

# **Impact of using social media to increase patient information provision, networking and communication**

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## **Dedication**

*To my dad Tudor, who has not lived long enough to see us go through education!*

*To my Nan Ecaterina, a mountain of inspirational strength and moral conviction,  
who nurtured in me the love for learning and caring and my other grandparents*

*To all very special people in my life! Thank you!*

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## Abbreviations

|        |   |
|--------|---|
| BKPA   | British Kidney Patient Association                      |
| BRS    | British Renal Society                                   |
| CDCP   | Centers for Disease Control and Prevention              |
| CHI    | Consumer Health Informatics                             |
| CMO    | Context-Mechanism-Outcomes                              |
| CMO1   | The role of SNS   |
| CMO2   | The role of Facebook                                    |
| CMO3   | The role of Twitter                                     |
| CMO4   | The role of Facebook                                    |
| CMO5   | The role of OC  |
| CMOP3  | CMO patient P3 - Satisfaction of information need       |
| CMOP12 | CMO patient P12 - Overwhelming of information           |
| CMOP5  | CMO patient P5 - Increase in self-efficacy              |
| CMOP10 | CMO patient P10 - Decrease in self-efficacy             |
| CMOP2  | CMO patient P2 - Consideration of employment            |
| CMOP13 | CMO patient P13 - Moderating challenges                 |
| CMOP7  | CMO patient P7 - Using information to make changes      |
| CMOP6  | CMO patient P6 - Social media is not for everyone       |
| CoP    | Communities of Practice                                 |
| CSE    | Self-Efficacy for Managing Chronic Disease 6-Item Scale |
| EC     | European Commission                                     |
| EDREN  | Edinburgh Renal Unit                                    |
| GMKIN  | Greater Manchester Kidney Information Network           |
| H1N1   | Swine flu   |
| HIV    | Human immunodeficiency virus                            |
| HKPA   | Hope Kidney Patients Association                        |
| GSE    | General Perceived Self-Efficacy Scale                   |
| KPG    | Kidney Patient Guide                                    |
| IMDB   | Internet Movie Database                                 |
| KPG    | Kidney Patient Guide                                    |
| KRUK   | Kidney Research UK                                      |
| NHS    | National Health Services                                |
| NMC    | Nursing and Midwifery Council                           |
| OC     | Online communities                                      |
| OECD   | Organisation for Economic Co-operation and Development  |
| PGI    | Patient generated information                           |
| QOL    | Quality of life   |
| RCGP   | Royal College of General Practitioners                  |
| RPV    | Renal PatientView                                       |
| SNS    | Social Networking Sites                                 |
| TAM    | Technology Acceptance Model                             |
| TPB    | Theory of Planned Behaviour                             |
| UCD    | User-centred design                                     |
| UGC    | User generated content                                  |
| W3C    | World Wide Web Consortium                               |
| WCAG   | Web Content Accessibility Guidelines                    |

