆ ਹੋਵੇ ਤਾਂ?

ਜੇ ਤੁਹਾਨੂੰ ਇਸ ਅਧਿਐਨ ਦੇ ਕਿਸੇ ਵੀ ਪਹਿਲੂ ਬਾਰੇ ਚਿੰਤਾ ਹੈ, ਤਾਂ ਤੁਹਾਨੂੰ ਖੋਜਕਾਰ ਨਾਲ ਗੱਲ ਕਰਨ ਲਈ ਕਹਿਣਾ ਚਾਹੀਦਾ ਹੈ: (ਹੇਠਾਂ ਮਿਸ ਮਿਸਟਰ ਚੌਕੀ ਸੰਪਰਕ ਵੇਰਵੇ) ਜਿਹੜੇ ਤੁਹਾਡੇ ਸਵਾਲਾਂ ਦੇ ਜਵਾਬ ਦੇਣ ਲਈ ਆਪਣੀ ਪੂਰੀ ਕੋਸ਼ਿਸ਼ ਕਰਨਗੇ. ਜੇ ਤੁਸੀਂ ਨਾਖੁਸ਼ ਰਹਿੰਦੇ ਹੋ ਅਤੇ ਰਸਮੀ ਤੌਰ 'ਤੇ ਸ਼ਿਕਾਇਤ ਕਰਨਾ ਚਾਹੁੰਦੇ ਹੋ ਤਾਂ ਤੁਸੀਂ ਖੋਜ ਸੁਪਰਵਾਈਜ਼ਰ (ਪ੍ਰੋਫੈਸਰ ਪੌਲਾ ਐਂਰਮੇਡੀ ਜਾਂ ਡਾ. ਕ੍ਰਿਸਟਿਨਾ ਵੈਸੀਲਿਕਾ, ਹੇਠਾਂ ਸੰਪਰਕ ਵੇਰਵੇ) ਨਾਲ ਸੰਪਰਕ ਕਰਕੇ ਸ਼ਿਕਾਇਤ ਕਰ ਸਕਦੇ ਹੋ. ਹੇਠਾਂ ਨਹੀਂ ਹੋਇਆ ਹੈ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਆਪਣੀਆਂ ਚਿੰਤਾਵਾਂ ਨੂੰ ਪ੍ਰੋਫੈਸਰ ਸੁਸੈਨ ਮੈਕ ਐਂਡ੍ਰੂ, ਹੈਲਥ ਰਿਸਰਚ ਨੈਤਿਕ ਪ੍ਰਵਾਨਗੀ ਪੈਨਲ ਦੀ ਚੇਅਰ, ਕਮਰਾ ਐਮ ਐਸ 1 9 1, ਮੈਰੀ ਸੇਕੇਲ ਬਿਲਡਿੰਗ, ਫਰੈਡਰਿਕ ਰੋਡ ਕੈਂਪਸ, ਸਲਫੋਰਡ ਯੂਨੀਵਰਸਿਟੀ, ਸਲਫੋਰਡ, ਐਮ 6 6 ਪੀ ਯੂ ਨੂੰ ਭੇਜੋ. ਟੈਲੀਫੋਨ: 0161 295 2778. ਈ:

[s.mcandrew@salford.ac.uk](mailto:s.mcandrew@salford.ac.uk)



ਕੀ ਮੇਰੇ ਡੇਟਾ ਨੂੰ ਗੁਪਤ ਰੱਖਿਆ ਜਾਵੇਗਾ?

ਤੁਹਾਡੀ ਛਾਪੱਛ ਦਾ ਅਧਿਐਨ ਪੂਰੇ ਅਧਿਐਨ ਦੌਰਾਨ ਕੀਤਾ ਜਾਵੇਗਾ ਅਤੇ ਜੇ ਜਾਣਕਾਰੀ ਤੁਸੀਂ ਮੁਹੱਈਆ ਕਰਦੇ ਹੋ ਉਹ ਹਰ ਸਮੇਂ ਗੁਪਤ ਰੱਖੀ ਜਾਵੇਗੀ. ਹਾਰਡ ਕਾਪੀ ਪ੍ਰਸ਼ਨਾਵਲੀ ਇਕ ਤਾਲਾਬੰਦ ਦਫਤਰ ਵਿਚ ਇਕ ਤਾਲਾਬੰਦ ਫਾਈਲਿੰਗ ਕੈਬਨਿਟ ਵਿਚ ਸੁਰੱਖਿਅਤ ਰੱਖੀ ਜਾਏਗੀ. ਜਿੰਨੀ ਛੇਤੀ ਸੰਭਵ ਹੋ ਸਕੇ ਪ੍ਰਸ਼ਨਾਵਲੀ ਡੇਟਾ ਨੂੰ ਇੱਕ ਇਲੈਕਟ੍ਰਾਨਿਕ ਡੇਟਾਬੇਸ ਵਿੱਚ ਦਾਖਲ ਕੀਤਾ ਜਾਵੇਗਾ ਅਤੇ ਕਾਗਜ਼ੀ ਪ੍ਰਸ਼ਨਾਵਲੀ ਨੂੰ ਸੁਰੱਖਿਅਤ ਢੰਗ ਨਾਲ ਤਬਾਹ ਕੀਤਾ ਜਾਵੇਗਾ. ਇਸੇ ਤਰ੍ਹਾਂ, ਇੰਟਰਵਿਊ ਦੇ ਬਾਅਦ ਸਿੱਧਾ ਇੰਟਰਵਿਊ ਡਿਜੀਟਲ ਰਿਕਾਰਡਿੰਗ ਨੂੰ ਰਿਕਾਰਡਿੰਗ ਡਿਵਾਈਸ ਤੋਂ ਹਟਾ ਦਿੱਤਾ ਜਾਵੇਗਾ ਅਤੇ ਇੱਕ ਪਾਸਵਰਡ ਸੁਰੱਖਿਅਤ ਕੰਪਿਊਟਰ ਉੱਤੇ ਰੱਖਿਆ ਜਾਵੇਗਾ, ਫਿਰ ਇੱਕ ਖੋਜ ਕੋਡ ਸ਼ਬਦ ਫਾਈਲ ਵਿੱਚ ਟਾਈਪ ਕੀਤਾ ਜਾਵੇਗਾ. ਡੇਟਾ ਅਗਿਆਤ ਹੋ ਜਾਵੇਗਾ ਅਤੇ ਇਕ ਖੋਜ ਕੋਡ ਨਿਰਧਾਰਤ ਕੀਤਾ ਜਾਵੇਗਾ, ਕੋਈ ਵੀ ਇੰਟਰਵਿਊ ਅਤੇ ਪ੍ਰਸ਼ਨਾਵਲੀ ਤੁਹਾਡੇ ਲਈ ਪਛਾਣਿਆ ਨਹੀਂ ਜਾ ਸਕੇਗਾ. ਨਾਂ ਅਤੇ ਖੋਜ ਦੇ ਕੋਡ ਅਤੇ ਖੋਜ ਡੇਟਾ ਫਾਈਲਾਂ ਦੀ ਮਾਸਟਰ ਸੂਚੀ, ਇਕ ਪਾਸਵਰਡ ਸੁਰੱਖਿਅਤ ਕੰਪਿਊਟਰ ਵਿੱਚ ਸਟੋਰ ਕੀਤੀ ਜਾਵੇਗੀ, ਜੋ ਸੇਲਫੋਰਡ ਯੂਨੀਵਰਸਿਟੀ ਦੇ ਅੰਦਰ ਸਿਰਫ ਖੋਜ ਟੀਮ ਲਈ ਜਾਣੀ ਜਾਂਦੀ ਪਾਸਵਰਡ ਹੈ. 5 ਸਾਲਾਂ ਲਈ ਖੋਜ ਤੋਂ ਬਾਅਦ ਤੁਹਾਡੇ ਡਾਟਾ ਨੂੰ ਗੁਪਤ ਰੂਪ ਨਾਲ ਸਾਂਭਣ ਲਈ ਯੂਨੀਵਰਸਿਟੀ ਦੀ ਕਾਨੂੰਨੀ ਜ਼ਿੰਮੇਵਾਰੀ ਹੈ ਤਾਂ ਜਾਣਕਾਰੀ ਨੂੰ ਸੁਰੱਖਿਅਤ ਢੰਗ ਨਾਲ ਤਬਾਹ ਕੀਤਾ ਜਾਵੇਗਾ. ਇਸ ਗੱਲ ਨੂੰ ਯਕੀਨੀ ਬਣਾਉਣ ਲਈ ਲੰਮੇ ਸਮੇਂ ਲਈ ਜਾਣਕਾਰੀ ਰੱਖਣਾ ਮਹੱਤਵਪੂਰਨ ਹੈ ਕਿ ਨਿਯਮਤ ਸੰਸਥਾਵਾਂ ਦੇ ਇਹ ਦੇਖਣ ਲਈ ਮੌਕਾ ਹੈ ਕਿ ਖੋਜ ਰਿਪੋਰਟਿੰਗ ਸਹੀ ਹੈ ਅਤੇ ਅਧਿਐਨ ਨੇ ਸਹੀ ਢੰਗ ਨਾਲ ਕੀਤਾ. ਜੇ ਮੈਂ ਅਧਿਐਨ ਵਿਚ ਹਿੱਸਾ ਨਹੀਂ ਲੈਂਦਾ ਤਾਂ ਕੀ ਹੋਵੇਗਾ?

ਸਾਰੇ ਭਾਗੀਦਾਰ ਇੰਟਰਵਿਊ ਦੌਰਾਨ ਕਿਸੇ ਵੀ ਸਮੇਂ ਵਾਪਿਸ ਲੈਣ ਦੇ ਯੋਗ ਹਨ ਜੇ ਉਹ ਚਾਹੁੰਦੇ ਹਨ, ਪਰ ਉਸ ਸਮੇਂ ਤੱਕ ਇਕੱਤਰ ਕੀਤੀ ਗਈ ਸਾਰੀ ਜਾਣਕਾਰੀ ਦਾ ਅਧਿਐਨ ਵਿਚ ਵਰਤਿਆ ਜਾਵੇਗਾ. ਸਾਰੇ ਖੋਜਕਰਤਾਵਾਂ ਦੇ ਸੰਪਰਕ ਵੇਰਵੇ ਹੇਠਾਂ ਦਿੱਤੇ ਗਏ ਹਨ.

ਖੋਜ ਅਧਿਐਨ ਦੇ ਨਤੀਜਿਆਂ ਦਾ ਕੀ ਹੋਵੇਗਾ?

ਅਧਿਐਨ ਦੇ ਨਤੀਜੇ ਨੈਸ਼ਨਲ ਅਤੇ ਅੰਤਰ-ਰਾਸ਼ਟਰੀ ਰਸਾਲਿਆਂ ਵਿਚ ਨਰਸਿੰਗ ਪ੍ਰੈਕਟਿਸ ਨੂੰ ਪ੍ਰਭਾਵਿਤ ਕਰਨ ਅਤੇ ਤਬਦੀਲ ਕਰਨ ਦੀ ਉਮੀਦ ਵਿਚ ਪ੍ਰਕਾਸ਼ਿਤ ਕੀਤੇ ਜਾਣਗੇ, ਉਸੇ ਤਰ੍ਹਾਂ ਦੇ ਅਨੁਭਵ ਵਾਲੇ ਵਿਅਕਤੀਆਂ ਦੀ ਦੇਖਭਾਲ ਕਰਨ ਵਾਲੇ ਸਮਰਥਕ ਪ੍ਰੈਕਟੀਸ਼ਨਰ. ਜੇ ਤੁਸੀਂ ਦਿਲਚਸਪੀ ਰੱਖਦੇ ਹੋ, ਤਾਂ ਰਿਸਰਚ ਖੋਜ ਦਾ ਸਾਰ ਤੁਹਾਡੇ ਘਰ ਦੇ ਪਤੇ 'ਤੇ ਡਾਕ ਰਾਹੀਂ, ਤੁਹਾਡੇ ਲਈ ਉਪਲਬਧ ਹੋਵੇਗਾ ਅਤੇ ਪ੍ਰਸਾਰਿਤ ਕੀਤਾ ਜਾਵੇਗਾ. ਹਾਲਾਂਕਿ, ਜੇ ਤੁਸੀਂ ਆਪਣੇ ਐਡਰੈੱਸ ਦੇ ਨਤੀਜਿਆਂ ਦਾ ਖੁਲਾਸਾ ਨਹੀਂ ਕਰਨਾ ਚਾਹੁੰਦੇ ਹੋ ਤਾਂ ਤੁਹਾਨੂੰ ਆਪਣੀ ਨਿਯੁਕਤੀ ਤੇ ਤੁਹਾਨੂੰ ਪੇਸ਼ ਕੀਤਾ ਜਾ ਸਕਦਾ ਹੈ, ਅਧਿਐਨ ਪਿੱਛੋਂ.

ਕੌਣ ਖੋਜ ਕਰ ਰਿਹਾ ਹੈ ਜਾਂ ਸਪਾਂਸਰ ਕਰ ਰਿਹਾ ਹੈ?

ਇਹ ਸਟੱਡੀ ਮੇਰੀ ਅਤੇ ਮੇਰੇ ਨਿਰੀਖਕਾਂ ਦੁਆਰਾ ਸਲਫੋਰਡ ਯੂਨੀਵਰਸਿਟੀ ਦੇ ਅੰਦਰੋਂ ਆਯੋਜਿਤ ਕੀਤੀ ਜਾ ਰਹੀ ਹੈ, ਅਸੀਂ ਸੈਂਡਵੈਲ ਅਤੇ ਵੈਸਟ ਬਰਮਿੰਘਮ ਹਸਪਤਾਲ NHS ਟ੍ਰਸਟ ਦੇ FLO ਪ੍ਰਦਾਤਾਵਾਂ ਨਾਲ ਸਹਿਯੋਗ ਕਰ ਰਹੇ ਹਾਂ.

ਹੋਰ ਜਾਣਕਾਰੀ ਅਤੇ ਸੰਪਰਕ ਵੇਰਵੇ:

ਜੇ ਤੁਸੀਂ ਖੋਜ ਵਿਚ ਹਿੱਸਾ ਲੈਣ ਵਿਚ ਦਿਲਚਸਪੀ ਰੱਖਦੇ ਹੋ ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਆਪਣੇ ਨਾਲ ਮਿਥ ਟੈਰੇਮ ਚੌਧਰੀ ਨਾਲ ਸੰਪਰਕ ਕਰੋ - ਈਮੇਲ: [T.Chaudhry@edu.salford.ac.uk](mailto:T.Chaudhry@edu.salford.ac.uk) ਟੈਲੀਫੋਨ: XXXXXXXXXXXXXXXX

ਜਾਂ ਸੰਪਰਕ ਸੁਪਰਵਾਈਜ਼ਰ: ਪ੍ਰੋਫੈਸਰ ਪੌਲਾ ਔਰਮੈਂਡੀ (ਸੁਪਰਵਾਈਜ਼ਰ): [P.Ormandy@salford.ac.uk](mailto:P.Ormandy@salford.ac.uk) ਟੈਲੀਫੋਨ: 0161 295-0453 ਡਾ. ਕ੍ਰਿਸਟਿਨਾ ਵੈਸੀਲਿਕਾ (ਸੁਪਰਵਾਈਜ਼ਰ): [C.M.Vasilica1@salford.ac.uk](mailto:C.M.Vasilica1@salford.ac.uk)

## Appendix 28. Tamil PIS

நோயாளியின் தகவல் தாள்

**ஆய்வின் தலைப்பு:** தென் ஆசிய நோயாளிகளுக்கு சுகாதார நடத்தைகள் மற்றும் தன்னியக்க நிர்வாகம் அதிகரிக்க உரை செய்திகளின் அனுபவங்களைப் பயன்படுத்தி ஆய்வு செய்தல்

ஆராய்ச்சியாளரின் பெயர்: மிஸ் தஹ்ரேம் செளத்ரி  
அழைப்பிதழ்

நான் தற்போது என் PhD க்காக படித்து வருகிறேன், தென்கிழக்கு ஆசிய மக்களிடையே நேர்மறை ஆரோக்கியமான நடத்தைகளை மேம்படுத்துவதற்கும், நீண்ட கால நிபந்தனைகளின் சுய நிர்வகிப்பை மேம்படுத்துவதற்கும், ஆதரவளிப்பதற்கும் பயன்படுகிறது. நீங்கள் பங்கேற்க ஆர்வம் இருந்தால், ஆய்வு பற்றிய மேலும் தகவலுக்கு கீழே விவரங்களை பார்க்கவும்.

ஆய்வின் நோக்கம் என்ன?

இந்த ஆராய்ச்சியின் முக்கிய நோக்கம் நோக்கம் தென் ஆசிய மக்களின் அனுபவங்களை ஆராய்வதோடு, சுகாதார நம்பிக்கை, கலாச்சார மற்றும் மதச் சங்கங்கள் போன்ற காரணிகளை நோயாளி செயல்படுத்தும் மற்றும் உரை செய்தியலில் ஈடுபடுவதா என்பதை ஆராய்வதாகும். இந்த ஆய்வு தலையீட்டைப் பயன்படுத்துவதைப் பற்றி ஒரு சிறந்த புரிந்துணர்வை உருவாக்கும், தலையீடு வழங்குவது மற்றும் நீண்டகால நோய்கள் அல்லது ஒரு சிறுபான்மை குழுவ்குள் உள்ள நிலைமைகளை நிர்வகிப்பதில் ஏற்படும் விளைவுகள் ஆகியவற்றை உருவாக்குவது என்று நான் நம்புகிறேன்.

ஏன் பங்கேற்க அழைக்கப்பட்டேன்?

இந்த ஆராய்ச்சியில் பங்கேற்க நாங்கள் உங்களை அழைக்கிறோம், ஏனென்றால் நீங்கள் தெற்காசிய ஆசிய இனமாக இருப்பதால், நீண்டகால நிலையில் வாழ்கிறோம். நாம் கொண்டிருக்கும் மக்களிடம் பேச விரும்புகிறோம்

- தங்கள் நிலைமையை சுய நிர்வகிக்க உதவ FLO உரை செய்தி அமைப்பு பயன்படுத்தப்படுகிறது
- முன்பு FLO உரை செய்தி முறைமையைப் பயன்படுத்தியுள்ளீர்கள், ஆனால் இனி அதைப் பயன்படுத்துவதில்லை
- அல்லது கணினியைப் பயன்படுத்த விரும்பாத அல்லது விரும்பாத நபர்கள்.

இந்த வெவ்வேறு குழுக்களிடமிருந்து வரும் மக்களுடன் உரையாடுவது, உரை செய்தி பயனுள்ளதாக இருந்தால், யாருக்கு, எப்போது, எப்போது, அல்லது அவர்களின் நோயை நிர்வகிக்க உதவும் பிற வழிகள் உள்ளதா என்பதைப் புரிந்துகொள்ள உதவும்.

நான் பங்கேற்க வேண்டுமா?

நீங்கள் விரும்பவில்லை என்றால் நீங்கள் பங்கேற்க வேண்டாம், உங்கள் ஈடுபாடு தன்னார்வ ஆகிறது. இது உங்களுக்கு இல்லையென்று நீங்கள் தீர்மானித்தால், இது FLO உடன் உங்கள் ஈடுபாட்டை பாதிக்காது அல்லது வேறு எந்த சுகாதார சேவைகளை உங்கள் அணுகல் பாதிக்கும். நீங்கள் பங்கேற்க முடிவு செய்தால், நீங்கள் கையொப்பமிட உங்களுக்கு ஒரு ஒப்புதல் வடிவம் வழங்கப்படும். நீங்கள் பங்கேற்கிறீர்கள் என்றால், நீங்கள் எப்போது வேண்டுமானாலும் திரும்பத் திரும்ப தேர்வு செய்யலாம், இருப்பினும், நீங்கள்

ஏற்கனவே வழங்கிய பணத்தை திரும்பப் பெறும் எந்த தகவலும் ஆராய்ச்சி பகுதியாகப் பயன்படுத்தப்படுகிறது.

நான் பங்கு பெற்றால் எனக்கு என்னவாகும்?

இந்த ஆய்வில் பங்கேற்க நீங்கள் உடன்படுகிறீர்கள் என்றால், நீங்கள் என்ன எதிர்பார்க்கலாம் என்பது பற்றிய சுருக்கம்:

1. ஆராய்ச்சியாளருடன் எந்தவொரு கேள்வியுடனும் கலந்துரையாடுங்கள் மற்றும் ஒப்புதலுக்கான வடிவத்தில் கையெழுத்திடுங்கள்.
2. ஆராய்ச்சியாளர் நேர்காணல் நடக்கும் இடத்திற்கு (உதாரணத்திற்கு, உங்கள் இல்லம் அல்லது ஒரு உள்ளூர் சமூக மையம் அல்லது மருத்துவமனை) உங்களுக்கு வசதியாக இருக்கும் இடத்தைக் கண்டறியவும்.
3. ஒரு மொழிபெயர்ப்பாளருக்கு உங்கள் தேவையைப் பற்றி விவாதிக்கவும், ஒரு திட்டத்தை ஏற்கவும், நீங்கள் கருத்தில் கொள்ளக்கூடிய வேறுபட்ட விருப்பங்கள் உள்ளன. அனைத்து ஆய்வு கேள்வித்தாள்கள் மற்றும் நேர்காணல்கள் பங்கேற்பாளர்களின் விருப்பமான மொழியில் மொழிபெயர்க்கப்படலாம். ஆராய்ச்சியாளர் வெவ்வேறு மொழிகளில் பேசலாம் (XXX) மற்றும் ஆங்கிலம் விரும்பியிருந்தால், சொந்த மொழியில் சில நேர்காணல்களை நடத்த முடியும். நீங்கள் விரும்பியிருந்தால், நீங்கள் புரிந்து கொள்ளாத விஷயத்தில் உங்கள் மொழிபெயர்ப்பாளராக செயல்படுவதன் மூலம் நேர்காணலில் உங்கள் குடும்பத்தினருடன் நீங்கள் கேட்கலாம். உங்களுடன் ஒரு குடும்ப உறுப்பினர் இருக்க விரும்பவில்லை என்றால், ஒரு மாற்று விருப்பம் என்பது வெளிப்புற மொழிபெயர்ப்பாளரைப் பயன்படுத்தி நடத்தப்படும் நேர்காணலை நடத்தலாம் (மருத்துவமனை மொழிகள் மொழி போன்றவை).
4. நீங்கள் முதலில் ஒரு சிறிய கேள்வித்தாளை நிறைவு செய்ய வேண்டும், இது உங்களை சுமார் 10 நிமிடங்கள் எடுத்துக் கொள்ள வேண்டும், நீங்கள் உங்களை எப்படிச் சமாளிப்பது மற்றும் உங்களுடைய வியாதிகளை எவ்வாறு நிர்வகிக்கிறீர்கள் என்பதற்கான கேள்விகளை கேட்க வேண்டும்.
5. கேள்வித்தாள் முடிந்தபிறகு, நேர்காணலில் பங்கேற்க அழைக்கப்படுவீர்கள். இது நோயாளி விருப்பங்களைப் பொறுத்து முகம் நோக்கியோ அல்லது தொலைபேசி மூலமாகவோ நடத்தப்படலாம். இந்த நேர்காணல் நீண்ட கால நிலையில் வாழ்கிற உங்கள் அனுபவங்களைப் பற்றிய கேள்விகளைக் கேட்கும், எப்படி நீங்கள் நிர்வகிக்கிறீர்கள், நீங்கள் எதை ஆதரிக்கிறீர்கள் என்று ஆதரிக்கிறீர்கள். உரை நிலை செய்தி சேவையைப் பயன்படுத்தும் நபர்களுக்கு, இது எவ்வாறு உதவுகிறது அல்லது அவர்களின் நிலைமையை நிர்வகிக்க உதவுவதில்லை என்பதற்கு கூடுதல் கேள்விகள் கேட்கப்படும். அனைத்து பேட்டிகளும் டிஜிட்டல் பதிவு செய்யப்படும்.

செலவுகள் மற்றும் கொடுப்பனவுகள்?

ஆய்வில் உங்கள் ஈடுபாட்டோடு நேரடி கட்டண செலவுகள் இல்லை. எனினும், ஒரு நேர்காணலில் கலந்துகொள்வதற்கு ஏதேனும் பயண செலவுகள் உங்களுக்கு வழங்கப்படும்.

சாத்தியமான தீமைகள் மற்றும் பங்கேற்பின் அபாயங்கள் யாவை?

ஆய்வில் பங்கேற்க எந்தவொரு குறைபாடுகளும் இருப்பதாகத் தெரியவில்லை, உடல் ஆரோக்கியத்திற்கு ஆபத்து இல்லை. எனினும், நீங்கள் கணக்கெடுப்பு / நேர்காணலின் உள்ளடக்கத்தால் துயரமடைந்தால், ஆராய்ச்சியாளர் உங்களை மனநல சுகாதார உதவிக்கான ஆலோசனையை வழங்கும் பல்வேறு தளங்களில் உள்ள மனநல சுகாதார அறக்கட்டளை சேவைகள் போன்ற எளிதில் அணுகக்கூடிய சேவைகளுக்கு கையெழுத்திடலாம். தொலைபேசி, மின்னஞ்சல்கள், கடிதம் மற்றும் முகம் ஆகியவற்றுடன் ரகசியமான உணர்ச்சி

ஆதரவை வழங்கக்கூடிய 'சமாரியர்கள்' அல்லது 'சானலைன்' போன்ற உதவித்தொகையாளர்களிடமிருந்து மனநல ஆதரவு தேவைப்படுகிறது. நீங்கள் கணக்கெடுப்பு / நேர்காணல்கள் அல்லது அசௌகரியமாக உணரக்கூடிய சில கேள்விகளுக்கு பதிலளிக்க விரும்பவில்லை என்றால், பேட்டியை நிறுத்தி மற்றொரு தேதி மற்றும் நேரத்திற்கு தள்ளி வைக்கலாம். எப்போது வேண்டுமானாலும் கணக்கெடுப்பு / நேர்காணலைத் திரும்பப் பெறலாம் மற்றும் வெளியேறலாம். தகவலின் இரகசியத்தன்மை எல்லா நேரங்களிலும் மதிக்கப்படும்.

பங்கு பெறுவதற்கான சாத்தியமான நன்மை என்ன?