## Glossary of terms

|                                |   |
|--------------------------------|---|
| Blog                           | Online publishing tool that enable users to self-publish (submit for review) blog entries or posts, which often allow comments from readers   |
| Browsing                       | The process of reading and collecting data  |
| Comment                        | A response (feedback) to blog posts or Facebook posts   |
| Content Management System      | Software package with various functions, allowing to create static Web pages, blogs, wikis, document stores   |
| Crowdsourcing                  | Content development generated from a variety of sources with an added perspective of individuals involved the process   |
| Conversationalist              | The process of creating content and providing feedback as a result of reading   |
| Facebook                       | A SNS platform, which allow individuals to create profile, create friendship connections and engage in conversations  |
| Follow                         | The act of subscribing to receive the tweets of another users – specific to Twitter   |
| Influencer                     | Active community member, who is regarded for his knowledge and contribution. It has the capability to influence other members of the community  |
| Keyword                        | A theme or descriptive term that categorizes the topic of a document  |
| Open-source                    | A software package, which allow access and further development  |
| Online communities             | Peer to peer communities enabling users with similar interest to virtually  |
| Tweets                         | A 140 character status update specific to Twitter   |
| Twitter                        | SNS and micro-blogging platform, which allow user to tweet updates  |
| URL                            | Uniform Resource Locator; the technical term for a Web address e.g. gmkin.org.uk  |
| Wall                           | A shared messaged board specific to Facebook, in which users can post updates and others can either like or comment   |
| Web 2.0                        | A term encompassing a generation of the Web (SNS,blogs, OC) that allow for user generated content   |
| Web, website, platform         | Bespoke website design which allow publishing   |
| Web Analytics                  | Analysis, measurement and reporting of website utilization  |
| Depression                     | A mood disorder that determines persistent feelings of sadness and loss of interest   |
| Diabetes                       | Disorders caused by fallen levels of insulin which glucose in good is no longer metabolized. With time high blood glucose affects the blood vessels, causing cardiovascular disease and loss of kidney function |
| Dialysis                       | Treatment of CKD, involves the artificial purification of blood to rid of waste and excess water  |
| Pre-dialysis                   | Impairment of kidney function   |
| CKD, Renal                     | Abnormality of function of both kidneys lasting more than three months  |
| Transplantation / Transplanted | Transfer of human cells, tissues and organs from a donor to a recipient   |

*(Adapted from IBM Glossary of social media terms & DH, 2004)*

## **Abstract**

*Background:* Social media are powerful communication systems that enable sharing, networking and information generation on an unprecedented scale. However, there is limited evidence as to how social media mechanisms are adopted by patients within health to engage with others, locate and generate information, or as a source of support. The primary aim of the study was to adopt social media to enable patients to engage in the process of producing and sharing health information and examine the impact of engagement on a patients' self-efficacy.

*Research approach:* A realist synthesis progressed in two phases (Oct 2011–March 2015) to determine the influential mechanisms (M) of the study, the context (C) in which they work and the outcome (O), known as CMO configurations. Phase 1: development of Greater Manchester Kidney Information Network (GMKIN), staff and patient training (Oct 2011–Sept 2013), moderation and site refinement (Sept 2013–Oct 2014). Phase 2: six steps of realist synthesis to identify, test, and extend a set of theories/ propositions (Oct 2011–March 2015); mixed methods realist evaluation, observation of on-line activity, self-efficacy scales, blogs and interviews (0/6 months) with 14 patients (Nov 2013–Sept 2014).

*Findings:* The study strengthened evidence that engagement plays a crucial role in a healthcare social media intervention, building on an existing engagement model and knowledge. Three levels of engagement were identified: influencing roles, the conversationalists and general browsing. Engagement, an overarching mechanism, was a continuous process; influenced by attention, novelty, sociability, information and interactivity factors. Disengagement was characterised by inattention, triggered by environmental factors and decoupling, resulting from overwhelming information, health issues and negativity. Notifications often persuaded patients' to re-engage. CMOs were identified and explored, outlining the role of each mechanism (Social Network Sites, Facebook, Twitter, blogging and forums) in triggering outcomes. Patients' engagement contributed to information generation, which satisfied information needs. Satisfaction of information needs thorough social engagement influenced self-efficacy (in 13 of 14 people) and better management of illness. Social outcomes included seeking employment and getting involved in other things.

*Conclusion:* This study refined and extended propositions based on a real life intervention. It combined Social Media mechanisms and engagement concepts in the context of health and tested what worked for whom, when and how. Using an innovative approach it generated new knowledge in understanding social media impact, health engagement practices and communities of practice.

# CHAPTER 1: INTRODUCTION TO TOPIC AND THESIS

## Introduction

The emergence of social media has revolutionised the way people communicate and engage with each other (Schneiderman et al., 2011). These platforms provide a new way for people to share and convey information (Weber, 2011) in the form of personal stories, opinions and reviews, when combined with the social web (information from multiple sources) become powerful tools (Boulos et al., 2010). Indeed, Social Media is associated with '*websites and applications that enable users to create and share content or to participate in social networking*' (Oxford Dictionaries, 2013). The key Social Media types range from collaborative Wikipedia type projects to social networking sites, blogs, microblogs, content communities, virtual worlds, gamefication (Barry & Hardiker, 2012). Examples of the most powerful platforms include: Facebook with 1.4 billion users (StatisticBrain, 2013a), LinkedIn with 238 million users (LinkedIn, 2013), Twitter with 554 million users (StatisticBrain, 2013b), and Second Life with 33 million registered users (gridsurvey.com 2013). In essence these tools developed on Web 2.0 fundamentals are social systems that harness collective intelligence (O'Reilly & Battelle, 2009).

In the healthcare context social media enables patients to seek and generate information related to their health, which increases empowerment and the ability to make informed choices (Van De Belt et al. 2010). This way social media becomes a facilitator of access to biomedical and emotional information (van De Belt et al., 2010; Zhang & Zhao 2013), which may address some of the existing patient online engagement issues (Qualman, 2011; Hardiker & Grant, 2011) via posting, commenting, sharing and networking. Indeed, researchers have started to identify positive correlations amongst social media support and well-being (Bond et al., 2010; Hoffman & Novak, 2012), transfer of knowledge (Michal et al., 2013) and overall physical and mental health (Seeman, 2008). However studies appear to present positive results (Merolli et al., 2013) and more work is needed to understand what social media tools works best for patients in a particular context and why (Light & Ormandy, 2013).

Social media, the development, use and workings of online platforms by people in relation to health is the focus of this PhD study. In particular how people with a chronic illness communicate, network and seek out health information that does or does not influence their health or self-care behaviour. To examine such complex relationships and to develop a useful and practical theory that can influence platform development in the future, the researcher from the outset adopted a Realist Paradigm combining a realist synthesis and



realist evaluation approach. The topic was of a particular interest to the researcher, who originated from a background of web development and technical expertise, and experience of evaluating social media awareness campaigns, which reinforced the lack of evidence surrounding social media.

This chapter introduces the researcher, the topic and the realist research paradigm to provide a clear overview and understanding as to how the Thesis is organised and presented. It is followed by the aims and objectives and finally an overview of all chapters.

### **Researcher and the topic**

There are many justifications supporting this study, but predominantly the passion for the topic lies in my personal motivation and the need to generate high quality evidence on social media engagement in healthcare. It soon became evident, whilst engaging with health focused research studies with users and the design of platforms that there was a lack of knowledge on how social media works to provide health information, for whom, when, how and why.

The starting point of this study emerged from my background in web development and more recently the use and application of social media engagement. Working in web development for over six years highlighted controversy around developmental decisions in terms of usability (navigation flow, content, colour, design). Website usability is linked to customer satisfaction (Belanche et al., 2012) yet negotiating a design that satisfies all stakeholders' needs is often a difficult process. An example is drawn from the healthcare context involving a project aimed to develop digital technologies to engage teenagers to look after their sexual health. The core decisions taken during the project included matching users' preferences to engage them in the process of self-care. The process faced many challenges not least the control exerted by health providers on the design imposing their own preference over the users. The rise of social media, with social engagement being the fundamental element of making these tools powerful, has deepened the questions referring to what engages users, when and why. A health campaign using digital media (Light & Ormandy, 2011) outlines the benefits of using digital tools to promote awareness of cervical screening and reinforced the need to understand how social media works in different contexts. Although the cervical screening was more about health promotion than managing health long-term the need to engage and retain patients over a period of time remained a challenge.

Within this project, from the outset, the researcher had multiple roles: the main researcher, the technical expert and developer, IT trainer and educator, the community

manager (creating, supporting, advising and monitoring), which remained a challenge throughout the project.