பங்குபற்றுவதில் தனிப்பட்ட நன்மைகள் எதுவும் இல்லை; இருப்பினும் இந்த ஆய்வு உங்களுக்கு மற்றும் பிற சிறுபான்மை சிறுபான்மை குழுக்களுக்கு கலாச்சாரரீதியாக ஏற்புடைய தலையீடுகளை எளிதாக்க உதவுகிறது. உங்கள் உள்ளீடு மிகவும் பாராட்டப்பட்டது, மற்றும் ஆய்வுகளின் விளைவானது உங்களுக்கும் மற்றவர்களுக்கும் உரைச் செய்திகளை வழங்குவதில் மாற்றங்களை தெரிவிக்க முடியும்.

உங்கள் பங்கேற்பு, பிற சேவை பயனர்கள் மற்றும் / அல்லது கவனிப்பாளர்களுடன் ஒத்துழைத்து, உள்ளூர் நோயாளி ஆதரவு குழுக்களுடன் தொடர்பு கொள்ளுதல், எதிர்கால நோயாளிகள் மற்றும் சமுதாய உறுப்பினர்களின் பங்கேற்பு ஆகியவற்றுடன் ஈடுபடுவதற்கு ஆர்வமாக உள்ள உங்கள் நோயாளிகளுடன் ஈடுபாடு ஊக்குவிக்கும்.

ஒரு பிரச்சனை என்றால் என்ன?

இந்த ஆய்வின் எந்தவொரு அம்சத்தையும் பற்றி நீங்கள் கவலையைப் பெற்றிருந்தால், ஆராய்ச்சியாளரிடம் பேசுவதற்கு நீங்கள் கேட்க வேண்டும்: (திருமதி. டச் செளத்ரி கீழே உள்ள தொடர்பு விவரங்கள்) உங்கள் கேள்விகளுக்கு பதில் சொல்ல அவர்கள் சிறந்தவர்கள். பேராசிரியர் பவுலா ஓர்மண்டி அல்லது டாக்டர் கிறிஸ்டினா வாஸ்ஸிக்காவைத் தொடர்புகொள்வதன் மூலம் நீங்கள் முறையாக புகார் தெரிவிக்க விரும்பினால், முறையாக புகார் தெரிவிக்க விரும்பினால் நீங்கள் இதை செய்ய முடியும்.

விஷயம் இன்னும் தீர்க்கப்படவில்லை என்றால், பேராசிரியர் சூசன் மெளண்டண்ட்ரு, சுகாதார ஆராய்ச்சி நெறிமுறை ஒப்புதல் குழு, அறை MS1.91, மேரி சீக்கோல் கட்டிடம், ஃப்ரெட்ரிக் ரோடு வளாகம், சால்ஃபோர்டு பல்கலைக்கழகம், சால்ஃபோர்டு, M6 6PU ஆகியோருக்கு உங்கள் கவலையைத் தெரிவிக்கவும். டெல்: 0161 295 2778. மின்: [s.mcandrew@salford.ac.uk](mailto:s.mcandrew@salford.ac.uk)

எனது தரவு இரகசியமாக வைக்கப்படுமா?

ஆய்வின் முடிவில் உங்கள் பெயர் தெரியாது. நீங்கள் வழங்கிய தகவல் எல்லா நேரங்களிலும் இரகசியமாக வைக்கப்படும். கடின பூட்டு கேள்வித்தாள்கள் ஒரு பூட்டிய அலுவலகத்தில் ஒரு பூட்டிய தாக்கல் அமைச்சரவை பாதுகாப்பாக வைக்கப்படும். முடிந்தவரை விரைவில் கேள்வித்தாளை தரவு ஒரு மின்னணு தரவுத்தளத்தில் மற்றும் காகித கேள்விக்குரிய பாதுகாப்பாக அழிக்கப்படும். இதேபோல், நேர்காணல் டிஜிட்டல் பதிவு நேர்காணலுக்குப் பிறகு நேரடியாக பதிவு சாதனத்திலிருந்து அகற்றப்பட்டு, ஒரு கடவுச்சொல் பாதுகாக்கப்பட்ட கணினியில் வைக்கப்படும், பின்னர் ஒரு ஆராய்ச்சி குறியீட்டு சொல் கோப்புக்குள் தட்டச்சு செய்யப்படும்.

உங்கள் தரவு அனமெய்யப்பட்டது மற்றும் ஒரு ஆராய்ச்சி குறியீட்டை ஒதுக்கீடு செய்யப்படும், எந்த நேர்காணல்களும் கேள்வித்தாள்கள் உங்களிடம் அடையாளம் காணப்படாது. பெயர்கள் மற்றும் ஆராய்ச்சி குறியீடுகள் மற்றும் ஆராய்ச்சிக் கோப்புகளின் மாஸ்டர் பட்டியல் கடவுச்சொல் பாதுகாக்கப்பட்ட கணினியில் சேமிக்கப்படும், சால்ஃபோர்டு பல்கலைக்கழகத்தில் உள்ள ஆராய்ச்சி குழுவுக்கு மட்டுமே அறியப்பட்ட கடவுச்சொல். 5 ஆண்டுகளாக

ஆராய்ச்சிக்குப் பின்னர் உங்கள் தரவை இரகசியமாக சேகரிக்க சட்டப்பூர்வ பொறுப்பு உள்ளது, பின்னர் தகவல் பாதுகாப்பாக அழிக்கப்படும். ஆராய்ச்சி அறிக்கைகள் துல்லியமாக இருப்பதை சரிபார்க்க ஒழுங்குமுறை அமைப்புகளுக்காக ஒரு வாய்ப்பாக உள்ளது என்பதை உறுதிப்படுத்த இந்த தகவலை வைத்திருக்க வேண்டியது முக்கியம், மற்றும் ஆய்வு சரியான முறையில் நடத்தப்பட்டது.

நான் படிப்போடு தொடர்ந்தால் என்ன நடக்கும்?

அனைத்து பங்கேற்பாளர்கள் வேண்டுமானால் பேட்டி போது எந்த புள்ளியில் திரும்ப பெற தகுதி, ஆனால் அந்த புள்ளி வரை சேகரிக்கப்பட்ட அனைத்து தரவு ஆய்வு பயன்படுத்தப்படும். அனைத்து ஆராய்ச்சியாளர்களின் தொடர்பு விவரங்கள் கீழே கொடுக்கப்பட்டுள்ளன.

ஆராய்ச்சியின் முடிவுக்கு என்ன நடக்கும்?

ஆய்வு கண்டுபிடிப்புகள் தேசிய மற்றும் சர்வதேச பத்திரிகையில் நர்சிங் நடைமுறையில் செல்வாக்கு மற்றும் மாற்ற நம்பிக்கை, இதே போன்ற அனுபவங்களை தனிநபர்கள் பார்த்து பார்த்து பயிற்சியாளர்கள் ஆதரவு வெளியிடப்படும். நீங்கள் ஆர்வமாக இருந்தால், உங்கள் வீட்டு முகவரிக்குப் பின், ஆராய்ச்சி முடிவுகளை ஒரு சுருக்கம் உங்களுக்குக் கிடைக்கச் செய்து, உங்களுக்கு அனுப்பப்படும். இருப்பினும், நீங்கள் வெளியிட விரும்பாதால், உங்கள் சந்திப்பின் முடிவில், உங்கள் சந்திப்பின் முடிவை நீங்கள் சமர்ப்பிக்கலாம்.

ஆராய்ச்சி ஏற்பாடு செய்வது அல்லது நிதியுதவி யார்?

சல்ஃபோர்டு பல்கலைக்கழகத்தில் உள்ள என் மற்றும் என் மேற்பார்வையாளர்களால் இந்த ஆய்வு ஏற்பாடு செய்யப்பட்டுள்ளது, நாங்கள் சாண்ட்வெல் மற்றும் வெஸ்ட் பர்மிங்காம் மருத்துவமனை NHS அறக்கட்டளையில் FLO வழங்குனர்களுடன் இணைந்து செயல்படுவோம்.

மேலும் தகவல் மற்றும் தொடர்பு விவரங்கள்:

நீங்கள் ஆராய்ச்சிக்கு ஆர்வமாக இருந்தால், திருமதி தஹ்ரேம் செளத்ரி என்னை தொடர்பு கொள்ளவும் -

மின்னஞ்சல்: [T.chaudhry@edu.salford.ac.uk](mailto:T.chaudhry@edu.salford.ac.uk) தொலைபேசி: XXXXXXXXXXXX

அல்லது மேற்பார்வையாளர்களைத் தொடர்புகொள்ளவும்:

பேராசிரியர் பவுலா ஆர்மண்டி

(மேற்பார்வையாளர்): [P.Ormandy@salford.ac.uk](mailto:P.Ormandy@salford.ac.uk) தொலைபேசி: 0161 295-0453

டாக்டர் கிறிஸ்டினா வசிலிகா (மேற்பார்வையாளர்): [C.M.vasilica1@salford.ac.uk](mailto:C.M.vasilica1@salford.ac.uk)

**Appendix 29. Original Consent Form**

## CONSENT FORM

**Title of study:** Exploring the experiences and use of text messages to enhance health behaviours and self-management in South Asian patients

Name of Researcher:

Please complete and sign this form **after** you have read and understood the study information sheet. Read the following statements and select 'Yes' or 'No' in the box on the right-hand side.

1. I confirm that I have read and understand the study information sheet  
Version **4** dated **17/12/2018**, for the above study.  
I have had the opportunity to consider the information and to ask questions  
which have been answered satisfactorily.
  
2. I understand that my participation is voluntary and that I am free to  
withdraw at any time, without giving any reason, and without my rights  
being affected.
  
3. I understand the timeframe for withdrawal, and that if I do decide  
to withdraw, any data and information given, cannot be removed  
once the qualitative analysis has begun.
  
4. I agree to participate in the PAM questionnaire surveys and  
the semi-structured interviews. I understand that all interviews  
will be audio-taped and transcribed verbatim.
  
5. I understand that my personal details will be kept confidential and will not be  
revealed to people outside the research team. However, I am aware that if I  
reveal anything related to criminal activity and/or something that is harmful  
to self or other, the researcher will have to share that information  
with the appropriate authorities.

6. I understand that direct quotes will be used and anonymised appropriately for the researcher’s thesis/research report/ and other academic publications and conferences. Yes/No
7. I agree to obtain a summary of the research results disseminated and sent out to me via post, once the study has been completed. Yes/No
8. I agree to take part in the study. Yes/No

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Name of participant	Date	Signature
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Name of person taking consent	Date	Signature
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### Appendix 30. Urdu Consent Form

مطالعہ کا عنوان: تجربے کی تلاش اور ٹیکسٹ پیغامات کا استعمال جنوبی ایشیا کے مریضوں میں صحت کے رویے اور خود مینجمنٹ بڑھانے کے لئے

محقق کا نام:

مطالعہ کی معلومات کے شیٹ پڑھنے اور سمجھنے کے بعد براہ کرم اس فارم کو مکمل کریں اور دستخط کریں. مندرجہ ذیل بیانات پڑھیں اور باکس میں 'ہاں' یا 'نہیں' کو منتخب کریں

نہیں/ جی ہاں

میں اس بات کی تصدیق کرتا ہوں کہ میں نے مطالعہ کی معلومات کا شیٹ پڑھا اور سمجھا ہے

مندرجہ ذیل مطالعہ کے لئے، ورژن 4، 17/12/2018 کی حیثیت سے

نہیں/ جی ہاں

میرے پاس معلومات پر غور کرنے اور سوال پوچھنا کرنے کا موقع ملا ہے

جس کو تسلی بخش جواب دیا گیا ہے

نہیں/ جی ہاں

میں سمجھتا ہوں کہ میری شراکت رضاکارانہ ہے اور میں آزاد ہوں

کسی بھی وقت، کسی بھی وجہ سے، اور میرے حقوق کے بغیر کسی بھی وقت واپس لے لو

متاثر ہو رہا ہے

نہیں/ جی

واپسی کے لئے ٹائم فریم کو سمجھتا ہوں، اور اگر میں واپس لینے کا فیصلہ کروں تو، اس کے بعد کسی بھی ڈیٹا اور معلومات کو ہٹا دیا جاسکتا ہے

نہیں/ جی

میں سوالنامہ کے سروے میں حصہ لینے کے لئے اتفاق کرتا ہوں اور

نہیں/ جی ہاں

نیم ساختہ انٹرویو میں سمجھتا ہوں کہ تمام انٹرویو آڈیو ٹائپ ہو جائیں گے اور فعالیت میں ترمیم کریں گے

میں سمجھتا ہوں کہ میرا ذاتی تفصیلات خفیہ رکھا جائے گا اور تحقیقاتی ٹیم کے باہر لوگوں کو انکشاف نہیں کیا جائے گا. تاہم میں جانتا ہوں کہ اگر میں مجرمانہ سرگرمی اور /یا کسی چیز سے متعلق کسی چیز کو ظاہر کرتا ہوں جو خود یا دوسرے سے نقصان دہ ہے تو، محققین کو اس معلومات کو مناسب حکام کے ساتھ اشتراک کرنا ہوگا

نہیں/ جی

میں سمجھتا ہوں کہ براہ راست حوالہ جات استعمال کیا جائے گا اور محققین کو تحقیق یافتہ رپورٹ /تحقیق کی رپورٹ /اور دیگر تعلیمی اشاعتوں اور کانفرنسوں کے لئے مناسب طور پر نامزد کیا جائے گا

نہیں/ جی

میں تحقیقی طور پر مکمل ہونے والی تحقیقی نتائج کا ایک خلاصہ حاصل کرنے پر اتفاق کرتا ہوں اور مطالعہ مکمل ہوجاتا ہے، پوسٹ کے ذریعے مجھ پر بھیجا جاتا ہے

نہیں/ جی ہاں

میں مطالعہ میں حصہ لینے پر اتفاق کرتا ہوں

نہیں/ جی ہاں

شرکاء کا نام

تاریخ

دستخط

رضامند ہونے والے شخص کا نام



### Appendix 31. Gujarati Consent Form

#### સંમતિ ફોર્મ

અભ્યાસનું શીર્ષક: દક્ષિણ એશિયન દર્દીઓમાં સ્વાસ્થ્ય વર્તન અને સ્વ-વ્યવસ્થાપન વધારવા માટે અનુભવો અને ટેકસ્ટ સંદેશાઓનો ઉપયોગ

સંશોધકનું નામ:

કૃપા કરીને અભ્યાસ માહિતી શીટ વાંચી અને સમજ્યા પછી આ ફોર્મને પૂર્ણ કરો અને સહી કરો. નીચેના નિવેદનો વાંચો અને જમણી બાજુના બોક્સમાં 'હા' અથવા 'ના' પસંદ કરો

1. હું પુષ્ટિ કરું છું કે મેં અભ્યાસ માહિતી શીટ વાંચી અને સમજી લીધી છે ઉપરોક્ત અભ્યાસ માટે, આવૃત્તિ 4, તારીખ 17/12/2018. મારી પાસે માહિતીને ધ્યાનમાં લેવા અને પ્રશ્નો પૂછવાની તક મળી છે જેનો સંતોષકારક જવાબ આપવામાં આવ્યો છે. હા/ ના
2. હું સમજું છું કે મારી ભાગીદારી સ્વૈચ્છિક છે અને હું કોઈ પણ કારણ વિના, અને મારા અધિકારો વિના, કોઈપણ સમયે પાછા જવા માટે મફત છું અસર થઈ રહી છે. હા/ ના
3. હું પાછો ખેંચવાની સમયસમાપ્તિ સમજું છું, અને જો હું પાછો લેવાનું નક્કી કરું છું, તો કોઈ પણ ડેટા અને માહિતી આપવામાં આવે છે, ગુણાત્મક વિશ્લેષણ શરૂ થઈ જાય તે પછી દૂર કરી શકાતું નથી હા/ ના
4. હું પીએમ પ્રશ્નાવલિ સર્વેક્ષણો અને અર્ધ-માળખાકીય ઇન્ટરવ્યુમાં ભાગ લેવા સંમત છું. હું સમજું છું કે બધા ઇન્ટરવ્યુ ઓડિઓ ટેપ અને ટ્રાંસ્ક્રાઇબ કરેલ શબ્દશ: હશે. હા/ ના
5. હું સમજું છું કે મારી અંગત વિગતો ગોપનીય રાખવામાં આવશે અને સંશોધન ટીમની બહારના લોકો માટે જાહેર કરવામાં આવશે નહીં. જો કે, હું જાણું છું કે જો હું ફોજદારી પ્રવૃત્તિ અને / અથવા કંઈક કે જે સ્વ અથવા અન્યને હાનિકારક છે તેનાથી સંબંધિત કંઈપણ જાહેર કરું છું, તો સંશોધકને તે અધિકારીઓને યોગ્ય અધિકારીઓ સાથે શેર કરવી પડશે. હા/ ના
6. હું સમજું છું કે ડાયરેક્ટ ક્વોટ્સનો ઉપયોગ કરવામાં આવશે અને સંશોધકની થીસીસ / સંશોધન રિપોર્ટ / અને અન્ય શૈક્ષણિક પ્રકાશનો અને પરિષદો માટે યોગ્ય રીતે અનામિત કરવામાં આવશે. હા/ ના
7. એકવાર અભ્યાસ પૂર્ણ થઈ જાય તે પછી, હું પ્રસારિત થયેલા સંશોધન પરિણામોનો સારાંશ મેળવવા અને પોસ્ટ દ્વારા મને મોકલવા માટે સંમત છું. હા/ ના
8. હું અભ્યાસમાં ભાગ લેવા માટે સંમત છું: હા/ ના

સહભાગીનું નામ	તારીખ	હસ્તાક્ષર
સંમતિ લેતા વ્યક્તિનું નામ	તારીખ	હસ્તાક્ષર

## Appendix 32. Hindi Consent Form

### सहमति पत्र

अध्ययन का शीर्षक: दक्षिण एशियाई रोगियों में स्वास्थ्य व्यवहार और आत्म-प्रबंधन को बढ़ाने के लिए पाठ संदेशों के अनुभवों और उपयोग की खोज

शोधकर्ता का नाम:

अध्ययन सूचना पत्र को पढ़ने और समझने के बाद कृपया इस फॉर्म को पूरा करें और उस पर हस्ताक्षर करें। निम्नलिखित कथनों को पढ़ें और दाईं ओर के बॉक्स में 'हां' या 'नहीं' का चयन करें।

1. मैं पुष्टि करता हूँ कि मैंने अध्ययन सूचना पत्र को पढ़ा और समझा है संस्करण 4 और दिनांक 17/12/2018, उपरोक्त अध्ययन के लिए। मुझे जानकारी पर विचार करने और सवाल पूछने का अवसर मिला है जिसका उत्तर संतोषजनक ढंग से दिया गया है।

हाँ / नहीं

2. मैं समझता हूँ कि मेरी भागीदारी स्वैच्छिक है और मैं इसके लिए स्वतंत्र हूँ बिना किसी कारण के, और मेरे अधिकारों के बिना किसी भी समय वापस प्रभावित हो रहा है।

हाँ / नहीं

3. मैं वापसी के लिए समय सीमा को समझता हूँ, और यदि मैं वापस लेने का फैसला, गुणात्मक विश्लेषण शुरू होने के बाद दिए गए किसी भी डेटा और जानकारी को हटाया नहीं जा सकता।

हाँ / नहीं

4. मैं PAM प्रश्नावली सर्वेक्षणों में भाग लेने के लिए सहमत हूँ और अर्द्ध संरचित साक्षात्कार। मैं समझता हूँ कि सभी साक्षात्कार ऑडियो-टेप और ट्रांसक्रिप्ट किया हुआ शब्दशः होगा।

हाँ / नहीं

5. मैं समझता हूँ कि मेरे व्यक्तिगत विवरण को गोपनीय रखा जाएगा और नहीं होगा अनुसंधान टीम के बाहर लोगों को पता चला। हालाँकि, मुझे पता है कि अगर मैं आपराधिक गतिविधि और / या ऐसी किसी भी चीज़ को प्रकट करता हूँ जो स्वयं या अन्य के लिए हानिकारक है, तो शोधकर्ता को उचित अधिकारियों के साथ उस जानकारी को साझा करना होगा

हाँ / नहीं

6. मैं समझता हूँ कि शोधकर्ता की थीसिस के लिए प्रत्यक्ष उद्धरणों का उपयोग और अनाम रूप से उपयोग किया जाएगा / अनुसंधान रिपोर्ट / और अन्य अकादमिक प्रकाशन और सम्मेलन।

हाँ / नहीं

7. मैं एक बार अध्ययन पूरा होने के बाद प्रसारित किए गए शोध परिणामों का एक सारांश प्राप्त करने के लिए सहमत हूँ और मुझे पोस्ट के माध्यम से भेजा गया है।

हाँ / नहीं

हाँ / नहीं

8. मैं अध्ययन में भाग लेने के लिए सहमत हूँ:

प्रतिभागी का नाम	दिनांक	हस्ताक्षर
सहमति लेने वाले व्यक्ति का नाम	दिनांक	हस्ताक्षर

### Appendix 33. Bengali Consent Form

#### অনুমতি ফর্ম

গবেষণা শিরোনাম: দক্ষিণ এশিয়ার রোগীদের স্বাস্থ্য আচরণ এবং স্ব-ব্যবস্থাপনা উন্নত করার জন্য পাঠ্য বার্তাগুলির অভিজ্ঞতা এবং ব্যবহার অনুসন্ধান

আপনি পড়া তথ্য শীট পড়া এবং বোঝার পরে এই ফর্মটি পূরণ করুন এবং সাইন ইন করুন। নিচের বিবৃতিটি পড়ুন এবং ডান দিকের বাক্সে 'হ্যাঁ' বা 'না' নির্বাচন করুন।

1. আমি নিশ্চিত যে আমি পড়াশোনা তথ্য শীট পড়েছি এবং বুঝি উপরের অধ্যয়নের জন্য সংস্করণ 4 তারিখ 17/12/2018 তারিখ। আমি তথ্য বিবেচনা এবং প্রশ্ন জিজ্ঞাসা করার সুযোগ আছে যা সন্তোষজনকভাবে উত্তর দেওয়া হয়েছে।

হ্যাঁ / না

2. আমার অংশগ্রহণ স্বেচ্ছাসেবক এবং যে আমি বিনামূল্যে জন্য বুঝতে কোনো কারণে, এবং আমার অধিকার ছাড়া, কোনো সময় প্রত্যাহার প্রভাবিত হচ্ছে।

হ্যাঁ / না

3. আমি প্রত্যাহারের জন্য সময়সীমা বুঝতে, এবং যে আমি যদি সিদ্ধান্ত না গুণগত বিশ্লেষণ শুরু হওয়ার পরে, যে কোন তথ্য এবং তথ্য দেওয়া, সরানো যাবে না।

হ্যাঁ / না

4. আমি PAM প্রশ্নাবলী সার্ভে এবং আধা-কাঠামোগত সাক্ষাত্কারে অংশগ্রহণের জন্য সম্মত। আমি বুঝতে পারি যে সমস্ত সাক্ষাত্কার অডিও-টেপ এবং প্রতিলিপিয়ুক্ত শব্দ হবে।

হ্যাঁ / না

5. আমি বুঝি যে আমার ব্যক্তিগত বিবরণ গোপন রাখা হবে এবং হবে না গবেষণা দলের বাইরে মানুষের প্রকাশ। যাইহোক, আমি সচেতন যে যদি আমি অপরাধমূলক ক্রিয়াকলাপ এবং অথবা নিজের বা অন্যকে ক্ষতিকারক কিছু সম্পর্কিত কিছু প্রকাশ করি, তাহলে গবেষককে যথাযথ কর্তৃপক্ষের সাথে সেই তথ্য ভাগ করতে হবে।

হ্যাঁ / না

6. আমি সরাসরি কোট ব্যবহার করা হবে এবং উপযুক্তভাবে anonymous গবেষক এর থিসিস / গবেষণা রিপোর্ট / এবং অন্যান্য একাডেমিক প্রকাশনা এবং সম্মেলন জন্য।

হ্যাঁ / না

7. আমি প্রচারিত গবেষণা ফলাফল সংক্ষিপ্তসার এবং পেতে সম্মত পোস্টের মাধ্যমে আমাকে পাঠানো হয়েছে, একবার গবেষণা সম্পন্ন হয়েছে।

হ্যাঁ / না

8. আমি অধ্যয়ন অংশ নিতে সম্মত হন:

হ্যাঁ / না

অংশগ্রহণকারীর নাম	তারিখ	স্বাক্ষর
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ব্যক্তির নাম সম্মতি গ্রহণ

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তারিখ

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স্বাক্ষর

### Appendix 34. Punjabi Consent Form

#### ਮਨਜ਼ੂਰੀ ਫਾਰਮ

ਅਧਿਐਨ ਦਾ ਸਿਰਲੇਖ: ਦੱਖਣੀ ਏਸ਼ੀਆਈ ਮਰੀਜ਼ਾਂ ਵਿਚ ਸਿਹਤ ਸੰਬੰਧੀ ਵਿਵਹਾਰ ਅਤੇ ਸਵੈ-ਪ੍ਰਬੰਧਨ ਨੂੰ ਵਧਾਉਣ ਲਈ ਤਜਰਬਿਆਂ ਦੀ ਜਾਣਕਾਰੀ ਅਤੇ ਟੈਕਸਟ ਮੈਸੇਜਾਂ ਦੀ ਵਰਤੋਂ ਕਰਨਾ

ਖੋਜਕਰਤਾ ਦਾ ਨਾਮ:

ਕਿਰਪਾ ਕਰਕੇ ਅਧਿਐਨ ਜਾਣਕਾਰੀ ਸ਼ੀਟ ਨੂੰ ਪੜ੍ਹ ਅਤੇ ਸਮਝਣ ਤੋਂ ਬਾਅਦ ਇਸ ਫਾਰਮ ਨੂੰ ਪੂਰਾ ਕਰੋ ਅਤੇ ਇਸ 'ਤੇ ਦਸਤਖਤ ਕਰੋ। ਹੇਠ ਲਿਖੇ ਸਟੇਟਮੈਂਟ ਪੜ੍ਹੋ ਅਤੇ ਸੱਜੇ ਪਾਸੇ ਵਾਲੇ ਖਾਨੇ ਵਿੱਚ 'ਹਾਂ' ਜਾਂ 'ਨਹੀਂ' ਚੁਣੋ।

1. ਮੈਂ ਪੁਸ਼ਟੀ ਕਰਦਾ ਹਾਂ ਕਿ ਮੈਂ ਅਧਿਐਨ ਜਾਣਕਾਰੀ ਸ਼ੀਟ ਪੜ੍ਹ ਅਤੇ ਸਮਝ ਲਿਆ ਹੈ ਉਪਰੋਕਤ ਅਧਿਐਨ ਲਈ ਸੰਸਕਰਣ 4 dated 17/12/2018 ਮੈਨੂੰ ਜਾਣਕਾਰੀ ਤੇ ਵਿਚਾਰ ਕਰਨ ਅਤੇ ਪ੍ਰਸ਼ਨ ਪੁੱਛਣ ਦਾ ਮੌਕਾ ਮਿਲਿਆ ਹੈ ਜਿਸ ਦਾ ਜਵਾਬ ਤਸੱਲੀਪੂਰਵਕ ਜਵਾਬ ਦਿੱਤਾ ਗਿਆ ਹੈ।  ਹਾਂ / ਨਹੀਂ