The role of researcher is an important aspect in this project because of the values and experience I brought to the research. Firstly, I was influenced by the realist evaluation. In Pawson's view, the distinctive feature of realism in evaluation acknowledges the nature of causation - 'what works?', which reflects my own paradigm. Realism is concerned with causal powers within objects, seeking to find the regularities that supports the causal links but does not leave out of consideration the irregularities (Pawson, 2005). During previous research I was introduced to realist evaluation, which is distinctive in indicating how programmes work and can be designed using theory to capture relationships between user's, social media tools and mechanisms to enrich understanding (Pawson & Tilley, 1997). In addition, within projects I am used to using a logic model to provide a road map of the project, and map project theory, indicating the trajectory of activities and how desired outcomes are achieved (University of Wisconsin, 2013). Both of these methods and approaches influenced the development of this study.

My experience in website development and focus on user (patient) engagement influenced the implementation of this project. Throughout my work, an important factor was to work with patients and healthcare professionals to adopt and work with newly developed technologies. That involved sharing practice, learning from each other and finding ways to increase sustainability of the community. Concepts such as communities of practice (CoP) by Wenger (1998) and the collective learning that occurs in a social setting (Lave & Wenger, 1991; Wenger et al., 2002) underpinned and played a major role throughout my work. In Wenger's view communities of practice are groups of individuals sharing the same interest and learning how to manage better after regular interaction with each other (Wenger, 2000).

Knowledge sharing and creation are key factors in social environments alongside social interaction and identity building. With this in mind, the study vision that combined, the power of social media with healthcare information provision and patient engagement was established. This involved the use of Facebook and Twitter integrated with a bespoke platform, designed for a specific cohort of patients. The opportunity to take forward the topic of the research became available after attending a meeting related to kidney patients, and the need to improve access to information for kidney patients to enable them to make informed decisions. The Hope Kidney Patients Association (HKPA), a charity run by kidney patients for fellow patients, carers, relatives and friends expressed an intention to develop a website to provide information to their members and general patient

population. It was agreed that I would take on this role and we would work together to develop a site or information portal for patients, which would also be the site for the research. The study was funded from a successful joint bid submitted to the British Renal Society [BRS] by myself, the Chair of the HKPA and my supervisor. Funding was requested to expand the project to engage and involve patients with no current access to technology and health expert moderation.

### **Philosophical stance**

Exposing and clarifying the research and researchers philosophical stance, early in the thesis, is important as it underpinned and informed epistemological decisions from conception throughout the study. The researcher's interest and alignment to realist evaluation techniques, to learn how to apply these techniques to the research topic, drove the choice of approach. When exploring other paradigms the realism ontology selected was considered appropriate to examine the 'real life' experience of patients using social media, and understanding what works for whom, when and how.

The paradigm of science and social science consists of many different schools of thought, four core philosophies include: positivism, realism, constructivism and critical theory (Table 1).

Positivism has been widely used as research paradigm (Sobh & Perry, 2006). Applied to social situations positivism states that humans in their own environment behave like molecules and by changing the settings, human reactions can be observed. The research role is to remain detached from the participants in the intervention to explain human behaviour as a cause and effect in specific environments (Sanghera, 2003). Like positivism, realism agrees that social arrangements depend on a context, which is seen as an external determinant to behaviour but unlike positivism, it argues that social connections are a result of specific social relationships (Pawson, 2005). Constructivism and critical theory opposes positivism, arguing that the world is constructed by humans, who construct knowledge based on their experiences and views, in which case these social constructions should be examined in social science research (Sobh & Perry, 2006). Critical Realism positions itself within the philosophy of science and social science regarded as key post-positivist perception, proposing a framework for scientific explanation opposing the traditional epistemological view of positivism (Pawson & Tilly, 1997).