2. ਮੈਂ ਸਮਝਦਾ / ਸਮਝਦੀ ਹਾਂ ਕਿ ਮੇਰੀ ਭਾਗੀਦਾਰੀ ਸਵੈ-ਇੱਛਤ ਹੈ ਅਤੇ ਮੈਂ ਮੁਫਤ ਹਾਂ ਕਿਸੇ ਵੀ ਸਮੇਂ ਬਿਨਾਂ ਕਿਸੇ ਕਾਰਨ ਕਰਕੇ ਅਤੇ ਮੇਰੇ ਅਧਿਕਾਰਾਂ ਦੇ ਬਿਨਾਂ ਕਿਸੇ ਵੀ ਸਮੇਂ ਵਾਪਿਸ ਲੈਣਾ ਪ੍ਰਭਾਵਿਤ ਹੋਣਾ  ਹਾਂ / ਨਹੀਂ

3. ਮੈਂ ਕਢਵਾਉਣ ਦੀ ਸਮਾਂ ਸੀਮਾ ਸਮਝਦਾ ਹਾਂ, ਅਤੇ ਜੇ ਮੈਂ ਵਾਪਸ ਲੈਣ ਦਾ ਫੈਸਲਾ ਕਰਦਾ ਹਾਂ, ਕੋਈ ਵੀ ਡਾਟਾ ਅਤੇ ਜਾਣਕਾਰੀ ਦਿੱਤੀ ਜਾਂਦੀ ਹੈ, ਜਦੋਂ ਗੁਣਾਤਮਕ ਵਿਸ਼ਲੇਸ਼ਣ ਸ਼ੁਰੂ ਹੋ ਜਾਣ ਤੋਂ ਬਾਅਦ ਇਸ ਨੂੰ ਹਟਾਇਆ ਨਹੀਂ ਜਾ ਸਕਦਾ  ਹਾਂ / ਨਹੀਂ

4. ਮੈਂ PAM ਪ੍ਰਸ਼ਨਮਾਲਾ ਸਰਵੇਖਣਾਂ ਅਤੇ ਅਰਧ-ਢਾਂਚੇ ਇੰਟਰਵਿਊਆਂ ਵਿੱਚ ਹਿੱਸਾ ਲੈਣ ਲਈ ਸਹਿਮਤ ਹਾਂ। ਮੈਂ ਸਮਝਦਾ ਹਾਂ ਕਿ ਸਾਰੇ ਇੰਟਰਵਿਊਆਂ ਆਡੀਓ-ਟੈਪ ਅਤੇ ਟ੍ਰਾਂਸਿੱਟ ਕੀਤੇ ਵਰਬੈਟਿਮ ਹੋਵੇਗਾ।  ਹਾਂ / ਨਹੀਂ

5. ਮੈਂ ਸਮਝਦਾ / ਸਮਝਦੀ ਹਾਂ ਕਿ ਮੇਰੇ ਨਿੱਜੀ ਵੇਰਵੇ ਗੁਪਤ ਰੱਖੇ ਜਾਣਗੇ ਅਤੇ ਨਹੀਂ ਹੋਣਗੇ ਖੋਜ ਟੀਮ ਦੇ ਬਾਹਰਲੇ ਲੋਕਾਂ ਨੂੰ ਪ੍ਰਗਟ ਕੀਤਾ। ਹਾਲਾਂਕਿ, ਮੈਂ ਜਾਣਦੀ ਹਾਂ ਕਿ ਜੇ ਮੈਂ ਅਪਰਾਧਕ ਗਤੀਵਿਧੀਆਂ ਅਤੇ / ਜਾਂ ਕਿਸੇ ਚੀਜ਼ ਜਾਂ ਕਿਸੇ ਹੋਰ ਚੀਜ਼ ਲਈ ਹਾਨੀਕਾਰਕ ਹੈ, ਤਾਂ ਖੋਜਕਰਤਾ ਨੂੰ ਇਹ ਜਾਣਕਾਰੀ ਉਚਿਤ ਅਧਿਕਾਰੀਆਂ ਨਾਲ ਸਾਂਝੀ ਕਰਨੀ ਹੋਵੇਗੀ  ਹਾਂ / ਨਹੀਂ

6. ਮੈਂ ਸਮਝਦਾ / ਸਮਝਦੀ ਹਾਂ ਕਿ ਸਿੱਧਾ ਹਵਾਲਾ ਵਰਤਿਆ ਜਾਦਾ ਹੈ ਅਤੇ ਖੋਜਕਰਤਾ ਦੇ ਸਿਧਾਂਤ ਖੋਜ ਰਿਪੋਰਟ / ਅਤੇ ਹੋਰ ਅਕਾਦਮਿਕ ਪ੍ਰਕਾਸ਼ਨਾਂ ਅਤੇ ਕਾਨਫਰੰਸਾਂ ਲਈ ਉਚਿਤ ਤੌਰ ਤੇ ਨਾਮਨਜ਼ੂਰ ਕੀਤਾ ਗਿਆ ਹੈ।  ਹਾਂ / ਨਹੀਂ

7. ਅਧਿਐਨ ਮੁਕੰਮਲ ਹੋਣ ਤੋਂ ਬਾਅਦ ਮੈਂ ਪ੍ਰਸਾਰਿਤ ਖੋਜ ਨਤੀਜਿਆਂ ਦਾ ਸਾਰਾਂਸ਼ ਪ੍ਰਾਪਤ ਕਰਨ ਅਤੇ ਡਾਕ ਰਾਹੀਂ ਮੇਰੇ ਲਈ ਭੇਜਣ ਲਈ ਸਹਿਮਤ ਹਾਂ।  ਹਾਂ / ਨਹੀਂ

8. ਮੈਂ ਅਧਿਐਨ ਵਿਚ ਹਿੱਸਾ ਲੈਣ ਲਈ ਸਹਿਮਤ ਹਾਂ:  ਹਾਂ / ਨਹੀਂ

ਭਾਗੀਦਾਰ ਦਾ ਨਾਮ

ਤਾਰੀਖ

ਦਸਤਖਤ

**Appendix 35. Tamil Consent Form**

ஒப்புமை படிவம்

**ஆய்வின் தலைப்பு:** தென் ஆசிய நோயாளிகளுக்கு சுகாதார நடத்தைகள் மற்றும் தன்னியக்க நிர்வாகம் அதிகரிக்க உரை செய்திகளின் அனுபவங்களைப் பயன்படுத்தி ஆய்வு செய்தல்

ஆராய்ச்சியாளர் பெயர்:

படிப்புத் தகவல் தாள் படித்து புரிந்து கொண்ட பின்னர் இந்த படிவத்தை பூர்த்தி செய்து கையொப்பமிட வேண்டும். பின்வரும் அறிக்கைகளைப் படிக்கவும், வலது பக்கத்தில் உள்ள 'ஆம்' அல்லது 'இல்லை' என்பதை தேர்வு செய்யவும்

1. படிப்பு தகவல் தாள் படித்து புரிந்து கொண்டேன் என்று உறுதிப்படுத்துகிறேன்

ஆம்/  
இல்லை

இந்த ஆய்வுக்கு 17/12/2018 தேதியிட்ட பதிப்பு 4. தகவலைப் பரிசீலிக்கவும் கேள்விகளைக் கேட்கவும் எனக்கு வாய்ப்பு கிடைத்தது அவை திருப்திகரமாக பதிலளிக்கப்பட்டுள்ளன.

2. என் பங்களிப்பு தன்னார்வ மற்றும் நான் சுதந்திரமாக இருக்கிறேன் என்று புரிந்துகொள்கிறேன் எப்போது

ஆம்/  
இல்லை

வேண்டுமானாலும், எந்த காரணமும் இல்லாமல், என் உரிமை இல்லாமல், பின்வாங்கவும் பாதிக்கப்பட்டிருக்கிறார்கள்.

3. திரும்பப் பெறும் காலத்தை நான் புரிந்துகொள்கிறேன், திரும்பப் பெற முடிவு செய்தால், எந்த தரவுகளும் தகவலும் வழங்கப்பட்டால், குஜராத் பகுப்பாய்வு தொடங்கப்பட்டவுடன் அகற்ற முடியாது.

ஆம்/  
இல்லை

4. PAM கேள்வித்தாள் ஆய்வுகள் மற்றும் அரை கட்ட மைக்கப்பட்ட நேர்காணல்களில் பங்கேற்க நான் ஒப்புக்கொள்கிறேன். நான் எல்லா நேர்காணல்களையும் புரிந்துகொள்கிறேன் ஆடியோ டாப் மற்றும் டிரான்ஸ்மிஷன் செய்யப்பட்ட விர்பாடிம் இருக்கும்.

ஆம்/  
இல்லை

5. எனது தனிப்பட்ட விவரங்கள் இரகசியமாக வைக்கப்பட்டு இருப்பதாக நான் அறிகிறேன் ஆராய்ச்சிக் குழுவிற்கு வெளியே உள்ளவர்களுக்கு வெளிப்படுத்தப்பட்டது. இருப்பினும், குற்றம் சார்ந்த செயல்கள் மற்றும் / அல்லது சுயநலத்திற்காக அல்லது பிறருக்கு தீங்கு விளைவிக்கும் ஏதாவது ஒன்றை நான் வெளிப்படுத்தினால், அந்த தகவலை பொருத்தமான அதிகாரிகளுடன் பகிர்ந்து கொள்ள வேண்டும் என்று எனக்குத் தெரியும்.

ஆம்/  
இல்லை

6. நேரடி மேற்கோள்கள் பயன்படுத்தப்படும் மற்றும் anonymised சரியான என்று நான் புரிந்துகொள்கிறேன் ஆராய்ச்சியாளர் ஆய்வறிக்கை / ஆராய்ச்சி அறிக்கை / மற்றும் பிற கல்வி வெளியீடுகள் மற்றும் மாநாடுகள் ஆகியவற்றிற்காக.

ஆம்/  
இல்லை

ஆம்/  
இல்லை

7. படிப்பு முடிந்ததும், இடுப்பு வழியாக என்னை அனுப்பிய ஆராய்ச்சி முடிவுகளின் சுருக்கத்தை நான் ஏற்றுக்கொள்கிறேன்.

8. ஆய்வில் பங்கேற்க நான் ஒப்புக்கொள்கிறேன்

ஆம்/ இல்லை
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பங்கேற்பாளரின் பெயர்

\_\_\_\_\_

தேதி

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கையொப்பம்

\_\_\_\_\_

அனுமதியின்றி எடுக்கப்பட்ட  
பெயர்

\_\_\_\_\_

தேதி

\_\_\_\_\_

கையொப்பம்

**Appendix 36. Table 20. Demographic Capture Sheet**

<b>Participant ID</b>	<b>Age</b>	<b>Gender</b>	<b>Ethnicity</b>	<b>Religion</b>	<b>Education Levels</b>	<b>Employment Status</b>	<b>Socioeconomic Status</b>	<b>Modality (Type of LTC)</b>	<b>Patient Activation Level</b>
U1	33	Male	Indian	Hindu	University	Employed	Professional	Diabetes, Hypertension	Level 4
U2	44	Male	Pakistani	Muslim	University	Employed	Admin	Diabetes, Hypertension	Level 4
U3	38	Female	Indian	Sikh	Secondary	Employed	Professional	Diabetes, Hypertension	Level 4
U4	37	Male	Indian	Sikh	University	Employed	Professional	Diabetes, Hypertension	Level 4
U5	75	Male	Indian	Sikh	University	Retired	Retired	Diabetes, Hypertension	Level 4
U6	42	Female	Indian	Sikh	Secondary	Employed	Admin	Diabetes	Level 4
U7	33	Female	Indian	Sikh	University	Employed	Professional	Diabetes, Hypertension, CKD	Level 4
U8	32	Male	Indian	No religion	University	Employed	Professional	Diabetes, Hypertension	Level 4
U9	28	Male	Pakistani	Muslim	University	Employed	Professional	Diabetes	Level 4
U10	76	Female	Indian	Hindu	Primary	Unemployed	Unemployed	Diabetes, Hypertension, CKD	Level 2
U11	73	Female	Bengali	Muslim	Primary	Unemployed	Unemployed	Diabetes, Hypertension, Hypothyroidism	Level 1
U12	39	Male	Pakistani	Muslim	University	Employed	Professional	Diabetes, Hypertension	Level 3
U13	58	Female	Pakistani	Muslim	University	Unemployed	Unemployed	Diabetes, Hypertension, CKD	Level 3
U14	44	Female	Indian	Christian	Secondary	Employed	Professional	Diabetes, Hypertension	Level 4
U15	33	Female	Indian	Sikh	Secondary	Employed	Professional	Diabetes, Hypertension	Level 4
U16	38	Female	Indian	Sikh	Secondary	Employed	Admin	Diabetes, Hypertension, CKD	Level 4
U17	55	Female	Pakistani	Muslim	Secondary	Unemployed	Unemployed	Diabetes, Hypertension	Level 1
U18	35	Female	Indian	Hindu	University	Employed	Professional	Diabetes	Level 4
U19	25	Female	Pakistani	Muslim	University	Employed	Admin	Diabetes	Level 4
U20	48	Male	Pakistani	Muslim	Secondary	Employed	Machine operative	Diabetes, Hypertension, CKD	Level 4
NU1	67	Female	Indian	Sikh	Primary	Unemployed	Unemployed	Diabetes, Hypertension	Level 1
NU2	77	Male	Pakistani	Muslim	Secondary	Retired	Unemployed	Diabetes, Hypertension, CKD	Level 1
NU3	70	Female	Indian	Sikh	Primary	Unemployed	Unemployed	Diabetes, Hypertension, CKD	Level 1



NU4	37	Female	Indian	Hindu	Secondary	Unemployed	Unemployed	Diabetes	Level 1
NU5	46	Female	Pakistani	Muslim	Secondary	Unemployed	Unemployed	Diabetes, Hypertension	Level 3
NU6	53	Female	Indian	Sikh	Primary	Unemployed	Unemployed	Diabetes, Hypertension	Level 3
NU7*	42	Male	Indian	Sikh	University	Employed	Professional	Diabetes, Hypertension, CKD	Level 3
NU8*	48	Female	Pakistani	Muslim	University	Employed	Professional	Diabetes, Hypothyroidism	Level 4
NU9*	67	Male	Indian	Sikh	Secondary	Employed	Machine Operative	Diabetes, Hypertension, CKD	Level 3
NU10	65	Male	Pakistani	Muslim	Secondary	Employed	Machine Operative	Diabetes, Hypertension	Level 1
NU11	55	Male	Indian	Sikh	Secondary	Employed	Professional	Diabetes, Hypertension	Level 1
NU12*	40	Male	Pakistani	Muslim	Secondary	Employed	Professional	Diabetes	Level 2
NU13	69	Female	Indian	Sikh	Primary	Employed	Machine Operative	Diabetes, Hypertension, CKD	Level 1
NU14	70	Male	Indian	Sikh	Secondary	Retired	Retired	Diabetes, Hypertension	Level 1
NU15	80	Male	Indian	Sikh	Primary	Retired	Retired	Diabetes, Hypertension	Level 2
NU16	60	Female	Pakistani	Muslim	Primary	Unemployed	Unemployed	Diabetes, Hypertension	Level 3
NU17	58	Male	Pakistani	Muslim	Secondary	Employed	Admin	Diabetes, Hypertension, CKD	Level 1
NU18	70	Male	Pakistani	Muslim	Primary	Retired	Retired	Diabetes, Hypertension	Level 2
NU19	38	Female	Indian	Hindu	University	Employed	Professional	Diabetes	Level 2
NU20 *	73	Male	Bengali	Muslim	University	Retired	Retired	Diabetes, Hypertension, CKD	Level 2

\*Previous Users

**Appendix 37. Table 25. Analytical Framework: Main Summary of Key Analytical Themes and Sub-themes**

<b>1- Factors associated with use of text messages and acceptance of technology and self-management</b>
<p><b>1a- Age</b></p> <p>In our day there was no such thing as mobile phones... this is just something that has become recent now... and something the children are more engaged with' (NU15)</p> <p>'Yes, but only a simple phone. I don't have a fancy, touch screen phone nor can I use it. I am too old for that now. (NU13)</p> <p>I'm quite savy with my phone so I'm quite good with using it. I think younger generations tend to be. (U15)</p> <p>I cannot text, so I don't use the FLO system, also my English is not great, and I feel I am too old now to be up to date with new technologies. (NU2)</p> <p>I do think the system is helpful as it would display blood results etc. But I don't feel interested in using technology, may be its an age factor. I am too old to take interest in these things now. It is for younger people. (U2)</p> <p>Although, when I talk to them about the condition, they come across as they know more about it then I do, it could be because they are younger than I am, but what I know can help them also. (NU7)</p> <p>My granddaughter showed me. She told me how to do email, texts and all this. The youngsters know more about technology. So now I can text whenever I want, and whoever I want. That includes receiving health messages and updates. (U10)</p> <p>Not everybody is good at using phones so if they are shown how to it may make a difference. I think it is how some people are naturally some are good some are not. It is not an age or ethnic issue as my aunty is nearly 70 and she is brilliant on her phone, she came from India.' (U4)</p> <p>I do think the system is helpful as it would display blood result etc. But I don't feel interested with using technology, may be its an age factor. I am too old to take interest in these things now. It is for younger people. (NU3)</p> <p>First generation people struggle more with such systems, for example my mom has had a falling out with the GP due to the self-check in system as she can't use it. she needs to be shown, I'm sure people of a similar age within the community would need support. Same thing with my dad, he is now 75 he has only just started using text messages and mobile phones. (U3)</p> <p>I really love using the system for managing my diabetes, however, I do wonder how such a system can be used by someone like my mom, who is in her seventies now, and doesn't have a clue of how to text. (U1)</p>
<p><b>1b- Gender roles</b></p> <p>In terms of food, I don't just leave it totally to my wife; I do have a go at the kitchen myself.</p> <p>Us women have too much to do around the house than to waste time on our phones. (NU5)</p> <p>My husband normally runs the household, and accompanies me during my appointments. I don't think he would approve of me signing up to mobile phone system. I doubt I would even check my phone I am normally quite occupied with household chores. (NU5)</p> <p>I normally respond to health messages whether it's appointment reminders or test results, whilst my wife is busy doing the house chores. She engages well but can get caught up with household responsibilities. (U13)</p> <p>I am able to engage with text messages, and run my household. I get a lot of help from my husband and kids. Since I have signed up to it and started changing my lifestyle, they have joined me. (U6)</p> <p>I don't really use my phone much... I have too much to do around the house... I am not really interested in texting...I only really use my phone to make important phone calls. Otherwise, I am very busy with household chores and cooking for my husband and family. (NU4)</p> <p>I don't really make my own decisions, my husband has supported me since I have come from India, he attends my appointments and helps me make the best choice for us. (NU4)</p> <p>I don't think he would be too happy for me to engage with a system I am not too familiar with, plus I have many responsibilities at home. (NU4)</p> <p>My husband normally runs the household, and accompanies me during my appointments. I don't think he would approve of me signing up to a mobile phone system. I doubt I would even check my phone I am normally quite occupied with household chores. (NU5)</p>

I would like to make changes to my diet, but then that would mean having to change for everyone... I don't think my husband would like to change the traditional food we normally have at home. (NU6)

I've always made sure we share the house chores equally, as me and my husband both works. I think it's only fair. Since my diagnosis he has been more supportive and helpful around the house especially. (U7)

I look after my wife; I like to make sure she's not over-doing it with the household chores. So, I do the cooking and cleaning most days. She has had a lot of health issues recently, and has had to stay in hospital since she was diagnosed with cancer, which has now resolved with treatment. (U8)

I really like the FLO system but I feel without my mom and sisters support, I would not be able to get back on track with my health. I appreciate the messages but I think I needed the extra support from my family to bring my sugar level back to normal. (U9)

Mothers are very nurturing in the SA culture, for them the children remain precious no matter how old we get. Our health and well-being will always be the most important thing for them. (U9)

Although the messages are good enough to support me with lifestyle changes, I do rely on my mother or sister when it comes to cooking at home, they normally do it so I leave it to them. Recently, they have been helping me eat better by cooking healthier meals. (U9)

My wife has helped me throughout with my diet and cooks healthier food so I can maintain a healthy life. (NU7)

My husband is very helpful he assists with the house work, he helps me do the laundry, especially over the last few years since I have developed multiple health problems such as diabetes and blood pressure. He also helps with medications and checking my blood sugars. (U10)

Sometimes my wife helps out with my management, but normally I manage alone. (U12)

In terms of food, I don't just leave it totally to my wife; I do have a go at the kitchen myself. (U5)

She does all the cooking for us, so when we take over that role, we don't always eat on time. That is the biggest problem I would stress, but you have to carry on I am afraid. (NU8)

South-Asian communities stress that only women do housework. But in our house hold even our sons do the housework and help their wives. My daughter-in laws work too, and one of them has a baby. But only now when I am not too well, I ask her to sometimes make the chapatti, but otherwise we are not backwards and do not follow the traditional cultural norm. (U10)

I think household (gender) roles should be equal, because what my age is and what my parents have taught me, I have just carried on with this tradition. Hopefully, my daughter won't carry on, hopefully she'll just put her foot down and say no I am not doing it. (NU8)

We all lead a busy lifestyle you know you have children to look after, it is like a daughter in-law in our community, who has to do all the cooking and cleaning, which I think is unfair in my opinion. But you know, I would not treat my daughter-in law like that, but according to customs and traditions they are expected to do all that. There would be a time where perhaps she did get a problem, but did not consider her own health and condition, but instead would look after the house. But now we are all becoming educated, and hopefully religious beliefs won't affect our decision-making. I think it is down to the generations, the older generations believed in all this, but the younger ones don't they believe in fairness.

We are all equal, aren't we? I mean I would gladly go to the kitchen and wash some dishes than have someone else go and do it for me, if they are there to be washed, I would wash them. I know there are people from India that have told me off for picking up dishes and washing them. So, it is attitudes. (NU8)

I think male and females should have equal roles within the household... Although I have some health problems I still work, my husband also works... He also helps around the house whilst I am cooking and cleaning...I think these small changes in our community make a difference. (U3)

Well, I am not happy about the gender roles in our culture, but there is nothing to do about it, there is no point to argue and force him to something he doesn't want to do. I don't like making conflicts of arguments, So I try to keep it at peace. (U16)

### **1c- Education levels**

Education definitely makes a difference to the way you self-manage your illness, having that advantage enables me to interact and engage with my healthcare providers through FLO and technology. (U1)

I do think most people who have a busy schedule like myself due to work, will find that the system is quite convenient. I definitely think employment and education are linked, and are quite relevant to be able to use a system like FLO. (U4)

Yes, education helps, but my background knowledge came by being admitted into hospital, I was admitted as an emergency case.

<p>It's that education, they don't have that education, they are very traditional, and like I said single, very tunnel visioned, they don't want to spread themselves out a little. I have studied up to my metrics (tenth grade). I came to the UK in the 90's, my wife came later. You have to make time for your appointments, and just your well-being as a whole. Education is very important especially when trying to understand your illness or condition. I have the knowledge to self-manage my condition well (U6)</p> <p>Well, I studied here and back in India, I studied and graduated in Law in India, but I couldn't finish Law as I was going to come to the UK. Here I did MBA, which is the masters, I also have other diplomas. (NU7)</p> <p>Having education and being literate definitely makes a big difference in self-managing illnesses. (U5)</p> <p>She is quite educated, not from the village where schooling is not so good, she's from the city in Pakistan. It is due to her being educated she is managing her illnesses. (U13) [Daughter of Participant]</p> <p>I think for my age I did reasonably well, I got 8 GCSE's I then went to a polytechnic, which is in-between college and university they were called polytechnic, which are slightly higher than a college, but slightly lower than a university. I did maths there, but then I dropped out. I do think having the education I do it has helped me manage my condition and even engage with messages, I have done quite well. (U20)</p> <p>She actually went to school in Bangladesh, she finished school at 15 and got married at 16. She left school at 15 and married at 16. So, her literacy levels are quite low, she doesn't speak or understand English, so we help with her insulin and everything else. (U11) [Daughter of Participant]</p> <p>Education definitely makes a difference to the way you self-manage your illness, having that advantage enables me to interact and engage with my healthcare providers through FLO and technology. (U7)</p> <p>I have been to college and have a job... I do believe education to be very important and an advantage when looking after your own health, as it overcomes communication barriers with doctors... I live with my husband and daughter who also support me. (U3)</p> <p>Coming from a background of healthcare I know the lack of interest our community shows towards their health. I think a text messaging intervention is a great idea to help overcome non-compliance instantly. (U5)</p> <p>Being a doctor for so many years, and being diagnosed with diabetes I finally understand what my patients go through and can understand the barriers that exist within our South-Asian community. I think our community would benefit from an such an intervention.... It can really help with monitoring their health .and reporting any issues they may face. (U5)</p> <p>I really struggle with taking medications... I do not really understand what it is for, I sometimes ask my son or daughter in-law to help with identifying each medicine... I did not attend high school back home [referring to India], so I cannot speak or read English messages; I sometimes ask my grandchildren when my daughter in-law is busy with cooking. (NU3)</p>
<p><b>1d- Other demographics</b></p> <p>I live alone, I was divorced a long time ago, my children all live far away from me. (NU6)</p> <p>I left India in 11<sup>th</sup> grade and got married young, but my Husband passed away quite young. (NU3)</p>
<p><b>1e- Place of birth</b></p> <p>I am in my sixties, I have my date of birth here, you can work it out. I came from India, city name Jalandhar. (NU1)</p>
<p><b>1f- Work priorities</b></p> <p>I am a restaurant manager which has a lot of responsibilities, and it is a lot of pressure which affected me not to take the metformin also. I normally work five days a week, sometimes it is six days a week... hour-wise it can be anything from 50 to 60 hours a week, so it does get in the way of my health (NU19)</p> <p>The whole taking insulin thing, is something I need to make time for, it isn't really due to work, it is just me managing my own time, I don't take my medications on time. (NU9)</p> <p>We are both retired pensioners, I used to work in a poultry factory. (NU14)</p> <p>Well, I'm not in contact with my family, I left home at 18. So, that going back a good few years ago. So, I have been quite work-oriented. (NU19)</p> <p>My work schedule really fits in well with my healthcare issues and my appointments. So, work does not get in the way, I prioritise my health before my job and my colleagues are supportive of it. (U14)</p>

### 1- Family, cultural and traditional roles that influence self-management

#### 2a- Household chores

It's always me doing everything and then at weekends my daughter will cook for me whilst I do the cleaning, my husband doesn't cook at all (*laughs*) (U17)

I take responsibility with the kitchen work, I do the cooking for myself, I don't like my daughter in-laws cooking, youngsters prefer very spicy food, I can't have that it's not good for my body. So, I get up early morning and normally have to take full responsibility of my diet, which will suit my needs. (NU13)

No, she just looks after herself mainly, and her health is the main priority. We don't live at home, so she doesn't have to make food for me or any of us. She's just got to make sure she's got her own food sorted for herself, that's it. (NU3) [Son of Participant]

I don't really use my phone much... I have too much to do around the house... I am not really interested in texting... I only really use my phone to make important phone calls. Otherwise, I am very busy with household chores and cooking for my husband and family. (NU5)

I don't really make my own decisions, my husband has supported me since I have come from India, he attends my appointments and helps me make the best choice for us. (NU4)

I am able to engage with text messages, and run my household. I get a lot of help from my husband and kids. Since I have signed up to it and started changing my lifestyle, they have joined me. (U10)

I am usually so busy at home; I don't really get time to monitor my blood sugars or my health... I have to look after the family, and also my in-laws who live with us too. (NU7)

#### 2b- SA family system and attitudes

Erm... Yes, it is a norm to marry young, but for me it just didn't happen. I am still at home with my parents, my mom is desperate to get me married off. But it's difficult to find someone. There's two of us, ... I have a twin sister so it's even worse (Patient laughs). (U15)

So, we live in a large extended family which is probably very rare these days, consisting of my dad's two brothers and their families. We all live together. It's 14 of us that live together. As you can imagine healthy lifestyle, especially foodwise has not always happened. (U15)

We are very traditional with what we do. So, my in-laws rule my house [laughs] with my children etc. they have a say in pretty much everything and are well-involved in our child care and the dietary choices, which may not always be the healthiest. (NU6)

I think people tend to be lazy in SA communities, some don't bother with their health they just sit at home, and there are some that also visit doctors and do take care of their health (U16).

Well, I'm not in contact with my family, I left home at 18. So, that going back a good few years ago. So, I have been quite work-oriented. My friends are not South-Asian either. I haven't really associated myself too much in the South-Asian community. (NU19)

My mother-in-law is very stubborn and won't change her ways (U6).

Speaking about illnesses like Diabetes, is common amongst family gatherings, as they ask how my health is and how I am keeping only then it comes about. But not community as a whole, I wouldn't like anyone finding out from the wider community. (NU9)

I live with my wife and children. My family are in Delhi, but my wife's family are all here in the UK. My mother's family were here too. It's quite common to live with extended family members but our house is not as big to accommodate for everyone. (NU7)

Our house-hold is male-dominated, however, my husband work hard, works full-time and so do I, I don't see why he can't help. But then again, he does work awkward hours from 11:00 in the morning and doesn't finish till about 10 at night. So, I don't really expect him to do the house chores. (U16)

The family have to eat whatever I have cooked (U16).

Me and my wife live in a six-bedroom house. We let the kids move out when they got older, if they want to live freely, then they can. (U5)

Well, I do have a family; I see my grandson, my daughter in-law, son and my wife. My wife is very unwell usually, so I can't look after her properly so my daughter in-law looks after her, so I live alone. (NU14)

I know they do keep asking when I will marry. I mean my parents didn't get an arranged marriage so they don't really expect us too either (U8).

I don't rely on my children I don't think they care to know how I am; no one is there for anyone. I guess every family is different. (NU1)

I would like to make changes to my diet, but then that would mean having to change for everyone... I don't think my husband would like to change the traditional food we normally have at home (NU6)

We are very traditional with what we do. So, my in-laws rule my house [laughs] with my children etc. they have a say in pretty much everything and are well-involved in our child care and the dietary choices, which may not always be the healthiest. (NU6)

Family support is very important along with FLO...we are there for one another. They really help me get through it... Since using the system, I began eating a lot better, and after I stopped, I continued. My wife has helped me throughout, with my diet and cooks healthier food so I can maintain a healthy life... I try to exercise also when I have extra time. (NU7)

Although the messages are good enough to support me with lifestyle changes, I do rely on my mother or sister when it comes to cooking at home, they normally do it so I leave it to them. Recently, they have been helping me eat better by cooking healthier meals. (U9)

I really like the FLO system but I feel without my mom and sisters support, I would not be able to get back on track with my health. I appreciate the messages but I think I needed the extra support from my family to bring my sugar level back to normal. (U9)

My sister and myself were shown by the nurse of how to administer it for my mum, but then I trained and showed my sister in-laws how to do it in case I or my sister are not there, so they know what they are doing now. It's the same with the text messages, we normally read the messages out to her in Bengali to update her on her health. (U11) [Daughter of participant]

I was a previous user of the FLO system; I think it was a great system so I informed my relatives who had similar problems with their diabetes to sign up to it. We also try to offer one another health advice... Especially myself, as I have had it a very long time now, so I try help as much as I can. (NU8)

Family support is very important...we are there for one another. They really help me get through it. We share everything with one another, including those from the wider community to try help and support one another (NU7)

#### **2c- Cultural traditions – festivals and weddings etc (may intervene with adoption of text messaging and self-management)**

She actually went to school in Bangladesh, she finished school at 15 and got married at 16. She left school at 15 and married at 16. (U11) [Daughter of participant]

Erm... Yes, it is a norm to marry young, but for me it just didn't happen. (U15)

I only have sugar in my tea, I normally eat vegetables as I am vegetarian. I don't eat Mithai either, only when it is Diwali. But I like sugar in my tea, us Punjabi's have our tea like that, but now I have stopped... I only have milk in my tea, no sugar. I am aware that I should not have sugar. (U3)

I love Asian sweets, but I don't have them because of my diabetes. I love mithai and ras-malai [referring to traditional Asian sweets] (NU19)

Even during weddings, our Asian weddings are never on time so we normally take something with us, in case the food is late, so we normally keep something with us all time that we can give her so she can have the insulin. So, we do keep all that in mind. (U11) [Daughter of participant]

If someone brings me herbal remedy and tells me it will bring your diabetes down, or it will eradicate it completely, I will not believe in it, I will carry on with this one as my belief is in this one (prescribed medications). (U7)

#### **2d- Gender preferences - seen by same gender health professional**

Yes, I am able to speak to the doctor is a nice young man, and the nurse is also a female so I can openly discuss my problems. However, I don't really feel embarrassed to speak to male health care providers either if I need to. (NU1)

I am not too sure, actually, I don't know what it is. It could just be a cultural thing of engaging with women rather than men in these cases. I think I would be more comfortable telling Jo I haven't been good. I feel less shy with female nurses and doctors. (U15)

I feel a bit embarrassed when I come for check-ups and find that it is a male healthcare provider. I feel more comfortable with female doctors and nurses, preferably those who can speak my language. (NU16)

#### **2e- Reliance or dependence on family members to aid self-management**

My wife, gives me oily fish salmon twice a week, or sometimes when I do over eat, or have a lot of sweets she tells me to stop. So, in that way. (NU7)

My sister and myself were shown by the nurse of how to administer it for my mum, but then I trained and showed my sister in-laws how to do it in case I or my sister are not there, so they know what they are doing now. It's the same with the text messages, we normally read the messages out to her in Bengali to update her on her health. (U11)

She takes all her medications on time, nothing comes in the way, as we all help and make sure she remembers. (U11)

I normally do administer insulin myself, but sometimes my wife helps me. (NU7)

I keep complaining to my wife about the problems I am experiencing and she keeps on telling me to make an appointment, so I do sometimes need someone to tell me and remind me that I need to look after myself. (NU10)

My wife mainly helps with my diet, but I have to manage on my own. (U5)

I do sometimes need to ask my daughter in-law, she can read English or my granddaughter, she is 14 years old, and she normally sorts everything out for me, all my paperwork. (U10)

The doctor told me to take it once, at the chemist they told me to take it twice, my family gave me two, it was a misunderstanding or miscommunication. It was 120 mg then it was changed to 240, it was for my kidney problems. (NU1)

I did ask my GP if I could change consultants, because I don't like it, then I began attending appointments with my son, it is better now. (NU3)

My sugars tend to be 6-7, night times can be a bit unstable sometimes, [Son]: it depends on what she eats, sometimes she can have hypos if she has not eaten enough, so her sugar does go down. So, we adjust her insulin for the next day ourselves. (NU3)

We administer the insulin for her, she doesn't do it herself, it depends on who is with her, if my sister or sister in-law is there then they will do it, but if I am there, I will do it. it is between us. (U11) [Daughter of participant]

She is completely reliant on us, she's not very confident... plus she is not healthy enough, her knees are bad because of her arthritis and stuff, really struggles with getting around, walking and going up the stuff, general stuff like that. (NU3) [Son of Participant]

My sister sorts out all of her medications then when we take her to the doctors, we tell her the doctors decreased or increased this because of this reason. She was taking tablets then, she could read how much she needed to take so she was able to manage herself, and it was just after when her tablets and other medications increased my sister helped sort out her medications for different things. My sister bought her one of those tablet organisers, so since then she hasn't done it herself. (U11) [Daughter of participant]

I normally remind my mum, like even tomorrow she has an appointment and I had to remind her. She is quite dependent on us. (U11) [Daughter of participant]

Well text messages were really helpful in terms of my poor memory, but regardless of the messages, I am still reliant on being accompanied on appointments. Whenever I get a letter home with my name on it, I show it someone at home who can come with me. (NU15)

I assist my wife with her management. I write down all her readings daily including blood sugars and hypertension and send them through the FLO system. In the last 24 months her diabetes has improved through the guidance provided. (U10)

I live alone but I don't need support from my family members. My Kids have grown up and live far away. I know my health issues well and my medications. (NU9)

The messages are great, but she can only adhere to them if one of us is at home with her... an advantage is that I just live next door to her, So I can pop in and check on her, and check the updates via FLO. (U11) [Daughter of participant]

She has made some improvements via FLO, but she is not 100% with her health and self-management. She is not as motivated; she says it's because she has had diabetes for a long time now, and it's never going to get better. Also, she relies on us to help out, she hates needles so me or my sister have to help her with insulin injections. (U11) [Daughter of participant]

My grand-daughter normally helps me read text messages, as I cannot speak or read English. Only then I am able to follow the advice provided to improve my health and condition. She also showed me how to check my blood sugars with the glucometer. (U10)

Family support is very important...we are there for one another. They really help me get through it. We share everything with one another, including those from the wider community to try help and support one another. (NU8)

I learnt from other people from the same community facing similar issues, and family have supported me throughout my illness. (NU9)

I am happy to begin the interview with my son present. I feel more comfortable as he knows my issues. I don't trust an outsider, what if they tell someone from the community? (NU10)

## **2- Health Beliefs associated with self-management behaviours and acceptance of or use of text messages**

### **3a- Views on Traditional remedies/alternative VS prescribed medications**

I just haven't had the need to explore alternative therapies. I am aware that people in our SA communities do visit herbalists and hakims. (U9)

I normally have things like that as I am vegetarian by culture and tradition. I have them in different way some time we make stuffed vegetables, particularly bitter melon and lady fingers. But not as a therapy. (U8)

I do take bitter melon that sometimes, it's good for blood pressure. I also try okra and spinach sometimes. I've also tried Nim (herbal leaf) which I specially got ordered from India, along with blue berry powder, they say it helps control blood sugars they tell me. My nephew bought it for me from India. (NU1)

I do believe these things are very effective, bitter melon, okra, lady fingers and desi wheat are all very good, I also make juices out of them. (NU11)

I have not really tried alternative routes, but I have been advised to try drinking this or try taking that. I just think I should stick to what I know, which is my normal medications. (U12)

I have tried it once or twice, as many people from the community have suggested to give it a try. I have been to a hakim (herbalist) and tried the remedy he gave me. It wasn't bad I suppose. (NU2)

Chick peas are good for reducing high blood sugars, I have tried that also, but it only seems to work on certain people, it is the same thing with medicines, it will work on some people and not on others. (NU3)

I think if I had a better idea of the alternative therapies, I would maybe try both, I would combine alternative methods with my medicines. (U10)

It's a proven fact, for example, If I stopped taking my insulin I would have fallen and I'd be admitted. The herbal medications are not proven to be scientifically effective, they're not real medications. If they were proven to be good for you, I would take them.

I have eaten bitter melon as well, I have also drunk water of that, I have had people from our community show me videos that if you dip your feet in crushed karela that will work, I was like that's not going to work... it's got to get into your blood. I guess it can help thin the blood, as it is very healthy, it is my favourite vegetables but that does not mean it will cure my diabetes, it won't replace my insulin, I wish it would but it's just another alternative to you know...but in reality, it won't control your blood sugars. (U7)

I have tired herbal remedies when I went to India...I will never go back to using them again. I think the most beneficial thing is my routine, which is to take the medications my health care provider has told me to. Ever since my doctor has signed me up to FLO, I have gained more confidence in managing my Diabetes, (U6)

I wouldn't really touch herbal medications, I mean I have vitamin tablets, but I wouldn't touch any Indian herbal medications, because I don't trust what's in there, I don't want it to affect my insulin or my health. (U18)

I do take a lot of bitter melon, my wife always tells me to buy Karela because it is meant to be good for this, some also say to eat pepper especially green pepper, but to eat these vegetables raw.

I do both (take alternative and prescribed medications). But I do take my prescribed medications regularly as and when I am supposed to. (NU18)

If someone brings me herbal remedy and tells me it will bring your diabetes down, or it will eradicate it completely, I will not believe in it, I will carry on with this one as my belief is in this one (prescribed medications). (U19)

Well, like Karela (bitter melon) as you have mentioned, I like anyway, but I would not use it to bring my sugar levels down, some people also day Daal-chini (cinnamon), that brings it down too. (NU13)

I do know that it has no harm or side-effects to try it. Similar, with garlic, people say it helps reduce blood pressure, so sometimes I take it with my food. (NU16)

Well, they have no side-effects for sure, if you take cinnamon, garlic or karela they are not going to do you any harm. (NU19)

Well, I would not recommend to anyone to take as an alternative to prescribed/ English medications. But they can still try it also, as it does not have any side-effects. (NU8)

There is no harm in trying so I do also support traditional remedies, like for example, turmeric and milk, I do try this as in India they say turmeric has healing and medicinal properties, so when we were young in India When we would have a bruise or an injury, they will advise us to drink this. (NU11)

I tried it for a year, but then I thought I'm not going to take anymore herbal tablets, because I am already taking enough tablets as it is. So now I just stick to what the doctors are telling me. (NU8)

My sister-in-law told me to start eating karela and so you know so I started eating that, and then they told me to start drinking the juice of karela, and going to get tablets with that karela in it. All sorts. (U14)

Yes, herbal medications do have fewer side-effects compared to normal medications. When I went to India there were so many people that were telling me to take different kinds of medicines, for different things, it was medicines they were actually making over there, it was the herbal medicines. I was like I'm not going to take any of that as I don't know what you have put in them, you know they were trying to sell all these to me, but I said no I am not going to buy any of that. (U16)



Yes, I do definitely prefer western over traditional. I know there are a risk of side-effects of tablets you're on, but if I don't take the medications, I know I won't be here, especially the insulin. (U8)

I have absolutely no... shall we say faith in traditional remedies. If someone can come up with some sort of treatment which they can prove to be right, which can work, I will personally get you an award for it, the best award in the world that you can get. (U6)

I can't really have bitter-melon, or other remedies... even desi tea I can't tolerate them, even if I wanted to try them I can't they're not good for me. Bitter melon is too hot for me I only rely on prescribed medications which benefit me. I do normally have freshly squeezed juice, as I have a juicer at home... I have heard that grass juice and leafy sachets is quite good for cholesterol. My sister has them; but I can't have those, so instead I grind juice. (U14)

I am more reliant on my prescribed medications; I don't believe in an alternative or 'desi' cure. A lot of SA individuals do consume it, but I don't take any. (U2)

I have heard about traditional remedies, Bitter melon is good for lowering blood sugars, but I don't have them every day because I get fed up of having them repeatedly. I do try desi remedies, I was told by Indian doctors on TV to have 'methi', to put them in water and then take. (NU1)

It is like dried seeds you put in water, and I drink it. I sometimes leave them in water overnight and have them in the morning. (NU3)

The doctors put me on tablets I couldn't even swallow, so I stopped taking them. I also tired bitter melon too as an alternative. (NU16)

I feel like I don't have enough time to discuss my health problems, the doctor always seems rushed. I have so many questions and uncertainties about my illness and medications. So, I don't really take all the medications, I mix it with some herbal remedies. (NU16)

I don't take traditional remedies, I tend to stick to my medications it's all down to them, and they are the one thing that will get me better. Although, that's not to say traditional remedies are bad, they're not good nor are they bad, they are good to some extent and safe to take. (U5)

I have done it once, where some Pakistani guys were doing a desi treatment by checking my pulse, and they asked me to have 6 litres of water every day, 4 'coco mugs', all that eater caused my body to swell extremely due to overloading my body with all that water, my stomach and legs were huge. Because of this I got a bungalow, from the health and social care services through the doctor. I couldn't climb stairs you see I was struggling as my legs were so big. My weight was 110 kg as a consequence so I never ever trusted these remedies again. (NU14)

I have purchased it once from a Hakim (herbalist), he charged me 10 pounds for one bag of herbal tablets, I tried them once they didn't work, so I didn't buy or try again. (U13)

Unless there is a miracle that actually works, in the form of traditional remedies. Otherwise, they aren't proven to work. (U6)

I have heard a lot about it, I mean every day consuming spices and certain foods, for example, garlic, ginger, and cinnamon or bitter melon are supposed to be good for you. (NU14)

I have tried beet root juice actually, and I think it does work. But then there might be some active ingredient in there, which are maybe in tablet form. Beet root juice works, erm, cinnamon does help you with cholesterol, so I have used cinnamon and garlic and ginger. Garlic is good for your heart, and ginger we use every day. I just feel that some of that stuff does work. (NU17)

If you have been diagnosed with a problem, you must take the advice of your doctor, you can still try these as supplements, but as long as they do not interfere with the doctor's treatment. (U20)

People don't want to go on prescribed medications; they would rather try the alternative therapies first. But you know if you have been diagnosed, it is a bit more serious than to just take supplements. (NU8)

I think to bring it under control you should go on to the doctor's regimes, and then if it is under control, perhaps you can add the other supplements. I mean I have a cod oil tablet every night. (NU8)

I think our supplements do help, vitamins do work but the active ingredient in them are not strong enough to help, so you need to go on to the doctors prescribed medications and advise. But You need to get a doctor's prescription, with the right strength so I am saying the same thing with alternative therapies, they are there if you think they can help you, I'd say if you got a problem you need to approach a doctor. (NU8)

If I felt that my western medications are not working, I would like to try something from the hakim, because I have seen claims being made that some of these things have cured people, so I would be interested to find out, you know, what the pharmaceutical companies have suppressed. I mean people have said that there has been a cure for cancer from back during the world war, but we still donating to the cancer donations, how much are the pharmaceuticals actually involved, I have had family members who have dies of cancer, if they

have suppressed it is not right. I mean where do you get the treatment for that if you are diagnosed with something like that, there is chemotherapy and radiotherapy, but is there something else out there? (NU12)

We do take her for foot massage at Chinese places, to help with her circulation and legs. (U11) [Daughter of participant]

She has tired and had bitter melon for years, but got very fed up of it, at the moment we give her pomegranate, we give her that, it is good for her kidneys we have heard, so we make juice from that sometimes. (NU3) [Son of participant]

I have heard of many SA people taking herbal medications, and people saying it prevents diabetes, prevents cancer. But I don't think they work. (U2)

I know there is a lot of speculation in South-Asia, but I have never tired it. For example, juice of Kerala, I am not a fan of Kerala, I most certainly would not drink the juice of it.

When I went to India, a relative told me to eat this leaf and not take my insulin, I actually had a fit that night by having that leaf. This was in 1993, I must have been ten. (U8)

I don't believe in herbal remedies I feel unwell if I try anything herbal, I don't think they work. (U3)

I do believe that traditional remedies do work and can be effective. I have tried amla and methi (green leaves) in water. (NU2)

I don't believe in herbal medications; I am not sure if they work. I haven't tired them but some of them my father believed in them, there use to be a herbal centre in Mumbai where they would buy 'rooh hafza' (rose flavour syrup) and we would use it for constipation. Allopathy medications have good and bad effects, but for complicated issues like mine they can't help me. (NU20)

I don't think I could keep up with FLO. It wouldn't help me; I am not used to the mobile phone as I have never been interested in learning how to use it. I also don't believe that texts will cure my disease. I am happy with the remedies I am trying such as Karela juice (Bitter melon), which I think are more effective than English [referring to prescribed medications] medicine. (NU18)

I do take a lot of bitter melon, my wife always tells me to buy Karela because it is meant to be good for this, some also say to eat pepper especially green pepper, but to eat these vegetables raw. (NU14)

I think my views regarding FLO and my illnesses are separate. I do believe the system to have helped me personally with my conditions. However, I also feel bad for wasting my money and believing that the remedy given to me by the herbalist can cure me. I have learnt that there is no cure to the diabetes... The system has improved my self-management. Therefore, I will continue to use it. (U13)

I went to Faisalabad (city in Pakistan) to see a hakim and they told me that they could cure my diabetes; I really should not have been so naive; I am going to continue to stick to what my doctor and FLO advices me to do. (U13)

My mom hates needles, she won't take the insulin unless me or my siblings assist her, she also thinks it doesn't work, so there's no point in her taking it (U11)

I prefer taking medicines that are natural or from the earth than English medications [referring to prescribed regime], things like raw vegetables and Karela (bitter melon) helps reduce Diabetes, I think if I continue to take it may cure the illness. (NU11)

I feel safe when taking herbal remedies as they are natural, there are many that I think can eventually cure my Diabetes such as Karela. (NU12)

I don't think I could keep up with FLO. It wouldn't help me; I am not used to the mobile phone as I have never been interested in learning how to use it. I also don't believe that texts will cure my disease. I am happy with the remedies I am trying such as Karela juice (Bitter melon), which I think are more effective than English [referring to prescribed medications] medicine. (NU13)

I have had karela but I know that it won't be harmful. At first when I was in denial, I tried all these remedies because I thought I could get better without the western medicines, but I know they don't work. (NU1)

We don't take karela as a herbal remedy we take it normally in our diet. If it could cure diabetes then no one would have diabetes. It depends on the body though, so it may work. (NU8)

I have tried herbal remedies, at the minute there is some concoction that has arrived from India that has been made up of loads of powders. However, I am not taking it, I have kidney failure I do not want to risk it. My in-laws give me some also, but I just put it in the bin. (U7)

### **3b- Toxicity of medications- i.e., side-effects, trouble taking medication ('trouble swallowing tablets', taking 'too many tablets' or 'fear of needles')**

I do fear that because of side-effects it makes things worse. I feel traditional remedies have no side effects; they only help people. I sometimes I feel I should take such remedies regularly to get better quick. I am also thinking this can help me lose weight... ginger and garlic are very good for that. (NU17)

Yes, side-effects do put me off, I mean with the statins I have trialled a few, but they have really bad side-effects such as stomach cramps, diarrhoea, nausea. I mean I can't be going into work with diarrhoea, so I stopped taking them, but then they put me on a different one, but I experienced similar effects. But now I have one and I don't feel that many side-effects anymore. (NU19)

Well, I would not recommend to anyone to take as an alternative to prescribed/ English medications. But they can still try it also, as it does not have any side-effects. (NU8)

Herbal medications do have fewer side-effects compared to normal medications. The doctors put me on tablets I couldn't even swallow, so I stopped taking them and tried bitter melon too as an alternative. (NU16)

She needs her medications, she can't do anything about her side-effects as she requires it for other stuff... But luckily, she's been okay with taking medications and side-effects etc. Well, obviously taking medications for so many years no its bound to take a toll over her body, she is saying she is full of medicine now. (NU3) [Son of participant]

I don't experience barriers as such, but I remember at one point there was a lot of medications I was taking and I felt very overwhelmed, for example, I am taking statins for my high cholesterol and ramipril for my blood pressure, so it already 5 or 6 tablets a day, but at one point it was even more. So, I think that was another thing... even though it was for my best interest it was still quite a lot of tablets. (NU19)

Otherwise, the doctors just kept putting me on more medications, different dosage and multiple of them, but I couldn't swallow them I had a lot of trouble. I do get confused as I have so many tablets to take. I also fear the side-effects because of taking so many, it may make me worse. (NU3)

One of the doctors gave me too many tablets to have, my GP was very surprised too. I was beginning to think I will develop a lot of side effects. I stopped them all because of that, I now only take metformin. (NU2)

My mom hates needles, she won't take the insulin unless me or my siblings assist her, she also thinks it doesn't work, so there's no point in her taking it (U11) [Daughter of participant]

I am not saying that the system is not good, it's just that I don't think using it will reduce the number of tablets I am taking it will only remind me to take all of them, which is what I am trying to avoid. I believe taking too many medications are bad for my health, however, doctors have told me the opposite that they are there to help me. If they want me to use the system (referring to FLO), they need to understand my beliefs. (NU13)

I take eight tablets in the morning and nine in the afternoon, I asked him (doctor) to reduce the number of tablets due to the side-effects associated with them, but the doctors said no. (NU13)

Even my GP was very surprised too. I was beginning to think I will develop a lot of side effects. I stopped them all because of that, I now only take metformin. (NU13)

### **3c- Stigma ('labelling') and taboo**

Well, doctors told me to go on to insulin but I refused to do so due to cultural stigmas and just not really wanting to go through taking injections. (NU15)

Yes, there is a stigma attached to disorders such as depression and other mental health problems in SA communities, because of this it is SA thing not to share these things in the open. (U6)

To some level there is a stigma not just in our community, rather as a whole and also job related. I think when working in a restaurant and you tell them you have diabetes, they won't let you try half the food, and act prejudice towards you. (NU19)

Yeah, there definitely is a taboo within our community to discuss or to not discuss certain elements of health. I have been in this country over forty years, so I was like that when I came in, but now moving around and working with people here, I got out of it. (NU18)