Table 1: Scientific paradigms (adapted from Sobh & Perry, 2006:p1195)

| Element              | Positivism   | Constructivism   | Critical theory   | Critical Realism  |
|----------------------|--|--|---|---|
| Ontology             | Reality is real and understandable                               | Multiple local and specific created realities                                      | The reality is virtually shaped by social, economic, ethnic, political, cultural, gender based values         | Reality is real but only imperfectly and knowledge from different sources is required |
| Epistemology         | True findings: established through the objectivity of researcher | Created findings: researcher is passionate participant of the environment examined | Value mediated findings: researcher is transformative participant who modify the social world of participants | Findings probably true: researcher is aware of significance and quality               |
| Common methodologies | Theory testing<br><br>Prone to quantitative methodology          | Mainly qualitative: interview, observations, action research, grounded theory      | Action research<br><br>Participant observation  | Theory testing<br><br>Mainly qualitative; interview, case studies                     |

Realism as a methodological orientation has been adopted in sociology, psychology, economics and evaluation (Pawson et al., 2005). Among the first pioneers of realism was the work of Bhaskar, who named it as critical realism (Bhasker et al., 1998). The domain of reality has three different ontological stances: the real (the structure and causal powers of the world), the actual (the acknowledged causal powers of the world) and the empirical (continued to be experienced) (Collier, 1994). Epistemologically, Bhaskar's work is divided into transitive (changing) and intransitive (unchanging) dimensions (Archer et al., 2013). The former concept refers to knowledge acquired at a certain point in time, whilst the latter is concerned with the mechanisms, which research attempts to identify. According to critical realism, knowledge is gained initially at empirical level (experience), which then is expanded to actual knowledge. The result is discovering the mechanism that works or not under certain circumstances, however identifying the 'real' is difficult, yet research is able to pinpoint the mechanisms that are able to work on other domains.

The realist paradigm closely aligns to the stance of the researcher. Pawson is one of the most prolific authors in health on the realist paradigm, suggesting it is concerned with demonstrable benefits, outlining what works for whom and why (Pawson et al., 2005; Pawson, 2006), enabling service providers to improve by learning from failure (Rycroft-Malone et al., 2012). It provides a powerful base to solve the issues of explanation underpinning the causal forces of why certain things happen. Realism is based on

assumptions that a real world exists but is perceived differently “*through human sense, volitions, language and culture*” (Meads et al., 2014:p2). As a technology expert and web designer this type of realist perspective is synonymous to designing and researching web based tools, therefore informs the underpinning epistemology for the research.

In this study, the realist epistemology starts with a theory of causal explanation (Pawson & Tilley, 1997). The programme theories, begin with a hypothesis (Pawson et al., 2005), which is refined as the study progresses. From the outset this study follows the realist paradigm because of its intention to develop a model of whether, or how and why social media tools work, and which is more efficient to engage patients in the process of crowdsourcing information to self-care. Features that appear match Pawson’s suggestions for a realist study: the interventions require active patient input; their activity is influenced by factors such as informational needs; they are part of multiple social systems and adopt elements from other services (Pawson, 2006).

According to the realist explanation, causality is a state of internal potential of a system triggered only in an appropriate medium. (Pawson & Tilley, 1997) A potential theory to address the aims and objectives of the study could be that: the development of a Social Media hub will engage CKD patients, who have a specific goal in mind, in the process of developing information, will satisfy patient’s information needs. From a realist view, in this scenario the outcome (satisfaction of information need) would be a result of the development of an optimum social media hub, which is aesthetically designed, enables novelty, interactivity, access, social support (mechanism) alongside patient characteristics such as technically proficient to use the hub, with the need to find information to satisfy a goal (context).

Alongside the realist perspective the researcher adopts the emancipatory perspective of critical realism (Table 1), acknowledging that individual’s knowledge is constructed around social contexts; hence reality is linked to the social actors, who contribute to the knowledge generation process (Dobson, 2002).

### **Realism and Technology**

Realism is concerned with studying social systems (Pawson & Tilley, 2006; Pawson, 2006). In this context Social Media is a type of social interaction continually shaped by users (Kaplan & Haenlein, 2010). Bijker and Law (1992) believe that technological developments have social implications; they cannot survive in isolation nor provide their own explanation; and arise in conflict and controversy. In reality social media tools are developed to serve different social groups with different practices and expectations from

use of technology; in this context achieving heterogeneity is a complex and fundamental strategy (Bijker & Law, 1992).