Well, obviously (laughs), there is a stigma. People think that to me personally, when my relatives especially when I went to India 'you got diabetes! Oh no, start taking this' 'don't take your insulin' 'don't do this'. They really have no insight. (U4)

I do believe there is some sort of stigma that leads us to hide or be embarrassed from their illnesses, I am not sure what the big issue is, but it is, especially with injecting insulin in public. ()

It is not just the stigma in our community regarding diabetes and other illnesses, she was afraid of needles. (U11) [Daughter of participant]

There is a stigma amongst SA communities... so one of our cousins had cancer, and the stigma there was 'you don't want to go there' or the person with diabetes 'you don't want to go there either'. (U6)

What it is, is that society withdraws itself, same is the case with the taboo of sexuality and mental health issues in Indian cultures, stigma does exist. In terms of health, kidneys disease, diabetes and cancer... whatever it is, it can happen to anyone doesn't matter what colour or race you are is can happen to any of us. (U6)

With stigma you can't change someone's views, especially those from the older generations, even when my mother in-law had a knee operation, I told her to exercise or use a walking stick, she said no, no I don't want to use a walking stick ever.... It's because of the stigma existent in our community, and it's hard to change people's minds because it's how they've been brought him, and the views they develop from a young age. (U6)

I was on the ward it was all old people; I was like where are all the young people gone, is this a disease that only old people get? I just wanted to hide myself, what is happening to me? (U6)

Depression and mental health issues are a taboo in SA society. Parents fail to accept their children or even adults fail to accept they are suffering with it. (U8)

I don't know, I think it is cultural as they are Indian like me also, so I think it's a cultural thing, or stigmas attached to certain health issues. Some GPs, you won't believe, they are doctors and they feel shy... I mean they are doctors they shouldn't feel shy... whereas, Caucasian doctors are reassuring through their gestures... like when they nod to confirm they understand... I mean doctors know all the parts of the body, and some of them are still shy. So, it can be uncomfortable discussing certain health problems (*laughs*). (NU7)

There is a stigma of injection and insulin in SA communities, but we just get on with it, it has to be done, it is fine. I am quite strong in terms of my health care management. (U2)

I think with me I knew what I had but I did not want to accept it. with Indians if anyone knows you have a disease, they wouldn't want to marry you. But you would think do you tell your in-laws? It's a taboo thing in this culture. (U7)

My in-laws knew I had diabetes before I got married, but it is something that parents don't want to tell anyone, but it is something you need to tell someone. Our community will cover up things. They are very narrow-minded. (U7)

I don't have the confidence to self-administer the insulin, especially in public. I feel even worse to tell the doctors and nurses, wat will they think of me? I do get help from my wife sometimes (NU7)

Like you said before about cultural issues and taboo to discuss confidential things can be a problem sometimes. For example, erectile dysfunction is something I am experiencing, and studies show it is to do with diabetes, but I find it difficult to discuss it with others (NU7)

There is a stigma of injection and insulin in SA communities, but we just get on with it, it has to be done, it is fine. I am quite strong in terms of my health care management. (U15)

There are certain health beliefs in the SA culture, especially a stigma for things like Cancer and Diabetes. There are a few people with diabetes in my family and they all tend to keep insulin administration a secret, I think it's because they find it embarrassing and wouldn't want the wider SA community finding out. (U15)

No, I don't go counselling. (*Patient laughs*) I think that a SA thing though, not to openly share your problems with everyone. (NU7)

I was labelled because every time we would go out to eat, they would pester me and say do you want something to eat, I'm like if I want to eat, I know where the food is, or sometimes they'd ask do you want a glass of orange... you know what I mean, if I want something and if my sugar levels are low, I will go get it myself. (U7)

### **3d- Cultural norms and practices**

No, not so ever. I don't really practice my culture; I only cook Indian food (*laughs*). I normally cook for my friends. (NU19)

They watch me eat, SA people are very tunnel visioned and very rigid, they don't want to change, but my mother in-law she has diabetes too I tell her to eat fruit, exercise and be healthy. (U6)

My mother-in law is very stubborn and won't change her ways. (U6)

Well, it is common amongst family gatherings to discuss well-being and illness, as they ask how my health is and how I am keeping only then it comes about. But not with community as a whole. (U9)

There is a Hindu community and we have got a little place where we all together for our garbas, do you know what a garbas is? Like old dances and occasions like that, but no one discusses anything related to their health problems. (U35)

We don't use things were not supposed to use in food, for example not many Asians use virgin oil, or sunflower oil or even oil they use for heart patients, we also use that instead of Ghee, which clogs up the arteries. I don't have Asian sweets, or flatbread and potatoes either. I have given up everything. (U5)

She has sacrificed the original Asian diet, to get better. (NU3) [Son of participant]

I go temple for company mainly, there are lots of other women there, we have tea and food there, I go there normally between 2 to 4 hours. (U10)

<p>We don't really have a lot of Asian food; we tend to cook more English food than Asian to be fair. We do have Asian food, just not every day. (U8)</p> <p>She is very adamant and stuck in her ways. (NU16) [Relative talking about her mother's attitude regarding her self-management]</p> <p>Whether we have to go to the hospitals or the doctors, my mum will normally say this is wrong or somethings not right. She is very stubborn with her beliefs. (NU3) [Son of Participant]</p> <p>She would love to go Bangladesh and stay for six months if she was well enough. Last time we were there because she had diabetes and she is from the UK, they feared she may react to medications there, they did not want to risk it. It depends where you are in Bangladesh, if you are in the capital, you will have foreign doctors that will look at her, but there is only so much they can do for her there. (U11) [Daughter of participant]</p> <p>Cultural factors do not affect my health or self-management.</p> <p>Unless we cook it yourself, we will just eat what our Mums made, which will be a big pot of curry with lots of oil in it. So, it is traditional Indian food. (U15)</p> <p>I try to maintain a healthy diet; I do like to eat apples and other fruits. I am vegetarian, as I am Sikh. (U6)</p> <p>I do consume sugar daily, even mithai, I don't really like to diet. I do have an awareness that I shouldn't, but these foods are apart traditional in our cultures and are hard to give up. (U15)</p>
<p><b>3e- Belief that God will fix the problem</b></p> <p>The disease is from Allah, we have all trust in Allah, only he can cure us, even advances in technology (mobile phones or text messages) don't have that power. (U17)</p> <p>Of course, I believe in God (<i>patient laughs</i>), I believe in all Gods. Yes, God has given me the condition and only he will cure me. (NU1)</p> <p>Although, technology is good and the texts are educating me, it doesn't matter how much you are suffering, only God can restore happiness and health. (U12)</p> <p>I have faith in God that he will fix it. I pray to him before I eat breakfast, erm.... But I don't really go to a temple or a church, I go to places to worship when I am free or ready, I pray at home, I don't need to go to a place to pray I can pray in my room or my front room or in the garden. (U6)</p> <p>Well, scriptures do say, God can do anything, he can cure you if he wants. (NU7)</p> <p>I am dependent on my medications as they will help me physically, so I have to take them no matter what, but the rest is in God's hands with whatever happens.</p> <p>I don't believe in a higher power helping me to manage my health. I'm not sure how that works out. (U8)</p> <p>I do believe whatever happens is for a reason. I am religious and believe in God. I am a firm believer and I look for guidance in God. God can do anything; he can cure me if he wanted to. I try not to get depressed about my illness because of my beliefs. (NU18)</p>
<p><b>3f- Embarrassed of condition</b></p> <p>In our community when we get together no one wants to say that they got high blood pressure or they got this because everyone is ashamed of what they have got.</p> <p>Well, in some cases I feel shy or embarrassed, I can speak to Angela, one of the diabetes specialist nurses, there are some things I may not be able to share with Dr De or my GP, due to cultural similarities. (NU7)</p> <p>I am not sure what the big issue is, especially with injecting insulin in public. The grown-ups in my family [referring to first generation family members] need to be better educated in regards to their illness. There needs to be a less stigmatised view and better self-management. I think a system like FLO can really help people like my mum. (U15)</p> <p>Although, there are health beliefs in our culture regarding illnesses such as diabetes, I never let it get in the way of my regime or even my use of FLO. It's quite irrelevant to me, I only care about my health and that's it. I am not embarrassed to have it. (U6)</p> <p>There are certain health beliefs in the SA culture, especially a stigma for things like Cancer and Diabetes. There are a few people with diabetes in my family and they all tend to keep insulin administration a secret, I think it's because they find it embarrassing and wouldn't want the wider SA community finding out. (U6)</p>
<p><b>3g- Influences of religious practices on daily routines</b></p> <p>My mum is always praying to be honest, does all her prayers and always reads her Quran. She does all that all the time. It gives her hope in getting better. (U11) [Daughter of Participant]</p> <p>I don't have particular rituals or cultural practices to get better, I think what I said earlier God gives you guidance and you follow it... that's it. Normally Sikh communities are quite strict. I am a Sikh but I am not orthodox, Guru Nanak's philosophy was we are all human beings first, then anything else after, and if you dint regard anyone or anything that meets</p>

you as good as you're self then you are not worth talking to. In other words, if you don't see God in another person's eyes, you won't see God (related in terms of self-management) (U5)

Well, religion tells me not to indulge in alcohol, smoking and things like that. So, it does play some part in my self-management (U5)

God doesn't ever give anything like that, my question would relate to 'would your mom and dad ever give you a disease'. No. So, how can God do this? When God made me, I was the healthiest child around. Whatever my condition is today, it is all because of my own fault, it was my routine- from what I was eating and misusing my body. I believe God has made the human body so beautiful, we spoil it, and if some organ fails, it's not because God caused it, or God has made the body badly. It's your own fault. (U5)

If God created us, he knows everything about us, and we were created perfect, we have made our selves imperfect, all these problems we are having are because of our own life style. I don't blame God I do believe that God will help me if I asked him, but it is down to me and to make a big effort in my daily routine. (U5)

I don't have a normal routine of going to the temple every week. But when I do pray to my God, I ask him to keep all three of us health, so I do, do my prayers. (U6)

I do go temple to worship and for faith, my religion and God helps. (U7)

### 3h- Does Text messages Intervene with God, religion or cultural practices?

No, text messages did not intervene. But the support can't be better than God. Nothing is better than God. (NU8)

No, text messages do not intervene with my practices at all. I actually think they are very useful in terms of self-management, good reminders etc. I think the internet is also a good source where you can type whatever you want and search for whatever.

No, no text messages don't intervene with religion; it would allow for a good communication, communication is good. (U18)

There is no connection between God and Technology. For me God does come first, but it has nothing to do with me using my phone. (NU2)

Every second, every minute God is with me. I feel technology and God are separate. For example, I can use my mobile phone to make a phone call to India, but God is everywhere I don't need to use technology to reach him, he is everywhere. The person who designed the mobile phone, was designed by God himself. Nothing is greater than God. (NU17)

God is enough for me; I don't need to use FLO. If I have God, I don't need anything else. (NU17)

### 3- Coping Behaviours

#### 4a- God helps me

No, no it cannot be God. This is all my doing. It is because of my eating habits I developed diabetes. I am devoted to the belief that God does help me (U15)

I do believe in God and his support. I do know there is a god out there, does not matter what faith you are, whether you're Muslim, Hindu or Christian, there is a God there and I pray to him every day. (U6)

I'm always looking after so many people. So, one way I look at it is God has given me this gift, I'll put it this way that you're looking after so many people, you need to look after yourself, that why he has given me diabetes. That's the way I look at it. (U6)

I do not just pray for myself I pray for everyone. I believe in all gods, Jesus, Indian gods, God is one. It gives me the hope to get better one day. (U6)

I do have certain beliefs that God puts you in touch with the right people like for example, Dr, De, nurses and my GP, and then they look after you. If you mean that then I will say there is some grace by God, in that sense. (U4)

I believe God helps you, if you have his grace or benediction, he puts you in touch with the right people. (NU7)

I do my prayers every day, so God gives me a reason to cope. (NU16)

The body has 10 points, God normally enters one of those points when you worship, and at night they get a very good feeling. God will never harm those who believe in him. I once saw on YouTube, that a Pakistani Imam was talking about this in the Muslim religion, which just shows that God is one for everyone; everyone just has a different way of worshipping and reaching out to God. God has many names, but God is God, and is one. We are all going to go to God one way or another, but that is our end. We all illuminate with light from God, when we all pass away, that light returns to God. God brings all the happiness and good feelings. (U5)

It can never be from God; I never blame God. It is self-inflicted I'm afraid. God made us perfect; we made our self-imperfect. I would never blame God for our problems, He can only help us, if we ask him. (U5)

Yes, God can help. I do believe in miracles, I don't think I have experienced them to be honest, but I have heard of them. (U16)

God can only help individuals; he would never make people feel pain or suffering (*patient laughs*). God only helps. (U13)

She does, she is a practising Sikh, we all believe in that, that God will help. It is a belief we all focus on otherwise you have no hope in anything. (U3) [Son of participant]  
 Yes, yes of course God helps me cope, we worship him, don't we? So, of course he will help. (NU5)  
 I have been very depressed since the diagnosis. My religion and faith in God have helped me feel more normal. FLO has also helped me bounce back with my life.  
 I attend the temple daily, praying to God and seeing people from the community has provided a lot of emotional support for me. (NU1)  
 God is enough for me; He helps me get through it. I don't need to use FLO. If I have God, I don't need anything else. (NU16)  
 I do believe whatever happens is for a reason. I am religious and believe in God. I am a firm believer and I look for guidance in God. God can do anything; he can cure me if he wanted to. I try not to get depressed about my illness because of my beliefs in God. (NU18)

#### **4b- Family and community support network**

I do have a good support network. my parents have passed away, but my brothers and sisters are all fine with me, they're always asking about me and looking after me, so I am absolutely fine, the support is there. I have a sister in Walsall and a sister in Leicester, then I have family in Manchester also. (U7)  
 I learnt from other people from the same community facing similar issues, and family have supported me. (NU6)  
 We all take turns to bring her to her appointments, so that the burden doesn't fall upon just one of us. So, it's just that we take it in turns, we got a bit of a routine, someone will say can you do it, I have work. My younger brother was meant to come today but he had a meeting, so he asked me as I was available, as I work from home sometimes. I have come from Wolverhampton today. (NU3) [Son of participant]  
 I do get lots of support from my children, as I live two or three minutes away. They all come according to their convenience; everyone is close by to me all my children, daughter in-laws, and grandchildren. (NU3)  
 Yes, I do value family support, they help keep me on the right path, best for my health. (NU11)  
 It has made me feel confident because I know the family know what to do if I have hypos. (U7)  
 I have a good support network, if you don't have this support, you can't be successful. Family is very important. (U2)  
 My family does support me, but only to some extent the kids don't do that much, they are busy with their own life. So, it is me that has to do that. Sometimes they ask if I have eaten, other times they don't. (NU1)  
 Well, she goes to the temple regularly, it gets her out the house, and she communicates with her community. Going to the temple allows her to socialise, then to sit at home all day. It's not just to get better. (NU3) [Son of participant]  
 They support me as much as they can. I don't mind as such even if I have to manage alone, because I want my kids to live their lives now, as we did, they have children also to look after. ()  
 Other members in the family, there are seven of us that have diabetes. But they are new to it so I can help them and can talk to them. (NU7)  
 I do meet up with people from the community who also seem to share their health problems openly with one another, for example, some say their knees hurt or their arms hurt, to one another. (NU3)  
 My family know I have diabetes, and those in the family that do have diabetes also, ask me how I control my sugars and how come I haven't put that much weight on. (U6)  
 I think I am supporting more than they are supporting me...in the beginning I did need the support which I did get from my husband, but now it's the other way around I'm telling people what to do in such situations. (U6)  
 Sometimes my wife helps out with my management, such as my diet, but otherwise I normally manage alone. (NU8)  
 I do have one sibling I am in touch with. But I do have good friends to support me, I can often turn to them. (NU19)  
 I have a lot of friends who understand me and my condition, as they have had diabetes or have had someone in the family with it. So, I feel I can turn to someone if I am feeling down. (NU19)  
 I have the support I need. My friends, everyone doesn't have that. I think there's a lot of people that are with their family and can't speak about their problems openly around family, you don't really get their support. (NU19)  
 I just know if I need something my daughter is there or my husband is there to support me. (U6)  
 I just talk it over with my daughter and my family... its family support, I just know that my family is there to support me. (U6)

I go gym three times a week, eat fish twice a week... but definitely through family support I would say. (NU7)

Yeah, I can figure out solutions on my own... but then again you have to discuss with the family and take it from there. (U19)

She knows why she's taking the medication, but it is different when she comes out of that house, we need to support her. (NU3) [Son of participant]

At first, I felt I couldn't even check my blood sugars, I didn't think I could prick and bleed myself to check, but then my grandson showed me and he could do it, so I thought if he can do it, I should be able to also, so I learnt too. (U10)

We receive appointments through the post, I would prefer it via text messages so I am informed instantly, as sometimes letter get missed. (NU14)

My son is also a nurse so we get a lot of help with medication updates and translation with text messages. All the family support me and my health including my sons, daughters, daughter in-laws, cousin brothers and sisters. They keep me going. (U10)

She will never forget to take her medication. At this present moment I [husband] am doing the chores and the cooking, or my daughter-in law will help out. (U10) [Husband of participant]

We support each other as a family. Family is very important in South-Asian communities, we are all very close-knit and offer support all the time. (U20)

FLO has given me hope, and has made me want to do better for myself and my family. I don't think I can manage as effectively without it. Since I have started using it, I have developed a better routine. I make sure I am checking my vitals, exercising often and eating right. (U20)

Although I have FLO, my family have been my main supporters without them, this journey would be impossible. (U20)

I am always there for my wife I take care of all her health needs; I make sure she takes her medication, insulin on time, eating on time. So, we are top of the game with the medications. (U10)

My colleague at work also has diabetes so we update and learn from each other with health information about diabetes. We always support each other in the work environment. (U7)

My husband is very helpful he assists with the house work, he helps me do the laundry, especially over the last few years since I have developed multiple health problems such as diabetes and blood pressure. He also helps with medications and checking my blood sugars. (U10)

Family support is very important...we are there for one another. They really help me get through it... my wife helps with my diet and cooks healthier food so I can maintain healthy life... I try to exercise to also when I have extra time. (NU7)

My family are really supportive of my medication regime... They will always remind me to take my medications... especially my wife she will take out my medications for me and advise me to check my blood pressure and blood sugars. (NU7)

Although I have FLO, my family have been my main supporters without them I this journey would be impossible. (NU10)

I learnt from other people from the same community facing similar issues, and family have supported me throughout my illness." (NU9)

Ever since FLO I am always learning something new, and my family are very supportive and want to learn with me so that they can help in case of a hypo, or anything else that can go wrong. (U6)

#### **4c- Experiences and Attitudes of living with a LTC and self-management**

I have had my diabetes for nearly 20 years, and it has only gotten worse. I have now also developed blood pressure problems [referring to his Hypertension]. I don't feel motivated anymore to take medications. I think they have done more harm than good. (NU15)

I feel hopeless with my condition sometimes, especially when I don't have anyone at home with me to help administer the medications. I normally have trouble then when I can't read the English labels on the medicine boxes, so I don't bother sometimes. (NU1)

I think I have become sicker since attending appointments by listening to doctors go on and on, I've been crying a lot at home and have become sick. (NU3)

I wouldn't wish it on my worst enemy if I honest, it is horrible. It is not the best thing to have to be fair. (U8)

She would do anything to go off the Insulin, because she feels that it just drags her down, for example if she goes abroad, she feels tied down as she needs one of us to be there. (U11) [Daughter of participant]

Well, according to me the cause of my illness is family problems at home, sometimes it can be the diet or food I am consuming, for example, curry isn't good. I do have to look after my diet, but I don't look after myself much, when I am caught up in household problems, I do miss meals sometimes. (NU1)



I normally experience low sugars and hypos; I always have some Lucozade with me as it is a recurrent thing sometimes. (NU19)

My dad kept saying to mum that she kept eating sugary sweet things, when she had her first grandchild. My dad passed away 15 years ago, but five years after he passed away, she was diagnosed with diabetes, then her kidney function went down, and that's when they found out she had a one kidney, which they said, could have been from birth. (U13) [Daughter of participants]

I would just feel thirsty all the time, but then I developed a really bad infection. Then I went to the walk-in centre, and my sugars were like at 26 and then I came here, but then it was like one thing after the other, and the infection got really bad. It was quite a negative experience. (U8)

We had a house visit from the doctor, and the doctor asked me to walk in a straight line, I couldn't really do it, so an ambulance was called and he suspected pneumonia. When I got to hospital, they did blood tests, and they realised that was not the case, and that's when I was diagnosed diabetic. (U8)

When I was first diagnosed as a diabetic, I had to take a sugary drink and then you have to wait two hours and then they check your sugars. I did not know what were the parameters or figures that indicated me as a diabetic, but I thought it was due to my weight. If they told me at the time that this is the plan they want to go off, and monitor me 12 months, I am sure I would not be on some of the medications I am on now. Perhaps they thought things are not going to change, better put-on medications. But I am more educated to when I first arrived to this country. (NU17)

I have a negative attitude towards my Diabetes and didn't take it seriously, it's with all sorts of illnesses. Even with asthma, when the doctors diagnosed me with asthma, my dad said I don't have it. He was in denial. He said you don't need an inhaler so I managed without it. (U7)

I really struggled with my regime; it was very difficult to remember to take metformin three times a day. (NU19)

I think the reason I developed diabetes is due to stress, especially when my son passed away it was a shock to my system. I was unable to control my blood sugars. (NU13)

My husband is very helpful he assists with the house work, he helps me do the laundry, especially over the last few years since I have developed multiple health problems such as diabetes and blood pressure. He also helps with medications and checking my blood sugars. (U10)

I do get lots of support from my children, as I live two or three minutes away. They all come according to their convenience; everyone is close by to me all my children, daughter-in-laws, and grandchildren (U10)

Also, she relies on us to help out, she hates needles so me or my sister have to help her with insulin injections (U11)

#### **4d- Emotional consequences- upset, depression, anxiety and hopelessness**

I want to fight this and get better. Many people in our community tend to get very upset but I try not to get upset about my health. I need to be strong for my children, so I try control it

Yes of course, I try not to worry but I look for way to get better, for example to eat better, that the least I can do right?... I know if I worry my blood pressure will increase. (U1)

Obviously, I am not happy, but I am beginning to come into terms with it, I know diabetes affects certain parts of the body, the doctors have kind of explained that to me. (U4)

I have been very depressed since the diagnosis. My religion and faith in God have helped me feel more normal. FLO has also helped me bounce back with my life. (U18)

When I first heard the diagnosis of Diabetes, I was really down, and when I was on the ward it was all old people, I was like where are all the young people gone, is this a disease that only old people get? I just wanted to hide myself, what is happening to me? My healthcare providers have really supported me and introduced me to FLO which has helped me even more. (U18)

I feel like I am stuck with it and I should just leave it. (*Participant laughs*) I do have a negative attitude towards my condition. (NU5)

I do not feel any stress or depression. I am living with the condition there is no point to worry it is not going to stop, it'll only get worse. (U8)

I definitely do feel both, anxious a lot, and depressed at times too. I don't know if it's related to my diabetes, but it's always like an emotional roller coaster. So, I can be up at one time and really low sometimes. (NU19)

You know how we previously spoke about my depression and mental state, I think at times I will be really good and take my medications, but at other times I will just think what's the point and not take them. (NU19)

To me depression means that you can't sleep properly, or have trouble getting to sleep at night... that what you call depression, even if you can manage 2, 3 or 4 hours of sleep it is still okay. Because those who are depressed don't sleep well, right? I don't have any issues sleeping. (NU14)

Like, I have diabetes, then I had a by-pass surgery and an aortic valve replaced... so related to that... well in life you have anxiety for various reasons so when I have anxiety, I feel like I have angina... you can say anxiety and stress come together. (NU7)

I have had it for 7 or 8 years now. At first, I didn't like it and I was thinking why have I got it, and all I did was cry, and then I didn't want to inject myself... (U14)

About my diabetes? I did at first felt depressed, but I am okay now, I have come in to terms with it that if I am not going to inject myself, I won't live... so you just get on with it, you know it is a way of life... I don't call it a disease anymore, I got diabetes it is just a way of life, and you just get on with it ... sorry it is just how I look at it. (U7)

I do over think things, and feel very depressed and anxious with what's happening to me. (U19)

I learnt what you and I both know, that whatever you put in your mouth and what sort of the effect it is going to have, so it is self-infliction. I don't feel stressed as such. I am far more educated than that, I don't let these things bother me. (U5)

Well, I'm not too sure; I don't know what's caused it all, what's happened has happened. I think it's the stresses of life that has made me unwell, we can't change the past we can only work forward towards the future. (NU1)

That comes part and parcel with diabetes (*laughs*). Depression is one of the things that comes with it. I probably suffered It at a really young age, like going back to 7 or 8 years when I didn't even know what it was, even when they ask you during the clinic 'are you depressed', because I didn't know what it was, I couldn't really answer yes or no. Do you know what I mean? (U8)

I used to have a lot of fits in my sleep to be fair, it was mainly my sleep when it would happen. On a level some hypos were self-inflicted. As in deliberately done, it was at a point when depression was the worst. (U8)

Stress does affect your eating I am afraid (*laughs*), I got a stressful situation at the moment my wife has just been diagnosed with a heart condition; she may need a by-pass by the end of it. (NU8)

I am not depressed or anxious about that I am actually looking forward to doing a bit more work to improve my figures. (NU8)

Not scared, but concerns, if the disease goes untreated, there is more chance of you getting a stroke, it can affect the optic nerve in your eye, eye sight. Feet, diabetes affects the feet; if it goes untreated it could lead to amputation, nerve damage to your legs. There are lots of concerns. (U2)

Obviously, she is not happy, but is beginning to come into terms with it, she knows diabetes affects certain parts of the body, we kind of explained that to her. She is quite negative but does feel that if she goes off the insulin, she would feel better, as she doesn't want it. (U11) [Daughter of participant]

I do feel depressed with my condition it gets in the way of my happiness. (NU19)

My mum also had gestational diabetes but she controlled it well, but me, I was very non-serious and didn't think much of it at the time. But now I realise the seriousness. I have had it a very long time now I was 19 years ago. But now I am self-managing better as my boys need me. (U6)

I used to be very upset about my health and had low motivation. But I have faith in God, and that he will make everything better. (NU1)

I am very upset due to all the health complications; I don't feel happy. I can't even go back to Bangladesh because of my kidney problems. (NU20)

When I first heard the diagnosis of Diabetes, I was really down, and when I was on the ward it was all old people, I was like where are all the young people gone, is this a disease that only old people get? I just wanted to hide myself, what is happening to me? My healthcare providers have really supported me and introduced me to FLO which has helped me even more. (U6)

I don't really think religion or God has any relevance to my condition. Although, I think FLO would help me improve my adherence, I really struggle with taking my tablets on time... I take multiple medications due to uncontrolled blood sugars and it becomes quite depressive. (NU19)

#### **4e- Fear consequences (complications) of condition**

I only fear God. I don't fear anything else. I think just I should continue to take medications on time, adhere to the health text messages sent and take care of my health. (U10)

Fear of what? I can only live as long as God as allowed me, everyone is going to die sooner or later. (NU15)

I do have fear of getting worse, but whatever is meant to be will be, if it is meant to be happen it will. (NU10)

She did fear for the worst, she always thinks if she doesn't do this that will happen, she is quite anxious, she has the drive to do it, as it'll get worse. (NU3) [Son of participant]

She says she is past stressing about things like her Diabetes, what's meant to happen will happen. (U11) [Daughter of participant]

Yes, there are emotional consequences... because sometimes you like to have good food but you can't, and sometimes your body... like I said my eyes feel sticky or I feel thirsty and I think it is the sugar... So, I have to be very careful. (NU20)

23If you are not taking the medications and if you have read about diabetes and what it can cause it is scary and fearful. (U7)

**4f- Religion and faith (for example, God is the cause, belief in pre-destination vs medical causes)**

I am very religious, my religion is very important; I can give up my life for it, if you like. But I believe in Guru Nanak's Sikh teaching, that every human being is equal. (NU3)

I feel happiness, sorrows, health and disease are all pre-destined. It is all written on our hand. (NU3)

I do believe in fate and reincarnation, but I haven't really thought about that, I have not really associated my diabetes with religion. (NU14)

My condition is due to medical causes, not God. (U5)

Well, it has happened now, I can't change the past. It was meant to be like this.