Technology emerges from established social, economic and technical relationships; thus influencing the philosophical and theoretical approaches to study technology from a social history and sociology point of view (Bijker & Law, 1992). Indeed successful developers have viewed technology not only as a technical innovation but as social, political and economic entities. However, the constructivist approach to technology argues that to achieve heterogeneity, scientific knowledge and technologies are developed based on social construction and negotiation, process dictated by participant's social interest (Bijker & Law, 1992), which is opposite to Pawson and Tilley's (1997) view on constructivism. Pawson and Tilley (1997) believe constructivism fails to recognize those: *'structural and institutional features of society which are in some respects independent of the individuals' reasoning and desires'* (Pawson & Tilley 1997: p23).

The philosophical perspective underpinning this study reflects a realist stance with a view that technology is being shaped and reshaped through user social interaction. In order to understand its impact (outcomes) it is necessary to identify the generative mechanisms and understand what influences users' decisions (context).

### **Realist Synthesis**

Similar to the study philosophy the methodology requires a brief explanation at the outset as the steps involved in the approach frame the layout and structure of the whole thesis. The study adopts a realist stance and takes forward a realist synthesis approach.

Realist synthesis is a methodological approach to synthesising literature, developing theory, testing out or evaluating theories and developing new theory and conclusions, often used to unpack the impact of complex interventions providing causal explanations to why things happen (Pawson & Tilley, 2004; McCormack et al., 2007; DeBono, et.al, 2012; Bonell et al., 2012; De Souza, 2013). This method is adopted by researchers to understand why, when and how different often complex social systems work (Pawson & Tilley, 2004). Social media is a complex intervention relying on a variety of tools, which produces different outcomes based on the user characteristics and context, so is well suited for such a methodology. Realist synthesis can be considered as a strategy to seek evidence and new knowledge, not a strict procedure to follow, leaving the field open to innovation in research design (Pawson & Manzano-Santaella, 2012). Whilst this provides an opportunity for innovation, it leaves the researcher open to a wide range of difficulties in conducting research (Greenhalgh et al., 2011). From the outset to overcome this issue

different frameworks were combined: such as the theory rich assessment (Pearson, 2012), to form an understanding of the theory rigour; and the logic model to present the findings and developing theory in a way that was meaningful for programme developers who account for input (resources, contributions, investments that go into the program), output (activities, services, events and products, people) and outcome (results or change) (University of Wisconsin, 2002). The logic model has been found to work well within realism to outline and expose links between inputs, activities, outputs and outcomes to better understand how programmes work (Subirana et al., 2013).

Realist synthesis follows a series of six steps: to clarify the scope of the project (Step 1), search for evidence (including grey literature) using a realist review to theoretically appraise the studies, synthesise theories (Steps 2, 3, & 4), test out the theories using realist evaluation (Step 5) and draw conclusions, new theories, new knowledge (Step 6) (Table 2).