God doesn't put people through pain like that, whatever it is, it is predestined and, in my fate.... God does not make people suffer. (NU10)

It was supposed to happen, it was in my fate, and God did this for a reason. (NU9)

I don't think religion has anything to do with self-management or my illness. I have never thought of it that way. (U15)

I don't think religion plays a role, I know there is a God out there at the end of the day, but physically if I do need help the doctors are there to help me. (U13)

I think my pancreas has just stopped working, that's it, it's just an individual thing, I don't think it is God. A person becomes ill naturally just like that, you see one individual with one disease and then someone else with another. It is not God. (U8)

It is a text from God, if it was in my hands, I would not make myself ill, some people have heart attacks, some have cancer and so on. It is all in God's hands. (NU9)

I believe more of the science side, than God in relation to my illness. (U8)

I think it is her own doing (*laughs*), but let me ask her. She said it's not a punishment it is a blessing from God, she has it for a reason. She feels like God knows what's happening. (NU3) [Son of participant]

I believe in all gods and religions. I feel that God helps me deal with my pain, even with my illness I feel it is because of God I have the strength to carry on. (U9)

I think whatever has happened... God has had a major play in this game, in life, because who wants to have diabetes, who wants to have kidney failure, who wants to go blind... but the way I look at it I tell you upside down, I think of it that God wants me to look after myself, that why he has given me this. (U6)

It is personal... going back to my experiences of when I had my by-pass, I had belief in God, and left it to him, and that he will look after me, it made me strong with his grace. (NU7)

They tried to persuade me, they kept telling me the complications, but I didn't care at that point, I thought if it is meant to be it will be. It is all in God's hands. It's the same with FLO, I don't think it's any good. (NU17)

Our beliefs have led us to believe that if it is meant to be it is meant to be, simple. It is all due to destiny. So, for that reason I fear nothing. (NU4)

I do believe in fate and destiny; I am not sure if God can make me better. I just believe that I am keeping it up and keep going. (U1)

I do believe in miracles and God can give life miracles. God gives me signs of getting better. (U6)

I used to be very upset about my health and had low motivation. But I have faith in God to make me feel better. (NU6)

If I am very depressed with my health status, I recite Quranic verses for faith. (U11)

I do believe whatever happens is for a reason. I am religious and believe in God. I am a firm believer and I look for guidance in God. God can do anything; he can cure me if he wanted to. (NU19)

If God has predetermined my illness, then only he will make it better, I don't believe in using a text messaging system to try improve my health. Only God can make me improve. (NU17)

Although, technology is good and the texts are educating me, it doesn't matter how much you are suffering, only God can restore happiness and health. (U17)

I am Hindu, but I don't really follow my religion. I don't think God or religion has anything to do with my condition. My condition is to do with my own doing. Diabetes is due to biological reasons not because of religion. I do think science and technology are quite common and important these days. (U18)

I am not really that religious, I do believe in God... But in terms of my health, I am more reliant on scientific evidence and treatments that can treat my symptoms. (NU19)

If God has predetermined my illness, then only he will make it better, I don't believe in using a text messaging system to try improve my health. Only God can make me improve (NU17)

#### **4g- Controlling symptoms of disease**

It's a bit of a downer when it is high in the morning, which is inevitable with diabetes, sometimes it is high, sometimes low. It's one of those things, but you just get on with it. (U7)

I try not to worry but I look for way to get better, for example to eat better, that the least I can do right?... I know if I worry my blood pressure will increase. (U7)

The most important thing is my health, If I remain ill, I can't function well at work. So, the best thing to do is to make sure all my symptoms are controlled and adhering to my treatment. (U7)

My symptoms are not well controlled at all. I feel thirsty most of the times, and find that I go toilet a lot of the time. (NU19)

Prior to being diagnosed, I'd always need to go toilet and would want to keep drinking, I would go to Tesco's or to Gourmet Burger Kitchen, and would come with five or six drinks, I would always be drinking. I didn't really understand the symptoms. (NU19)

The symptoms are well controlled; I know what I am doing. I just get on with it, as I have had it a while. (U8)

Erm... I don't think I'm fully confident, but I do feel I have some responsibility to make my symptoms better. I feel there are somethings beyond our control. (NU16)

I am quite happy with my blood sugars and am in the process of getting it even better. (NU8)

I wouldn't say symptoms are under perfect control, but I have an awareness and importance of it. It wasn't when I was younger though. (U17)

I remember I used to wake up in the night and I used to go in the cupboard and drink cordial because I was always thirsty, and I used to wet the bed, because I was having a high blood sugar and was needing to wee a lot, when I was younger, I can remember these things from that far, which is kind of strange. (U8)

I know how to improve them, but I don't know how to prevent them, I don't know if there is such a thing as prevention in this. (U8)

My sugars tend to be 6-7, nigh times can be a bit unstable sometimes, [Son]: it depends on what she eats, sometimes she can have hypos if she has not eaten enough, so her sugar does go down. So, we adjust her insulin for the next day ourselves. (NU3) [Son of participant]

I do keep a good diet to keep my blood sugars controlled. I don't eat Mithai anymore, and also do not purchase any juices, mango juice especially as it is very sugary.

I really look after my health and control my symptoms well. I never eat more than I should need to, I also eat less sugary things. (U12)

My symptoms are not controlled too well I have too many illnesses which has led to a lot of complications with my heart and kidneys. I want to make myself better and live for at least another 10-12 years. (NU2)

#### **4h- Needs carers**

I cannot entirely self-manage my condition, I have a carer that comes to visit me, and she does the house cleaning. However, I can prepare my own food whilst sitting on a chair. (NU13)

I sometimes have carers five times a week who assist me with cooking and cleaning. (NU1)

#### **4- Self-management Activities (Activation)**

##### **5a- Confidence to independently self-manage condition**

If I'm at work I normally console my manager, if I'm at home it'll be my Mum or my friends. (U19)

Yes, my family come to visit on weekends, but still, I know I have to look after myself on my own. (NU1)

She's very switched on with watching the TV, the Asian channels that have medical professions on there that advise you on what to do to control your condition and she will listen to them and try them herself independently. (NU3) [Son of participant]

I never really could discuss my problems in the past, but now I am more confident and honest with not looking after myself, or sharing that I could be doing this better but I'm not.

Whereas, before I would just say yeah, yeah everything is okay, just to be done with it. But now I am more honest and do think I do need help with certain aspects of my health. (NU15)

She's normally capable on her own. For example, if she has high blood sugar, she knows what medication to take. (NU16) [Daughter in-law of participant]

I don't require assistance normally, I just take my medications, I just take that on time. (NU19)

I normally do administer insulin myself, but sometimes my wife helps me. (NU7)

I am quite good I just get on with whatever it is that I need to do, but then at the end of the day if I am poorly, I'm poorly. (U7)

He does his medications and I do mine. He's a diabetic as well. Were both independent. (Patient describing how her and her husband both independently manage their diabetes and take medications). (U7)

I am quite confident and independent in terms of my own health; I mean by being a professional in healthcare myself I know how it is. When I was doing my dentistry, I qualified from the university of Bombay, which means we used to see 250 patients a day. Also, when I went for a knee operation the consultant said to me, I am the best patient he has ever had, it was six weeks recovery period, but I asked him if I could play badminton now, he said yes. (U5)

She does control it herself; she knows she's got high sugars, so she will do something about it. (NU3) [Son of participant]

She is confident in her self-management regime dosset box assists her. So, she does not need help from the family. (U3) [Son of participant]

Medications have helped, but the bigger contributor is her self-belief that she has to do something about it herself, and also if she is not meeting her targets, she needs to take action to sort of prevent it. (U10) [Husband of participant]

I know what to do, but I wouldn't say I am confident it is just okay. (NU10)

I am very confident in myself; I have had a fair bit of education regarding diabetes and I know what my glucose levels should be and what my HB1A figure should be. Yes, I know what diabetes is all about. (U15)

I don't think I am self-managing confidently. I would like more education on my condition and well-being as it will benefit my well-being, as I have many health problems. (NU19)

**5b- Non-adherence to medications and poor health outcomes- (views on taking medications, monitoring health parameters)**

She said if she stops her medications maybe she can improve her self-management. (U11) [Daughter of participant]

My blood sugar was very high, at 96, and I now need injections, but I said I do not want to take injections. (NU1)

I feel scared, so I negotiated with my healthcare providers to only administer insulin injections once a week only. (NU1)

My lifestyle is not healthy at all; I like to eat everything that is bad for me. I don't bother too much. (NU20)

Some people struggle with swallowing the metformin like me. I would prefer it in a different form such as in powder form. I sometimes stop taking it because I have trouble swallowing it, which has affected my health a lot. (NU19)

I'm terrible at adhering to my medications, but I am getting better. Also, we don't get long breaks at work, so the job takes over, and everything else gets put behind the back burner. I normally take my medications to work but I leave them in the staff room upstairs, so I don't always manage on time. (NU19)

I don't experience barriers as such, but I remember at one point there was a lot of medications I was taking and I felt very overwhelmed, for example, I am taking statins for my high cholesterol and Ramipril for my blood pressure, so it already 5 or 6 tablets a day, but at one point it was even more. So, I think that was another thing... even though it was for my best interest it was still quite a lot of tablets. (NU19)

I didn't realise how serious it was, I was with big bottles of coke and that. I did not know the symptoms, and I didn't know what was wrong with me. (NU19)

Well, according to me the cause of my illness is family problems at home, sometimes it can be the diet or food I am consuming, for example, curry isn't good. I do have to look after my diet, but I don't look after myself much, when I am caught up in household problems, I do miss meals sometimes. I just can't seem to follow my regime when I am stressed with other things at home. (NU1)

I used to have hypos before, but now my sugars are always too high, I can't bring it down to normal sometimes. So, it is not well controlled, I felt a lot of heat in my body, so they changed my injections, but it has taken time to get used to the injections. (NU13)

I have previously been very ill in hospital, I've had to stay in, and my sugars were between 28-29; they even tried to teach me how to administer insulin, but I refused to, I didn't want to inject myself. (NU2)

Ten years ago, I did not care, but now I most definitely do. As I feel I am only getting worse. (NU10)

She kept refusing to even go on to the Insulin the doctors kept asking her over the years, she said no. She said she is just very fed up of taking medications. (U3) [Son of participant]

The insulin she wouldn't do herself, because she said from the very beginning, she's not doing it. So, we said we will do it. (U11) [Daughter of Participant]

I didn't really pay attention to it, but if I knew what I know now, the indications etc, I think things may have possibly been different, if they were explained in more detail, and in depth as to what the complications could be. (NU8)

I don't exercise or diet but I am losing a lot of weight, my sugar levels are increasingly high. So, I have come here. (NU5)

I don't check my blood sugars daily; I don't find it important and also no one has ever told me to monitor it regularly. (NU11)

I think my diabetes came into play when I got pregnant. It got very seriousness it affected my eyes, I developed retinopathy. This was all due to poor compliance. But I have realised the effects and getting back on track (NU7)

My blood sugar was 11mmols today because I had good food, I also had two bananas (laughs). I tend to do what I feel. (NU20)

#### **5c- Daily routines**

I think peoples tend to be lazy in SA communities, some don't bother with their health they just sit at home, and there are some that also visit doctors and do take care of their health. (U15)

My wife, gives me oily fish salmon twice a week, or sometimes when I do over eat, or have a lot of sweets she tells me to stop. So, in that way. (NU7)

Well, I have had it for so many years now, I have it under control. I have gotten used to living with it. (U6)

I am trying to improve; I stopped taking sugar in certain things, such as in my tea. But I didn't like it so I started again. (NU9)

I go jogging. I usually go around the block once or twice; it keeps my legs fit. I get bored sat at home. (U1)

Well, I am vegetarian, but on Friday we like to have a sin day, the kids like to have fish and chips, I tend to have spring roll and chips. But I like to cook lentils, fruits and vegetables; I love fruits like apples, peaches, banana and watermelons. (U7)

It is just standard medications that I have been taking for a while, 6 or seven years, or maybe even more. So, it is just continuous and is routine. (U7)

Well, I used to take my medications after breakfast, but I would often forget. But now what I do is when I wake up, I brush my teeth; I take all my medications and then do all my prayers. In the evening when I take my food, I take the other bits. (U6)

Okay, so in the morning I have all my tablets, like my diabetes, my blood pressure tablets, and my thyroxine tablets and the rest of them that I have in the morning, and then I go to work and have my tablets in the evening that I need to have. (NU8)

I eat less spice now, and only have chapatti once a day; in the evenings I normally have boiled food. (NU1)

She'll eat tomatoes like she said, and eat before 6 o'clock, also doesn't have many foods with carbohydrates such as potato or rice. So, she has her routine. (NU3) [Son of participants]

I don't eat chapatti regularly; I have it very less, I sometimes have boiled vegetables, or something like bread. I have been a vegetarian for 25 years now. (NU3)

I don't feel too stressed, I am strict with myself. Particularly with my diet and the timings of when I eat, for example, I have breakfast sharp 8:00, if it goes over 8, I have to reduce the amount I take. (NU3)

She doesn't check sugars daily anymore because it's stable, we got it checked today and they said it was okay, that was it. (U13) [Daughter of participant]

Well, I don't like to have breakfast; I always used to wake up with my blood sugars high, so I was never in the mood for food first thing in the morning. So, I would wake up, check my blood sugars, at the present moment they're okay I still wouldn't eat anything until a couple of hours later, and then I probably just about 'stomach' a small banana. I wouldn't have anything bigger than that, like not even a bowl of porridge, or anything substantial if you know what I mean. (U8)

I guess it's just become part of a routine if you know what I mean, literally as soon as I wake up, I do my blood, because I am excited to see what it is. (U8)

She doesn't have a normal timetable that normal people have, at the moment what she does is because she goes to bed late, she has her breakfast late, so she is also having her lunch late because of it, we are constantly nagging her to correct it. (U11) [Daughter of [participant]

I remember which ones to take as it has become part of my daily routine, and I can read the labels if I forget. But I know I take two in the evening, two in the evening. (NU1)

#### **5d- Adherence to positive lifestyle – Interested in health and making changes to diet/exercise**

For example, my diet. I don't really eat much I just can't really exercise much, although it is summer now.... I do sometimes feel like taking walks and exercising. But I only eat two chapattis in the day. I haven't eaten since morning though... I took a taxi to get to my appointment the driver was a nice Indian man who assisted me on my travels. (NU13)

In the morning I have brown bread with margarine and jam, but the nurse told me to stop having jam, so I will stop it. But otherwise, I don't eat sweets or cakes with my tea, I have my tea without sugar. (NU13)

I manage through family support which is most important, and also through diet and exercise. (U1)  
 I don't have Asian sweets, or flatbread and potatoes. I have given up everything common in the SA diet. (U5)  
 She has sacrificed the original Asian diet, to get better. (NU3) [Son of participant]  
 I have promised the doctor that I will diet, exercise and lose weight. I do try to walk but I cannot walk long distances due to developing arthritis in my legs. (NU19)  
 She knows what's healthy; we have entered her into a diabetic healthy eating plan. (NU3) [Son of participant]  
 Doctors put me on medications and I must adhere to them. I do go out to exercise and walks also. (U17)  
 I am trying to improve; I stopped taking sugar in certain things, such as in my tea. But I didn't like it so I started again. (NU1)  
 I go jogging. I usually go around the block once or twice; it keeps my legs fit. I get bored sat at home. (NU7)  
 I am exercising more; I am eating healthier... I am going through the menopause at the moment, so I am feeling quite bloated and my hairs getting thin. I am controlling eating chocolates, crisps and sugary things like ice-cream because you know what it's doing to your body. I mean there is such a thing as a treat as we're all only human at the end of the day, were not robots, sometimes you want something cold and cool and sweet. But you just need to control it and balance in your life. (U6)  
 I go gym three times a week, eat fish twice a week... but definitely I feel most support from family I would say. (NU7)  
 Myself and my family are adopting healthier lifestyle; recently we have joined the slimming world. (U7)  
 I think it's got to the point where she has to do it whether she wants to or not, because of the conditions, like eating healthier. (U11) [Daughter of participant]  
 She was having a lot of medications and she felt the important thing for her was to reduce the tablets and focus on other stuff she can do herself to control it. Tablets help, but it's not the main thing at the end of the day it is also your lifestyle and what you eat. (U11) [Daughter of participant]  
 In terms of exercise, she will go out, she walks, and also goes to the temple and meets other people from our community, rather than to sit at home on her own. (NU3) [Son of participant]  
 I want to improve my health; I want to make sure it doesn't get any worse. I have been talking to other people and shown an interest to get better. (NU3)  
 I was exercising before but now I don't. After my operation I don't feel as motivated I feel I need to rest more. I do eat healthy though, all the 'mithai' and 'ras-malai' (traditional sweets) has gone out the window. The doctors also tend to ask me what I am doing as my blood sugars are well controlled, I keep a good diet and walk everyday no matter the weather outside is like. (NU2)

#### **5e- Understanding, knowledge and adherence of each of prescribed medications and regime**

I know which medications to take for my sugar levels, and blood pressure and all the rest. (U5)  
 Yes, I know my regime; I am currently taking insulin and tablets to control my diabetes. (U7)  
 I am fully aware that I should not do that. I think sometimes I may need someone else to pick that cake up before I do. (U15)  
 I never miss or forget my medications. I always remember to take them on time. (U1)  
 I don't know my medications like that, I can't read the names of the tablets as they are in English; I'll have to show you what they are.... It's normally, blood pressure control, cholesterol tablets and for sugar. (NU1)  
 It is just standard medications that I have been taking for a while, 6 or seven years, or maybe even more. So, it is just continuous and is routine. (U7)  
 The doctor told me to take it once, at the chemist they told me to take it twice, my family gave me two, it was a misunderstanding or miscommunication. It was 120 mg then it was changed to 240, it was for my kidney problems. When I took the increased dose, I blanked out, my eyes wouldn't open, and my body felt heavy, I was lucky my son was at home, so they called the ambulance, they gave me more injections, and took me hospital straight away. (NU1)  
 I wouldn't say she understands them fully a 100 percent, but she knows the basics, for example if she had high blood pressure, she'll know why she is taking it etc. (NU3) [Son of participant]  
 I understand my regime very well as I live alone there is no one else to give it to me. So, I understand it quite well. (NU20)  
 I have a good knowledge of diabetes; I have had it for 33 years, so it comes with 33 years of experience. (U5)  
 I have got full knowledge of all my medications. I have an aspirin tablet which thins the blood, I got the blood pressure table obviously for my blood pressure, an anti-cholesterol table to lower my cholesterol, but also if you can cut out the saturated fats you wouldn't need that tablet. So, yeah, I do know my tablets. (NU8)

I know what to take for my illness, but I do get confused as I have so many tablets to take. (NU16)

I know how to take my tablets properly, I experienced hypos with glicazide, so I stopped taking them altogether. I would only take them If my sugars are very high. (U7)

I know all my medications very well and also about my condition. I think I understand more than the healthcare provider (laughs). I am able to speak confidently with the doctors if there is a problem. (NU20)

It is very important to have a good understanding of my illness... only then you know what your medicine is for and the benefit of it... my doctor is very good and helps when I need, I feel satisfied and confident with what I know. (U2)

**5f- Understand my health problems or condition, consequences of poor compliance and treatment options**

Education definitely makes a difference to the way you self-manage your illness, having that advantage enables me to interact and engage with my healthcare providers through FLO and technology. (U1)

I have diabetes, high blood pressure and cholesterol, diabetic retinopathy. I've had a lot of treatment in the eye, so I can see a lot of floaters... So, I've had a lot of laser treatment for that. I am also deficient in vitamin B12 and Vitamin D. (U4)

I understand that it is the medication is for my health, and that the responsibility is with me to take, otherwise my health will deteriorate. So again, sometimes I think that's what we struggle with, it took me a long time to understand what the importance of controlling my diabetes, the meaning of being diabetic and the complications it can lead to such as kidney problems, eye sight problems and problems with your feet. I didn't really process that very well. (U4)

Yes, I am aware that if I do not go see the doctor my health and condition will worsen. (NU17)

Without taking insulin regularly I wouldn't be here, I wouldn't have survived. (U7)

I know when I have certain problems, it is necessary I go to the doctor. I was telling Dr De, that I feel really thirsty, and my eyes are sticky... for me it is a sign of high blood sugar. (NU4)

If you are not taking the medications and if you have read about diabetes and what it can cause it is scary and fearful. (U8)

I know, especially when I have hypo, I know what I need to do. (U7)

I can't afford to miss a dose, because of my blood pressure tablets as well, If I don't take that as well then, I am buggered for the rest of the day because my blood pressure is high, if I don't take it, I won't feel myself at all, all day. (U7)

Diabetes is very dangerous, and I am not going to end up in hospital by not doing what I feel like. I'd rather do what I've been told to do. (U19)

I did take my medications, but I was a little bit apprehensive and that do I have to take them? but I found out when I went to the course why I needed to do this why I needed to take that, it educated me a little bit more, then I was okay. (U15)

If she finds there is a problem, she will identify it herself, she may not know what the real root cause is and she may need to go to the hospital or to the doctor, but that's no different to you and me, for example, we can complain of this hurting or that hurting, but we don't know why. But she doesn't have great awareness of the treatments available, without talking through it with the doctors of course, of what cures are out there. (NU3) [Son of participant]

I know that with diabetes you do have to be strict with diet and give up certain foods, but even then, if my sugars aren't controlled, I take my tablets and normally bring it down to 4-5mmols. (NU19)

She needs assistance with administering the insulin; but she knows she's got high sugars, so she knows we have to do something to bring it down. (U11) [Daughter of participant]

My sugars haven't necessarily gone down due to medications; it is mainly due to diet. I know that if I eat too much or too little the sugars will come up to at least 10mmols. (NU1)

I do have an idea, the doctor would tell me when I was younger, but I wouldn't take the medications at the time, I would throw them away, because I did not want to take them. (U8)

I don't know what caused it actually, it could be due to family history of diabetes, although when I first got diagnosed it none of us had even heard of it in our family. (NU12)

I mean when she was first diagnosed with her diabetes it was a big thing, and she was very stressed with eating on time, and having her tablets at the right time. But now because it is well controlled, she doesn't really mention it now. She isn't taking tablets now for her diabetes, as she her sugars were stable; the metformin was not good for her kidneys, as her kidney function went down, but she hasn't needed it since. (U13) [Daughter of participant]

I have had diabetes for ten years, high blood pressure, and recently they have identified protein leaks in my kidneys, but I have been told they are getting better. It is part of diabetes unfortunately. (NU2)



From today's follow-up the readings show there has been a weight-reduction, a cholesterol reduction and a protein leak reduction in my figures. I am interested in something that can help me come off all the medication. So, I can come back in a couple of years and say I did what you had asked me to do and it has worked. (NU8)

I do know the cause of my illness; it's mostly to do with myself to be honest. My eating habits have mainly been the issue. I have cut back on the amount of carbohydrates I am eating per day, and also watching how much fat is in the food I eat. It is all about food labelling, a few years ago I wasn't even interested, but now I want to see a change and I am making an effort, and looking at the food labelling now. (U15)

They say it can be due to my previous abdominal operations and the disease probably started because of that. But I don't worry about it much I don't think "why have I got blood pressure", Instead I know that I need to control it, right? (NU13)

To begin with I was quite shocked I didn't really know what diabetes was. People were saying it around me, as I presented with symptoms, but I didn't really have an understanding of it. I was drinking more, going toilet a lot. One of my aunties actually said to me are you sure you're not diabetic, and I was like I don't even know what that is, until I first got diagnosed. (U6)

I was quite young when I got diagnosed with it, I did not really take much notice. But it is due to consuming too much sugar, what else could it be? (NU1)

Well, it just happened., people in our community all have diabetes for some reason. (NU5)

When I was a teenager, this is talking probably 20 years ago, I don't know if people had eye problems or protein leakage in the urine etc. Do you know what I mean? I don't think it was that complex or whether it was even associated with diabetes, or whether it was associated with poor control even, should I say. Erm, I don't know if it was known then or discovered, so I don't know. It was just never explained that this could happen, or that could happen. (U8)

I definitely think employment and education are linked, and are quite relevant to be able to use a system like FLO. (U4)

#### **5g- Text messages aid self-management**

Yeah, she manages through the technology and use of text messages which normally prompt her, even the BM monitors and blood pressure machines all have a rating or reading to give an indication. (NU3) [Son of participant]

I felt like I was on top of my health because of the text messages. I think it was better whilst I was using the system, you know like 'Big Brother'... someone is watching you and you are having support... and I want to keep my health going well. So, in that way it was helping. (NU12)

I think systems such as FLO are brilliant, especially to help remind me to check my parameters at the right times. The messages are educational with advice of controlling my blood sugars. (U6)

Text messages are very effective and aid in the self-management. In the last two years my wife's healthcare outcomes have really improved through the guidance provided via texts. (U10) [Husband of participant]

For me the FLO has done wonders, I signed up to a study a few years ago, I really loved it, it has helped me so much in terms of my self-management. I am no longer using it since the study stopped, but I think it has really helped me adopt a better lifestyle. (NU7)

FLO has helped me get back on track, the messages were very informative for me especially after being newly diagnosed. It sent me good reminders for my follow-up appointments and also good advice to keep my blood sugars under controlled. (U9).

The system is very good it has helped my family assist me to manage my diabetes. (U10)

The system is very handy and helpful, especially in our situation, we know when mum has an appointment, and when her blood sugars or Insulin are due. (U11) [Daughter of participant]

She has made some improvements via FLO, but she is not 100% with her health and self-management. (U11) [Daughter of participant]

Generally, from the information you have provided about the system, it sounds pretty good, especially for those needing reminding to check blood sugars and blood pressure daily. [NU13]

FLO has helped me; the texts are very good. I manage with the system but sometimes when I need to send my readings for blood sugars or blood pressure, I ask my daughter to help me. I think translated messages would be better. (U13)

If it was not for FLO, I think I would be forgetting to take my medications on time and have difficulties to remember to monitor my blood sugars. I have a busy schedule so having FLO is convenient. (U14)

I really love FLO I have been using 'Patient Knows' but that only shows me my blood test results. On the other hand, there's FLO which has really helped me keep on track with my Diabetes care. I love receiving reminder texts regarding my blood sugars and updates on my treatment options. (U15)

I am not a FLO user but I think it can assist and improve self-management for those struggling. I am doing fine for now so I don't think I need to use it. (NU16)

I think a system like FLO would really help me remember to take my medications on time and check my blood sugars when needed. (NU19)

FLO messages have been just great. I think it is very quick and easy to use. They keep me well informed with new updates and encourage me to keep a record of my self-management progress. (U18)

Messages are easy to follow, very educational and provide good tips on improving my health. (U8)

Generally, the system is okay, it is easy to use, provides support for those who may have difficulty remembering or adhering to their regime. I think the system could be even better if messages were translated for those people experiencing problems with English. (U1)

The system offers good support for self-management but can be improved to suit patient needs better in terms of timing of delivery. (U12)

I think so far FLO has been okay in helping me to remember my regime and checking my blood sugars. (U17)

I think FLO would really help me with my regime. I have heard about other people I know, that use the system to also manage their regime. However, I won't be able to follow the prompts or messages as they are English. (NU1)

I think a system like FLO can help me. I have heard the messages provide good reminders to check blood sugars on time etc. But English messages cannot help me. (NU3)

Messages are very useful and helpful. Has helped me connect with my care providers when I need support. The information provided in texts helps me do better. (U20)

**5h- Support from healthcare providers, confidence to discuss issues related to condition and visiting healthcare provider when needed.**

I'm probably more comfortable talking to Jo, which is the diabetic nurse. I think it's because she's a little more attentive. (U15)

Me being the person that I am... I tend to go by guidance from other people normally, I usually go to doctors and nurses for advice for what I should and should not be doing, or the encouragement to say 'I really don't think you should eat that piece of cake. (U15)

I never really could discuss my problems in the past, but now I am more confident and honest with not looking after myself, or sharing that I could be doing this better but I'm not. Whereas, before I would just say yeah, yeah everything is okay, just to be done with it. But now I am more honest and do think I do need help with certain aspects of my health sometimes. (U15)

She doesn't shy away from problems; she expresses her needs okay. (NU3) [Son of participant]

I am not embarrassed by the doctors (*patient laughs*), but I do struggle especially at night especially when my blood sugars are high. (NU1)

I've been advised by healthcare providers to only administer subcutaneously in my stomach region nowhere else. (NU17)

I feel like the staff does support me as they have my best interest at heart, maybe more than what I do. So, yes, I do feel there is a good support system, and I do feel that they listen, especially the nurses, they do listen which is good. (U8)

The doctors and nurses are very good; these are the people I met when I first got diagnosed. They've helped me a lot over the last twenty years. (U6)

I go to the doctors soon as possible when I need to see someone. The doctors are close by to where I live. (NU19)

I visit the doctors usually if I don't know something about my health. (NU16)

I don't know, I think it is cultural as some doctors are Indian like me also, so I think it's a cultural thing, or stigmas attached to certain health issues. Some GPs, you won't believe, they are doctors and they feel shy... I mean they are doctors they shouldn't feel shy... whereas, Caucasian doctors are reassuring through their gestures... like when they nod to confirm they understand... I mean doctors know all the parts of the body, and some of them are still shy. So, it can be uncomfortable discussing certain health problems (*laughs*). (NU7)

What I believe is the best you manage the better you get. With the aid with GP, doctors and nurses, I am managing. (NU8)

Susan (diabetes specialist nurse) helped me out quite a bit, like how to inject myself, so she really helped me with educating me more in regards to Diabetes. (U7)

When I go to the doctors, my doctor just tells me what I need to have and what not to have. But if it's not working, I go back and say look this tablet not working. (NU19)

I could self-manage well before, but now my mind is elsewhere, my husband passed away also so I have lost that focus on my health, I could speak to the doctors at first too and also understand them more confidently, but now my mind is somewhere else, I sometimes don't remember or I just don't realise I have to take my medications on time. I now feel more reliant on my family to communicate with my healthcare providers; I can't always express my needs. (NU1)

If I have any problems at all, I also tell the nurses and the doctors too. I normally dialyse Tuesdays Thursdays and Saturdays if I experience issues there, I let them know if something is bothering me, then they deal with it from there. (NU9)

Yes, like I have given you an example, Angela... I can share with her without being judged... And I appreciate if I can get more information about my condition. Which is why I wanted to participate in your study. (U15)

Susan the diabetic nurse has told me I need to bring it down to single figure. In the night my sugar goes down but, in the morning, it is very high like 12mmols. (U19)

FLO has been amazing I don't know how I ever managed without it. It has really optimised my self-management and really motivates me. I think an advantage is that it is very simple to use. I haven't had any issues with it. (U2)

### **5- Experiences of utilising technology and text messaging**

#### **6a- Duration of FLO text messages**

I think I have been using it for at least three years. I do like it very much so. I was actually one of those who retired and did not like to use computers... but then mobile phones came after especially smart phones. (U5)

We have used the system for a few for two years, In the last 24 months her diabetes has really improved through the guidance provided. (U10) [Husband of participant]

I have been using the text messaging system for 3-4 years. I like the system as it provides good reminders, and updates me about my health and well-being. I don't have any issues. (U8)

#### **6b- Impact of text message on self-management behaviour**

I felt like I was on top of my health because of the text messages. (U2)

I don't think I have a particular rapport with my healthcare providers, but I established it with time, and I feel I can see them when I need to. Text messages have helped encourage me to adopt a healthier life style. (U5)

The system was quite good. My blood pressure is well controlled now, I am not even on any medications now it is all diet control. (U9)

I think the system is good. It has helped with my self-management, because I know that I have to take them, it would be the same with checking my blood sugars, because right now I am terrible at that stuff. Overall, it would lead to a more positive attitude. (NU13)

The feedback from messages is always positive and motivates me to carry on with my self-management in the best way. It gives me hope. (U2)

The messages would ask for blood pressure readings, so it would prompt us... I would check her blood pressure and send it off, if the blood pressure was high or the reading was not as good, it would provide some advice through messages, also they gave us a booklet as a guide. (U10) [Husband of participant]

Messages are easy to follow, very educational and provide good tips on improving my health.

Text messages have helped encourage me to adopt a healthier life style. I exercise, eat healthy, attend appointments and never miss out in taking my medications. The messages are very motivational which persuade me to do the best I possibly can. (U19)

My experience with FLO has been very positive so far, it offers good support and continuously motivates me. (U16)

For me the FLO has done wonders, I signed up to a study a few years ago, I really loved it, it has help me so much in terms of my self-management. I am no longer using it since the study stopped, but I think it has really helped me adopt a better lifestyle. (NU7)

I do not want to change my lifestyle. Therefore, I don't want to start using the system now. I cannot change what I have been doing my whole life. (NU11)

I Like my current lifestyle, to eat things like curry and samosas, pakoras, biryani is our food. It is our identity. I don't think me or my family will ever change that. We don't eat fried food as often anyway so it is okay. I don't think a text messaging system will make me change my ways. I guess they can offer good advice but for me that won't work, I don't think I will follow it. For that reason, I never signed up (NU11)

When I was faced with a diagnosis of a long-term illness such as diabetes and CKD, it came as a shock to me. I did not know what to do, I mean... the help was there but I thought what's the point. I did not feel like trying anymore. But once I was introduced to FLO, my life changed. (U20)

FLO has given me hope, and has made me want to do better for myself and my family. I don't think I can manage as effectively without it. Since I have started using it, I have developed a better routine. I make sure I am checking my vitals, exercising often and eating right. (U20)

The FLO messages are really good, they are really educational and informative, whilst, motivating at the same time. They always prompt me to check my blood sugars on time, and recommend the best ways to control my symptoms. I definitely believe that such systems could really help alter negative behaviours and mindset. (U1)

My experience with FLO has been very positive so far, it offers good support and continuously motivates me to eat better and make healthier lifestyle choices for myself. (U8)

I am not really good at doing my blood sugars, exercising or eating healthy, so something like FLO would be quite useful for me as a reminder, perhaps text messages can help encourage me. (NU10)

FLO is a very good system, in all the time I used it I never had any issues. Messages really helped me keep on top of my health goals. (NU8)

#### **6c- Use and adherence to the system – views on the FLO system, likes and challenges or recommended improvements**

Personally, I like to know information about my results and health outcomes before I come to my follow-up appointments. Although, I don't always understand the medical terminology, but I do often get messages about my bloods so I can understand things like 'hb'. (NU8)

To be honest I do receive text messages regarding my health, also appointment reminders, I do read them often they normally ask me to feedback to them regarding my health or bm results, but I do not know how to. I also can't see without my glasses; I don't like to wear them regularly so sometimes I miss important messages. (U13)

The system was straight forward and simple. (U1)

Although, I am not using the system, I think it is really good. But I think probably for people who have dementia or those that have poor memory, it would be better for them. But at the moment I am okay because I know when to take my medications and everything, personally for me I am okay with how things are, but I think for older people it is great. (NU12)

I don't think the system would make a difference. Because when you're having a hypo, you're out of it anyway, I'm not going to look at my phone at the middle of the night. (NU12)

I am reliant on a similar system which gives me updates and appointment reminders with the dentist is tomorrow, even non-health related things such as banking, where you receive messages regarding over-draft warnings is via text messages too. So, I think this system is definitely heading the right direction. (NU3) [Son of participant]

It is very good; it keeps us informed of blood results, and important tests that need to be done. Also, it provides good reminder for appointments, as we had no idea about this appointment, I only found out about it yesterday. (U13) [Daughter of participant]

But I do think in terms of appointment reminders, they can be a bit more informative for example it did not mention which department to visit and that it was the diabetes clinic, it just gave the time. I think it should, as it makes it easier for us to find. (U13) [Daughter of participant]

It makes life easier with this service, it is similar to emails, very quick and easy to speak to people, particularly healthcare providers when needed. (U12)

I suppose the prompts could be better, in terms of the way they are sent, as I have to usually wait for an email then I receive the message. I think that could be due to the way I set it up when I first joined it. The thing is the clinic doesn't run every day so you don't know if they're in or not. For example, the nurse text me telling me she is not in tomorrow, but will get back to me the day after, so it is good, I think. You get prompt updates. (U8)

The text messaging system was very straight forward and easy to use. (U14)

Messages would prompt me to be healthier, but I cannot exercise I feel a lot of pain especially in my hips. So, for that reason I cannot exercise. I feel quite dizzy. Although, the system could support me and remind me to eat healthier. (U13)

Messages in my own language would be useful, but I have my granddaughter, who checks and reads messages regarding my health and appointment reminders. I generally feel happy with the messages. (U10)

I don't know how to text, it's not because I don't want to learn, I just don't feel interested in the system. I think I am fine with how I am; I don't want to engage with mobile phones. I don't even like making phone calls. I am quite old fashioned. (NU13)

I think text messages dictate how to live your life, does not really give you free will to live how you want. (NU20)

I think if messages were translated in Urdu, I would be very keen to receive them. I don't understand English for that reason the system wouldn't be effective for me. (NU10)

I don't really have a very good understanding of my condition; I don't always know when to take my medications. Language barriers don't always help either. I think there needs to be better translating services, or maybe FLO can offer that. (NU10)

I am not really good at doing my blood sugars, exercising or eating healthy, so something like FLO would be quite useful for me as a reminder, perhaps text messages can help encourage me. (NU10)

Messages are easy to follow, very educational and provide good tips on improving my health. (U19)

FLO is a good system; the messages are informative and educational. I also find the reminders convenient. However, My English is just okay, it's not the best, so my husband reads the messages, but I think there should be translated content instead, to help others who don't read English at all. (U10)

I really love FLO I have been using 'Patient Knows' but that only shows me my blood test results. On the other hand, there's FLO which has really helped me keep on track with my Diabetes care. I love receiving reminder texts regarding my blood sugars and updates on my treatment options. (U15)

FLO is quicker and easier to use and messages are quick to access; whereas, when using 'Patient Knows' I normally have to login and wait for it to upload, and it can sometimes take a while. (U15)

If it was not for FLO, I think I would be forgetting to take my medications on time and have difficulties to remember to monitor my blood sugars. I have a busy schedule so having FLO is convenient. (U3)

FLO has helped me; the texts are very good. I manage with the system but sometimes when I need to send my readings for blood sugars or blood pressure, I ask my daughter to help me. I think translated messages would be better. (U13)

The system is very handy and helpful, especially in our situation, we know when mum has an appointment, and when her blood sugars or Insulin are due. (U11) [Daughter of participant]

The system is very good it has helped my family assist me to manage my diabetes.

FLO has helped me get back on track, the messages were very informative for me especially after being newly diagnosed. It sent me good reminders for my follow-up appointments and also good advice to keep my blood sugars under controlled. (NU17)

Messages are very useful and helpful. Has helped me connect with my care providers when I need support. The information provided in texts helps me do better. (U6)

FLO has given me hope, and has made me want to better for myself and my family. I don't think I can manage as effectively without it. Since I have started using it, I have developed a better routine. I make sure I am checking my vitals, exercising often and eating right. (U20)

#### 6d- **Alternative methods or systems**

I am on that site already for diabetics, but that is on the internet, so if I need help ever, I can just access that site if I need to. So, I don't really need an alternative site or system. (NU9)

For those that can't text or respond to texts, these days there is video calling too if you are desperate to be seen there's that as well, then to waste time. (U7)

You can even use similar systems such as videos, FaceTime etc. to watch for example someone operating in the states and do the same thing whilst they are guiding you, isn't that brilliant? Technology is marvellous. (U5)

I think the system is good with the way it is at the moment. However, I don't really use technology, I don't know much I just check messages and answer phone calls. Perhaps there can be an alternative system which helps with self-management via phone calls? (NU1)

The system helps, but we do that anyway as we have a booklet, we have to write down all her blood sugar readings, it also has all her insulin and medications, and what doses we give her for her diabetes. We keep it as a report to reflect on. (U11) [Daughter of participant]

Along with the FLO system I am also using 'Patient Knows Best' which also helps me manage my health just as effectively. This also lets me access my results and provides appointment reminders. (U15)

I am a user of FLO and 'Patient Knows'. Such Systems are very good if you know how to use technology, I prefer the format of FLO it is more advanced to 'Patient Knows, it is easier to follow, messages are more personalised to me and it is user-friendly. (U15)

I think along with FLO, other platforms could also be very good such as FaceTime, other text messaging systems, voicemails, emails etc. it would save a lot of paper work and reduce appointment reminders. If you had an issue, it can be communicated in seconds. (U9)

I do think the system is helpful as it would display blood result etc. But I don't feel interested with using technology, may be its an age factor. (NU15)

For those people who cannot text, phone calls would be beneficial in a translated language to discuss results and health care information. This would be a more convenient method of communicating with health care providers. (U1)

I like to use the internet to discover the side-effects of medications and how they will benefit me. (NU6)

I have a google system at home which reminds me about my daily routine for example it will remind me to take my medications. I think this is better than texts, text messages and mobile phones are a waste of time. There was a 'Health alert system' it would send messages early morning, which I found very disruptive and annoying, no preferences of time taken into account. (NU20)

I really hate receiving texts, I don't like reading them. ALEXA is better, I just talk to the system and it responds to whatever I ask for. I sometimes set alarms and ask ALEXA to remind me in regards to my medications and checking blood sugars. I think for me this is fine. (NU20)

I am not really a technology user; throughout my life I have not found it important to use it. I am quite old-fashioned and much rather prefer to receive information and updates via the post. (NU14)

I don't really think I would follow the messages as I am not good with technology... I can speak to the doctor face to face when I need to. (NU2)

#### **6- Barriers associated with poor self-management outcomes and use of text messages to optimise treatment outcomes (Language differences and Communication)**

##### **7a- Language barriers to communication – i.e., prefer text in own language**

I think the system could be even better if messages were translated for those people experiencing problems with English. (U1)

I won't be able to follow the prompts or messages as they are English. I can't read English. It would be beneficial to design systems that would be more tailored to suit our needs, such as better translated content and services. (NU1)

Messages in Hindi would be really useful for me as I won't need to be reliant on anyone. I will get reminders that I could follow and adhere to. Right now, my self-management is all over the place, it is not as good as it can be. (NU1)

I think a system like FLO can help me. I have heard the messages provide good reminders to check blood sugars on time etc. But English messages cannot help me. (NU3)

I think FLO text messages can help me, but language is an issue. Reminders could help me, but only in a language I understand. (NU3)

I think my self-management level can be even better if reminder messages were in Urdu, it would help me respond effectively to the advice given. (U17)

I cannot text, so I don't use the FLO system, also my English is not great, and I feel I am too old now to be up to date with new technologies. (NU15)

She wouldn't been able to read English texts, plus the complexity of the phone, she even has difficulty of trying to make telephone calls, so we have to ring her. So, it's just the confidence and the complexity to use it. NU3 [Son of participant]

I think it would be a good idea as well to get health updates and appointment reminders. However, messages get delivered to me only, as she is unable to read and understand English. But getting some additional results would be useful as I usually have to chase them up. If we can have all health records, we can easily show them to our GP. (NU3) [Son of participant]

It is a very good system that prompts us about health updates, health advice and also appointment date reminders. The only problem is, she can't use the system due to not being able to read them in English, so they get delivered to us. (U11) [Daughter of participant]

Messages normally get sent to mine or my sister's phone, as my mum doesn't really use mobile phone to text. She also doesn't really understand the messages much with English not being her first language. (U11) [Daughter of participant]

The only barrier is, if the person doesn't know how to speak or read English, then it is difficult, because then they can't read what's for their own benefit. (U3)

I can't read English properly so sometimes I am not using FLO, but I manage okay because I know the basics such as to control my blood pressure and my sugars. Especially if my sugar is high, I know to avoid sweet food, and if it is low, I know to avoid it... I know it like that. (NU18)

Well, I can speak a little English, so I can speak to them about basic things for example, my urine test and blood results... I usually know which words to say. I can also follow simple instructions given by the nurse sometimes. I can communicate for myself... like when booking transport to come to my appointments for example, when booking a taxi. Although sometimes I do struggle to explain to the driver of my location after the appointment, so I sometimes get assistance. (NU14)

I usually get someone at home to read the medications information leaflet to in my own language, but she knows what each of her tablets are for, as she's taken them for a long time now. (NU13)

I look at the dosage, for example he knows one of his tablets for his diabetes is 2 mg, that helps him identify his medicines. I don't read English at all. (NU15)

The doctor will speak to me in English, and I will translate in Punjabi to my Mum. (NU3) [Son of participants]

It's like my cousin's wife has come from India, he is also from India, and so English is not great. But if you speak to them in Punjabi, they will understand it like I understand English. So, they want the explanation in their own tongue, not in English, and I see that in a lot of elderly patients as well, one was saying that they could do with some feedback in Punjab. (U10) [Husband of participant]

My mum normally relies on me to translate; hence I take her to all her appointments. (U11) [Daughter of participant]

When I was using the system, my son received the messages, I can't read the English texts, so my son tells me when he receives messages about appointment reminders and also updates regarding my health... However, he lives in Wales, as he works there and his family are there. He has been there for a while. Sometimes I receive phone calls from an Indian receptionist to inform me directly of my appointment. (NU3)

I think messages can be in a language she understands then it is okay. (NU3) [Son of participant]

Language barriers is a big problem, a lot of people from our community don't have an understanding, we need translated services tailored to our need, it is the same with text messages... they should be translated in our local languages. (U6)

For me the system is good, is not an issue but for someone who struggles with language barriers, something must be in place for example, Punjabi. If FLO was in Punjabi, it would have more users as you would be able to communicate directly with your care providers. (U15)

If you had a system that offers translation into Punjabi, you can get better health outcomes and more Punjabi users. (NU3)

I think messages can be improved through translation options and be better for users. It would be better for my wife. (U10) [Husband of Participant]

FLO text messaging systems can be a very complicated system for those who have low literacy and English skills. Education is an important factor. (NU4)

The messages are great, but she can only adhere to them if one of us is at home with her... an advantage is that I just live next door to her, So I can pop in and check on her, and check the updates via FLO or sometimes they get sent to me or my sisters. (U11) [Daughter of participants]

I don't find the system interesting to use, My English is not great I don't think I will be able to adhere to messages very well. (NU5)

#### **7b- Preference to see doctor that speaks same language (same culture, gender)**

They kept me in and were trying to get me to go on to the insulin, they even sent an Indian nurse to teach me how to administer insulin due to language barriers, but I refused, I did not want to learn to inject myself. I said I will try, but I will not take them. (NU3)

I would much rather speak to a doctor who speaks Hindi or Punjabi. I think then I can get my point across, I can't always express myself with the English clinicians as I don't think they understand my English or what I am trying to say. (NU15)

Translated information sheets, text messages and material can help people like me understand and learn more about my condition. English is not my first language so I don't comprehend with the information being provided by the doctor or nurse, unless they are speaking Urdu or Hindi. (NU10)

I do prefer to consult an Indian doctor who speaks the same language as me, I feel like I can express my needs better. (NU2)

The doctor speaks Punjabi so I can communicate my needs effectively without barriers. (NU1)

I also prefer to be seen by an Indian or SA health care provider who can understand my issues and my needs. I can't really express my healthcare needs due to this. (NU15)

My English is not too bad, I can read the names of them. I also know the times to take them also for example, morning, evening, lunch time, dinner time. (NU14)

I do struggle with English. But if the doctor is Indian and can speak the same languages, I understand then I can discuss my health problems. (NU13)

My main doctor is Indian, but I sometimes don't always get the chance to see him as they send patients to be seen by trainees, who are not always Indian nor can communicate with me in my language. (NU1)

She says she doesn't like translators, because she feels why does someone else get to know her business, also the relationship isn't there, but there are certain appointments where you have to have a translator, she had that last month, she was not happy with her translator. So, it is her preference to speak to a healthcare provider that speaks her language, to speak about private matters. (U11) [Daughter of participants]

I do prefer a Hindi speaking doctor as I can communicate my needs, I was not aware I had to monitor important parameters at the beginning of my diagnosis. They could provide a better education for me. (NU5)

I would like to see an Indian lady doctor but I do not always get to see one. I would be able to share more of my concerns and feel more confident. (NU1)  
 My grand-daughter normally helps me read text messages, as I cannot speak or read English. Only then I am able to follow the advice provided to improve my health and condition. She also showed me how to check my blood sugars with the glucometer. (U10)

**7c- Unable to express health care needs**

I now feel more reliant on my family to communicate with my healthcare providers; I can't always express my needs. (NU10)  
 I can read and understand text messages, But I do not speak English very well, so I cannot always express my needs well to health care professionals. (NU1)  
 I always feel stressed in life, the lifestyle we have. You cannot share these things with anyone even with healthcare providers. I can't express my healthcare needs properly, as I am not sure myself with what is wrong with me. (NU13)  
 I think some people are fearful to speak maybe, especially in a doctor-patient relationship; it could be due to status or cultural factors where patients may not feel comfortable to discuss their problems. It is different if the doctor speaks Punjabi also, but languages like Urdu and Hindi, she may understand differently and may misinterpret and understand it incorrectly. So, if the doctors speak in English, I will translate it to her, so she understands it. (NU3) [Son of participant]  
 I am not really able to express my needs, I would prefer it if I was able to see a female doctor, who speaks same languages as me, as they can provide useful information, I would prefer to see a female doctor as I feel more comfortable and can open more about my health concerns. (NU13)

**7d- Lack of confidence to self-manage**

I don't think I'm fully confident, but I do feel I have some responsibility to make my symptoms better. I feel there are somethings beyond our control. (NU11)  
 I do sometimes need to ask my daughter in-law, son or husband, when it comes to taking my medicines, she can read English or my granddaughter, she is 14 years old, and she normally sorts everything out for me, all my paperwork. (U10).  
 She's not that confident to have a conversation, I think she is frightened, and she finds it easier if I do the talking and translation with the doctors, I mean nowadays I don't really have to come, but she prefers if one of us go with her, just so that she has that reassurance that someone is with her. I have to translate for her, even though I strongly believe that she does know what he's saying, but not 100%. (NU3) [Son of participant]  
 I make an emergency appointment and visit my doctor. For example, they'll send me letters for when I need to get my bloods done urgently or text messages come through. I am doing the right things aren't I? I don't think I have full confidence in self-managing if my sugars are high etc. I can't express my needs either as I do not speak English. (NU13)

**7- Behavioural outcomes whilst using the text messaging system**

**8a- Motivated by text message to make lifestyle change – Positive health behaviour change (Exercise etc)**

When I was faced with a diagnosis of a long-term illness such as diabetes and CKD, it came as a shock to me. I did not know what to do, I mean... the help was there but I thought what's the point. I did not feel like trying anymore. But once I was introduced to FLO, my life changed. (U20)  
 I am always improving now according to my annual appointments and that is the way forward, all thanks to FLO. (U20)  
 Ever since FLO I am always learning something new, and my family are very supportive and want to learn with me so that they can help in case of a hypo, or anything else that can go wrong. (U6)  
 The FLO has had a very positive impact in my life although I am no longer using it, I would have suggested it to my close relatives and the wider community who are dealing with similar issues to me. (NU7)  
 FLO messages have been just great. I think it is very quick and easy to use. They keep me well informed with new updates and encourage me to keep a record of my self-management progress. (U18)  
 FLO has also helped me bounce back with my life. (U18)  
 Text messages have helped encourage me to adopt a healthier life style. (U9)  
 The text messages also help prompt me and encourage me to stay healthy. (U19)



I think the system is good. It has helped with my self-management, because I know that I have to take them, it would be the same with checking my blood sugars, because right now I am terrible at that stuff. Overall, it would lead to a more positive attitude. (U7)

Text messages from FLO, have helped encourage me to adopt a healthier life style. I exercise, eat healthy, attend appointments and never miss out in taking my medications. The messages are very motivational which persuade me to do the best I possibly can. (U8)

My experience with FLO has been very positive so far, it offers good support and continuously motivates me to eat better and make healthier lifestyle choices for myself. (U8)

Text messages in Urdu can really motivate me, as I would have a better understanding of what I need to be doing. Right now, I struggle with my regime, sometimes I even forget to take my medications on time or even check my blood sugars daily. (NU10)

I am not really good at doing my blood sugars, exercising or eating healthy, so something like FLO would be quite useful for me as a reminder, perhaps text messages can help encourage me. (NU10)

The FLO system had a positive impact on my behaviour and health outcomes on my self-management activities, it encouraged me to adopt a healthier lifestyle. (U3)

The texts have encouraged me. I have been doing exercise at a women's club, the instructor is very good she helps me with my depression through therapy classes, I have also been exercising, they even take us out there in groups. (U2)

Messages would prompt me to be healthier, but I cannot exercise I feel a lot of pain especially in my hips. So, for that reason I cannot exercise. I feel quite dizzy. Although, the system could support me and remind me to eat healthier. (NU8)

I am eating healthier too after using the system, I do eat a lot of fruit and veg, more so than I do meat, I am a fussy meat eater, I am not a big fan of meat anyway. (U8)

FLO does motivate me to be healthier; I think that is the purpose of such interventions. It is a brilliant idea, we all tend to find excuses to get out of it, especially when we are watching a film on telly, you want to wait until it is finish, you don't put it on record, and say you need to go start your activity instead you want to sit there and watch the TV. So, it is good idea to get a prompt like this, to take your medications or to start an activity. Very useful I would say. (U5)

I don't think I have a particular rapport with my healthcare providers, but I established it with time, and I feel I can see them when I need to. Text messages have helped encourage me to adopt a healthier life style. I exercise, eat healthy, attend appointments and never miss out in taking my medications. (U5)

If Urdu text messages were sent, I may learn to like the system. I think such messages would motivate me more that way, and allow me to engage in a healthier lifestyle. (NU18)

FLO has been amazing I don't know how I ever managed without it. It has really optimised my self-management and really motivates me. I think an advantage is that it is very simple to use. (U2)

#### **8b- Text messaging intervention helped prompt and monitor health (check blood sugars and parameters, take medications, exercise, promote health)**

Oh, that sounds very good, prompts to check blood sugars and other health parameters would be very ideal. (NU1)

FLO does motivate me to be healthier; I think that is the purpose of such interventions. It is a brilliant idea, we all tend to find excuses to get out of it, especially when we are watching a film on telly, you want to wait until it is finish, you don't put it on record, and say you need to go start your activity instead you want to sit there and watch the TV. So, it is good idea to get a prompt like this, to take your medications or to start an activity. Very useful I would say. (U5)

I do think the system is helpful as it would display blood result etc. But I don't feel interested with using technology, may be its an age factor. (NU2)

I think systems such as FLO are brilliant, especially to help remind me to check my parameters at the right times. The messages are educational with advice of controlling my blood sugars. (U6)

The system is very handy and helpful, especially in our situation, we know when mum has an appointment, and when her blood sugars or Insulin are due. (U11) [Daughter of participant]

I think even messages asking If I have taken my medications to confirm that I have, will help me. (NU10)

I think my condition was better when I was using the system, because at that time I was being monitored I would also keep check on my parameters weekly. But now without it I am checking my parameters fortnightly or monthly (*laughs*). The messages were constantly reminding me, which was good. (NU20)

It is a good system; it has a lot of benefits, especially since it reminds me to attend my appointments on time and when I need to send my important parameters such as my blood pressure or blood sugars. (U1)

If it was not for FLO, I think I would be forgetting to take my medications on time and have difficulties to remember to monitor my blood sugars. I have a busy schedule so having FLO is convenient. (U14)

I love receiving reminder texts regarding my blood sugars and updates on my treatment options. (U15)

I think so far FLO has been okay in helping me to remember my regime and checking my blood sugars. (U17)

I make sure I am checking my vitals, exercising often and eating right. (U20)

It is a very good system, it reminds me about my treatment regime and also my appointments, because I forget sometimes, so it is good. (U13)

The doctor wanted to know my average blood pressure over a period of certain time, so I was using the system because of that. FLO was quite good. My blood pressure is well controlled now, I am not even on any medications now it is all diet control. (NU8)

It is more helpful for the doctor to get an idea of your readings and also it makes you aware because you are checking your blood pressure regularly, and checking your readings regularly. It helps you to understand your own levels and what you should be at. (NU12)

Readings were sent to the doctor so it could be looked at, it was easier for them to look at it and monitor it. So, in that sense it was good. (NU9)

Whenever I get a message to check your account, it prompts me to check my health records and look it up straight away. (U15)

It was messages regarding my blood pressure and blood sugars, some of them I don't remember. But it was very good. It reminded me to do what I was supposed to do, and when to check my blood sugars and blood pressure. (NU17)

It (the FLO system) prompts me to monitor my blood sugars, take medication time and also when I have appointments coming up. (U7)

It reminded me to do my bloods pressure reading, and it also told me if I was doing okay, or if it was too high. There was a lot of motivational messages in there as well. (NU7)

Appointment's reminders would be good, I am not using the FLO text messaging system anymore, but would like to be part of it again as it would benefit my self-management through the various health messages sent. It would help remind me to take my medications twice a day for my kidney problems. The system also sounds quick and easy to use, and communication seems instant. (NU17)

I really struggled with my regime; it was very difficult to remember to take metformin three times a day which is why the text messaging system would be good for providing reminder messages. (NU19)

I don't always remember to take my insulin on time. I am trying my best to remember. Such a system can be useful to prompt me. (NU6)

I think our community (SAs) would benefit from an such an intervention.... It can really help with monitoring their health .and reporting any issues they may face. (U10) [Husband of participant]

It is a very good system that prompts us about health updates, health advice and also appointment date reminders. (U13) [Daughter of participant]

### **8c- Good appointment reminders**

Yes, the texts are good; I get health updates and also appointment reminders to remind of the date I need to come in. I do prefer them over letter, when I used to receive letters; I would put them on the side and would forget to check it. (U19)

FLO has a lot of benefits, especially since it reminds me to attend my appointments on time and when I need to send my important parameters such as my blood pressure or blood sugars. (U13)

If it wasn't for the FLO system I would forget when my appointments are. I have missed a few in the past as I forgot to attend, but since receiving texts, it has helped my memory. (U17)

It seems very good, at monitoring health particularly; it is good for appointment reminders. I think I would really benefit from it. (NU1)

It is very good; it keeps us informed of blood results, and important tests that need to be done. Also, it provides good reminder for appointments, as we had no idea about this appointment, I only found out about it yesterday. (U13) [Daughter of Participant]

It is a very good system, it reminds me about my treatment regime and also my appointments, because I forget sometimes, so it is good. (U18)

I think for me personally, I have got a really bad memory, but the text messages will remind me that I have an appointment, for me that really good. (U7)

It was both of those factors of being prompted and reminded... we also get current appointment reminders, which I think is also really good, because sometimes you can slip up with the dates. Like today's appointments I could not remember, so the reminders really helped. (U10) [Husband of participant]

I would prefer to get messages updating me with my appointments, as I sometimes have multiple appointments in a day, and sometimes I miss them. I think that's one reason messages would really help me. (NU15)

#### **8d- Prompt to take medications**

Well, the system had a lot of benefits, such reminding me of the correct times of when to take the medications, because of this I still take medications at the right time after using the system. (NU8)

It would be a useful and nice device, if a person needs it and gets help. It would have positive outcomes for people that need reminding to take their medications on time. (U12)

It is very useful and it does prompt her do things on time, such as taking medications on time. (U13) [Daughter of participant]

#### **8e- Provides support – feel supported**

I think it is good to keep in touch through such a system, as I come to my annual 6-month review, and they give you the information and advice and you follow it... but over time your health can change and you may have questions, you can go to your doctor, but he doesn't know you like your consultant you feel closer to them regarding your health issues, than you would with your doctor. It's good to keep that regular contact so you know if you know what you're doing is right or wrong, so that next time you see them you're on track. It's that communication it is good. (U6)

The system was giving me guidance, and I felt confident that someone was monitoring me, which in these days is rare as people don't have time. (NU7)

I felt like I was on top of my health because of the text messages. I think it was better whilst I was using the system, you know like 'Big Brother'... someone is watching you and you are having support... and I want to keep my health going well. So, in that way it was helping. (NU17)

I think it is useful as it helps the medical professionals to monitor patients, and makes them aware of where patients are up to. (U5)

It's good, it allows instant communication with healthcare providers and the additional support. I was texting the diabetes specialist nurse today regarding my parameters. It encourages me to send blood sugar results in, so they can have a look at it and make suggestions from the trends they are facing. Because they look at it in more depth and can offer me support. (U8)

FLO has really helped me understand the importance of being able to manage my condition independently. It makes me feel I am in control of my health. That includes what I eat, when I exercise and taking my medications the right way. I would definitely recommend it to others struggling. (U14)

### **9- Content and timing of text messages**

#### **9a- Timing of text messages**

The content could be better. There was no section to say... for instance if you didn't get access to the system to send your figures, because you have no Wi-Fi, I won't receive the messages to check my reading, I would normally have to wait to come home and send my readings off. But messages on text messages were different because you have access to texts anyway, but my blood pressure monitor was always at home, so the timing of messages was not convenient. Although, there was a reminder to check my readings, which was good. (NU8)

It would be good if text messaging systems such as FLO would send messages at a time preferred by myself. There was a 'Health alert system' it would send messages early morning, which I found very disruptive and annoying, no preferences of time taken into account.

I think it would be good if the messages were sent earlier on in the day, to prompt, like I received this message regarding the appointment only yesterday. (U3)

It would be good if text messaging systems such as FLO would send messages at a time preferred by myself, preferably out of work hours, it is less disruptive. (U9)

The system offers good support for self-management but can be improved to suit patient needs better in terms of timing of delivery. (U12)

Messages sent to me outside of working hours would be beneficial as I can respond more promptly without rushing or missing key information. (U9)

#### **9b- Information provided in texts, preference of information or prompts (for example, translated information or information regarding self-management) to optimise self-management**

When something new happens to us we go on the internet, or maybe rely on health text messages don't we? We all do it, we try to self-diagnose our self, but that's not always the right approach, you still need to see a professional who know far more than yourselves. Text messages don't always provide all the information you may need. I think for that reason messages need to be edited to contain more information. So, I still approach a doctor, I still like to know the background to my problem, so I can ask the right questions. (NU8)

I think FLO text messages can help me, but language is an issue. Reminders could help me, but only in a language I understand. (NU3)

Messages in Punjabi will help me, I will be able to get a better understanding of my treatment regime as I will be receiving updates I can read. Maybe then my sugars will be controlled. (NU3)

I feel excluded as I can't understand the messages sent, which is unfair. There should be translations to messages available for people like me, for whom English is not the first language. I think only then the system can be good and effective, if they are delivering information, we can actually read and follow. (NU3)

My English is just okay, it's not the best I'm lucky I can read the messages, but I think there should be translated content instead, to help others who don't read English at all

I have been using the system for some time now, information provided is great but could be better if it was in Urdu. At least, then I will be able to read and understand it quicker. (U6)

If texts were in Urdu, they would be good to prompt me to take medications and monitor my blood sugars regularly. Currently, I rely on family members to translate the content sent. I think my self-management level can be even better if reminder messages were in Urdu, it would help me respond effectively to the advice given. (U17)

I am unable to use this system independently sometimes as I am not great with English, I cannot communicate with the texts I receive. If texts were in Urdu, they would be good to prompt me to take medications and monitor my blood sugars regularly. Currently, I rely on family members to translate the content sent. (U17)

I think the system could be even better if messages were translated for those people experiencing problems with English. (U1)

I do think in terms of appointment reminders, they can be a bit more informative for example it did not mention which department to visit and that it was the diabetes clinic, it just gave the time. I think it should, as it makes it easier for us to find. (U13) [Daughter of participant]

The thing is she is seen by different people for her kidneys, and for her ears too as she has tinnitus so the text didn't say what the appointment was for and who it was with. It would be beneficial to receive location on messages too. (U13) [Daughter of participant]

The information provided in the messages is useful as they make you aware of your own blood sugar levels or blood pressure, and what you should be aiming for when self-managing at home. (U7)

I get messages to say I got appointments coming up, and my blood results which is updated on FLO which is quite handy as I sometimes forget important dates for my appointments. It also allows me to keep a record of my blood sugars so I can compare it to my previous appointment (U15)

If FLO messages were sent in Punjabi, then yes, if it was a translated message then yes that could work well. (NU2)

Some messages are very basic not enough information at all in some of them, especially when you want to learn more about the condition. For example, what causes diabetes, and is there actually a cure. (U16)

I normally receive messages from the nurses and Dr De, like today it was in relation to my blood glucose results, I have a urine sample, they made a cock up of that, so I was able to text Dr Due to request another via the post so I can do it again. (U8)

The messages would ask for blood pressure readings, so it would prompt us... I would check her blood pressure and send it off, if the blood pressure was high or the reading was not as good, it would provide some advice through messages, also they gave us a booklet as a guide. (U10) [Husband of participant]

The text messaging system is good it provides educational information regarding Diabetes. I can refer to information quickly and easily if I need extra support, for example, what to do in case of a hypo or if my levels are too high (U19)

#### **10- Patient Information Needs regarding LTC's, symptoms, treatments options, outcomes and optimal self-management**

##### **10a- Do participants have adequate information regarding treatment/condition for optimal self-management?**

I sometimes struggle with my regime and really think a written care plan, or information leaflet about my medications will help me remember why I am taking the medications I am, and how I am going to improve from it. Recently, I haven't been doing too well with taking medications on time. (NU6)

I have taken on board the advice I have been given by the nurse and the doctor, and they have shown me the results that I am heading towards the right direction. (NU7)

I like to take my time during appointments when I go in, and find out what my figures were and where I am at the moment, and the important thing is what levels I should be aiming for, and that all comes through advice. (NU8)

We go to the doctor, who tells us what the medications are for, and then we tell her. But yes, we do look at the information leaflet also. We tend to check on her weekly, and explain to her what she is taking her medications for. (NU3) [Son of participant]

It takes weeks to just be seen, by the time the doctors arrange to see me I feel like my health has gotten worse. If I'm honest I don't think anyone cares [referring to the healthcare system]. I have a lot of uncertainties regarding my condition and regular appointments can be helpful to catch up with the doctor regarding my progress. (NU3)

No, I didn't feel it was necessary to ask the doctors about my treatment, but there is a treatment for it right? (NU1)

Do you mean like with my diabetes? Yes, I would know what to do if my blood sugars are too high or low. (NU15)

I don't know how my statins are actually helping me and whether it even makes a difference, only when I get my bloods done, I can know the effect of it. I feel metformin and insulin have a more obvious effect. I actually asked the nurse today what my cholesterol was, she told me it was 3.2 which was very good, considering South-Asians normally have high cholesterol. So, my dose changed, I was having 40mg of Simvastatin, but now I am only on 2mg of a different statin. My wife takes a statin similar to this, she takes 2mg every other day or two. (NU19)

#### **10b- Does messages satisfy SA educational needs?**

The information provided in the messages is useful as they make you aware of your own blood sugar levels or blood pressure, and what you should be aiming for when self-managing at home. (U6)

I did lack knowledge; all I knew was that I have to take my medications. Text messages really helped me from an educational aspect as I required more knowledge. I now know why I am taking medications for my condition. (U7)

Text messages have been very informative in terms of my health care needs, I have a better understanding of my treatment regime. they have also help me adopt a healthier lifestyle. (U3)

I feel that text messages really help satisfy my educational needs, but I do need more education on my treatment regime. I like to know what's new, how I can change and improve. (U8)

Texts are great, they provided adequate information for me, but I also like to read a lot with what's going on and what sort of research is going on in diabetes. I would tell people and patients that I know. Which is a good thing, by updating them on what is available for them. (NU8)

#### **10c- Inadequate knowledge due to language barrier**

She does not feel like checking her blood pressure is not as important as her blood sugars. She has not really discussed this with the doctors or nurses to confirm that this is okay, as she feels they won't understand her. (U11) [Daughter of participants]

I feel hopeless with my condition sometimes, especially when I don't have anyone at home with me to help administer the medications. I normally have trouble then when I can't read the English labels on the medicine boxes, so I don't bother sometimes. (NU1)

I feel like I don't have enough time to discuss my health problems, the doctor always seems rushed. I have so many questions and uncertainties about my illness and medications. So, I don't really take all the medications, I mix it with some herbal remedies. This is when I don't understand the English medication labels. (NU16)

She refuses to take her insulin and does not really know the actual cause and benefits of why she is taking it. The doctor has tried to explain the effects of it, but she did not really understand the reason. So, I now go with her to her appointment to translate important information. (U11) [Daughter of participant]

I don't know my medications like that, I can't read the names of the tablets as they are in English; I'll have to show you what they are.... It's normally, blood pressure control, cholesterol tablets and for sugar. (NU1)

The doctor told me to take it once, at the chemist they told me to take it twice, my family gave me two, it was a misunderstanding or miscommunication due to language barriers. It was 120 mg then it was changed to 240, it was for my kidney problems. When I took the increased dose, I blanked out, my eyes wouldn't open, and my body felt heavy, I was lucky my son was at home, so they called the ambulance, they gave me more injections, and took me hospital straight away. (NU1)

With regards to medical health needs for my parents, they would really benefit from translation and Punjabi messages. If someone spoke to them in Punjabi, they would understand better with what they had to do to achieve optimal health outcomes. For example, my Mum signed a DNAR form but she did not understand what she was doing, if she had someone to explain to her in Punjabi, she would know what she is doing. (U13)

I don't understand everything the doctor says in English regarding my LTC and treatment regime, so I am normally accompanied with an English-speaking family member to communicate. (U13)

We do tell her why her medications are being reduced, but she doesn't know exactly which medications are for what. She doesn't understand that. (U3) [Son of participant]

#### **10d- Awareness of what is permitted and what is not**

Text messages have been educational. I have learnt if you cut too much sugar out of your diet it increases your blood sugar levels; you can have it moderately which should not have too much bad effect on your levels. (U8)

Well... the doctors told me it's because I am over weight, and that causes diabetes, too, right?... I did tell the nurse I am going to try lose weight. The nurse told me if I control my weight, I can stop taking injections. (NU13)

I do consume sugar daily, even mithai, I don't really like to diet. I do have an awareness that I shouldn't, but these foods are apart traditional in our cultures and are hard to give up. (NU11)

I Like my current lifestyle, to eat things like curry and samosas, pakoras, biryani is our food. It is our identity. I don't think me or my family will ever change that. We don't eat fried food as often anyway so it is okay. (NU11)

I learnt from the deep end, if you know what I mean, but through that process and that time I gained a lot of knowledge, that I actually worked in one of these diabetes refresher courses, I made a few friends there, and there was this girl there who wasn't feeling very well and she said she doesn't feel very well... I looked at her and said you're having a hypo, aren't you? And she went yeah, I am. So, I got up quickly and went up to one of the nurses and said she needs some Lucozade or dextrose tablets, she is having hypo. After she come back and was alright, I asked her what did you have for lunch, she said I only had soup, and I said that's why... you had no carbohydrates it was her diet... you know the pressures for us women to look skinny and you know. (U6)

Well, talking about my experience and having diabetes for over 10 years, and seeing Dr De, and all the team that are managing my diabetes, they are saying to me that my diabetes in within normal control. But if I wasn't following that pattern, how would I know, or if I wasn't taking these medications, it might have gone worse. That is why I like to take them. (NU8)

They do say to have carbohydrates and fresh fruits, but even fresh fruits have sugar, so for diabetics you still need to know which ones take and which ones to avoid. Five portions of fruit a day, is an awful lot for diabetics. (NU8)

I have been trying to work out what is good for me, what is not. So, I am actually avoiding the stuff that is not good for me, and it has shown that education has played a role in that. (NU3)

I eat very well I eat a lot of vegetables and fruit, especially since I have developed diabetes. I also monitor my blood sugars daily. (U12)

I control my sugars through diet and tablets. I used to love sugary desserts especially mithai but now I have stopped now. (NU19)

I like to snack at night especially chocolates, I just feel hungry so I get up and check the fridge. I know there are a lot of lifestyle changes to make such as diet and exercises, but I am too greedy (laughs), I am human no one is perfect. I can't eat less and diet, I eat whatever I want. (NU20)

#### **10e- Education resources - Were text messages educational? other technology-based Platforms? Education from healthcare providers**

Yes, I am interested in health, even health interventions such as this educational text messaging. Even whilst sat here, I'll see a health leaflet laying around and will wonder what it says or what's that poster over there, I'm like always enquiring, erm...websites on diabetes and emails, there's also a forum where they' talking about diabetes. (NU8)

Although, we I am using the text messages which are very beneficial and useful, I still like to stay tuned with the latest information or receive updates regarding my health, I tend to go on the internet a lot. (U5)

Although these fancy systems are out there to help people like us, I still think education in a language they understand can make a difference. For example, my Mum who is also diabetic from many years, not to this day can she go and get her medications for herself on her own, because she doesn't speak English very well. I think if services were tailored in

terms of language, they can teach her, because we do tell her but she doesn't listen. I think if a doctor or a nurse tried to tell her she would understand it a lot better. I think education is a huge thing. (U15)

I was seven stones...because I didn't really know what was happening, so it wasn't really just education that helped, it was the nurses and doctors looking after me that had told me this is what you got and this how you're going to look after yourself. (U6)

When I first got diagnosed, I didn't understand the insulin pump, what the insulin was doing, why I was using syringes to inject, oh and the nurse talked about a device being attached to me, I didn't really understand it all, and then like earlier on having hypos and being in and out of the hospital it was like an education for me from my healthcare providers. (U6)

I think healthcare professional who are into all this, and know it all, should have groups of people in communities and go out to explain to them what diabetes is, because a lot of South-Asians from our community think 'oh god she just got diabetes, that's disease', it's not a disease it's a condition. (U7)

In addition to text messages. A lot of people look at the net don't they? Or on the diabetes website, but some of these sites need updating. When I spoke to the nurse, she said the NHS consumption of carbohydrates is 200 something, but they need to be revised, as we have new trails and new stats. So, she has actually given me a different figure to work on. (U6)

Her GP is very good. He is the one who explained to her really nicely about going on the insulin, so that made her go on the insulin, he explained why she needed to go on the insulin instead of tablets. She is saying that her doctor seems very caring towards her, and even the nurse we see here for her diabetes is really nice too. They are all really nice. (U11)

[Daughter of participant]

I think people would benefit from speaking to peers who have been through it to guide you, as well as a healthcare provider. Those with a limited understanding could really learn from others experiences to better their self-management. (NU7)

#### **10f- Views of the healthcare system and healthcare providers**

How will you healthcare providers improve? I am just generally asking can you help me personally? I feel there is a need for tailored services in the UK, because of language barriers a lot of people are not able to adhere to medication as they need to. (U1)

I believe the healthcare system is good- with the aid with GP, doctors and nurses, I am managing. (NU2)

The diabetes specialist nurse helped me out quite a bit, like how to inject myself, so she really helped me. (U8)

When I go to the doctors, my doctor just tells me what I need to have and what not to have. But if it's not working, I go back and say look this tablet not working. (U19)

I called to the nurses can I just say that the two students who ever they are they have just come over, and I have not understood what they are talking about, for example what a honey moon period is, I can't focus, they need to come down a level, maybe use a mickey mouse language, she was talking to me as if she was reading out of a text book. (U6)

There are many problems in the SA community in regards to health outcomes, particularly limited knowledge of the condition they present with... this study can hopefully help address this issue. I think it can help facilitate changes to the health care system, perhaps by delivering culturally tailored care. (U1)

My doctors were not as nice, they were not giving me the information that I needed, and they weren't putting me on the right medications, that's why I ended up on the insulin in the first place. But as soon as I got put on the insulin by Dr De, they were brilliant, no complaints about them, and Susan also referred me to the get-togethers and the courses, and that really helped me, I bought my daughter with me, so at least she knows what to do if I have a hypo. She has learnt from that a well. (U7)

Here in the diabetes clinic everyone is good, but my GP no one really bother much or care for you, my feet are very painful but they don't care. I have arthritis, I am not happy with the care I am receiving; I can't even clip my toe nails, so my daughter in-law helps me. (U7)

Even the hospital meals are so unhealthy for diabetic patients that are admitted, they would give things with potatoes, which would increase my sugars. I don't think they realise the speciality the patient is under, and the conditions they are facing, because like she said she could have anything she wanted on her inner menus whilst she was here, such as custard and jelly etc. (U3) [Son of participant]

I came to this country in 1968, they scanned me and checked that I have only one kidney and they were surprised, I overheard them speaking about it, so I told them that in Pakistan no one checks these things at that time. But I was still fine, and then I was diagnosed with diabetes 20 years ago. I must say though, the health care system here is so much better, it is very thorough here compared to back home. (U13)

Nurses and doctors have helped a lot, but it is down to the patient to make the changes and like you said it is easier for patients to be on medications than to make changes. I don't want to go onto insulin, or anything stronger, I want to try come off them. So that is my aim, to continue working hard. (NU8)

I had a very bad back for six months I felt that the doctors didn't really help me. It is very difficult to get an appointment with doctors nowadays. There should be something in place for those who urgently need to see a doctor especially diabetic patient. (NU15)

#### **11- Miscellaneous**

People at work don't really have an insight, and need to be better education to know what it is. In my industry everything seems to be about allergies and intolerance because that can affect people's health, but so can diabetes and the impact of it. They don't actually know how were coping. (NU19)

I know that not everyone is educated and certain people don't know what they're talking about, you know so I was a little bit disappointed of those people because they didn't know the ins and outs of diabetes. (U7)

I have been very depressed since my son passed away; I think this contributes to my ill health. (U13)

I am not religious minded so I am not afraid to die. If I was to become house bound there is no point of life. (U8)

I have also done Hajj I do believe in God. But now due to my health and mobility issues I don't always get the chance to perform ablution and perform prayers. (NU20)



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