*Table 2: Steps of Realist Synthesis (adapted from McCormack et al., 2007:p9)*

| Steps / Purpose  | Thesis Chapter  |   |
|--|---|---|
| Step 1<br><i>Scoping</i>   | <i>Chapter 2</i><br>Identify Question & purpose   | <ul style="list-style-type: none"> <li>• What is the nature and content of Social Media</li> <li>• What is the context of use</li> <li>• What are the policy objectives</li> <li>• What are the nature and form of the outcomes or impacts</li> </ul>                     |
|  | Identifying Theory  | <ul style="list-style-type: none"> <li>• Seek theory related to social media, information need and engagement</li> <li>• Create a list of theories</li> <li>• Create framework</li> </ul>   |
| Step 2<br><i>Searching</i>   | <i>Chapter 3</i><br>Realist Review  | <ul style="list-style-type: none"> <li>• Apply search concept in long term conditions</li> <li>• Update framework</li> </ul>  |
| Step 3<br><i>Appraising</i>  |   | <ul style="list-style-type: none"> <li>• Extract results using the framework</li> <li>• Compare and contrast findings</li> </ul>  |
| Step 4<br><i>Synthesising Theory</i>                               |   | <ul style="list-style-type: none"> <li>• Use findings to inform the review objectives</li> <li>• Seek contradictory findings</li> <li>• Refine theories</li> </ul>  |
| Step 5<br><i>Realist evaluation</i><br><i>Testing out theories</i> | <i>Chapter 4</i> GMKIN<br><i>Chapter 5</i> Methodology,<br><i>Chapters 6-8</i> Findings | <ul style="list-style-type: none"> <li>• Development of research test environment (GMKIN)</li> <li>• What are the best evaluation methods</li> <li>• Use of realist evaluation to refine and strengthen the findings</li> <li>• Test out propositions/theories</li> </ul> |
| Step 6<br><i>Conclusions new theory</i>                            | <i>Chapter 9-10</i>   | <ul style="list-style-type: none"> <li>• Dissemination of findings, conclusion and recommendations</li> </ul>   |

Although there is no strict technical procedure underpinning the realist synthesis, this type of enquiry is often unique and provides a theoretical focus to outcome analysis, which engages participants through a qualitative approach to reflect on the programme, from which to validate theory and compare with existing knowledge. Since realist research is concerned with explaining outcomes patterns, it is recommended that baseline and follow up data be collected, to monitor evolution and theory rigour (Pawson & Manzano-Santaella, 2012).

Fundamental to the realist approach to developing middle range programme theory and evaluation is the recognition of the interplay of three core concepts: Context Mechanisms and Outcomes (Pawson & Tilley, 1997: pXV).

$$\text{Context (C) + Mechanism (M) = Outcome (O)}$$

*Context* is the setting and external constraints (such as access to technology, an individual's culture, and beliefs); *Mechanism* is the stakeholder idea about how change occurs (maybe social discussion through Facebook/Twitter), and *Outcome* refers to intended and unintended patient outcomes (for example meeting an information need, increased self-efficacy) (Greenhalgh et al., 2009).

These three concepts flow throughout the thesis and are central to each step of the realist synthesis, forming the focus of the scoping of the study, the literature, developing theory, the choice of methods and data items, through to analysis and new knowledge. The next section highlights the study aims and objectives within the realm of realist synthesis.

### **Study aim and objectives**

The primary aim of the study is to adopt social media to provide health information to patients with a chronic illness and measure whether it has any impact on their self-efficacy and illness self-management. This will be achieved through the development and pilot of the Greater Manchester Kidney Information Network (GMKIN) Hub (phase 1) and realist synthesis; realist review and realist evaluation of the social media strategies applied (phase two); to understand what mechanisms work better for patients, in what circumstances and what are the outcomes.

A secondary aim is to understand the challenges of adopting and managing social media tools, the influence of healthcare professionals and other factors in engaging with patients via this medium and establish a series of management guidelines.



The study responds to the question: What social media mechanisms increase information provision, networking and communication for patients, how, and in what context?

*Five key objectives were identified:*

- Develop a Social Media Hub (GMKIN) that provides patient specific information and opportunities for CKD patients to communicate to each other and share their experiences.
- Train and educate patients and health professionals in the effective use of deploying and using Web 2.0 tools within the Social Media Hub.
- Explore and examine the engagement of CKD patients using GMKIN to better understand the process of engagement with social media and influential factors.
- Explore and examine the information generation practice of renal patients using GMKIN to better understand the impact social media on information need, self-efficacy and illness management.
- Add to the theory of patient information need, patient engagement and use of social media in health to inform practice and develop mechanisms that optimise the use of social media in healthcare settings.

The two phases of research were interconnected and ran concurrent over a three year five month period (Table 3).

*Table 3: Phase 1 and phase 2 time scale of events*

| <b>Phase 1</b>  | <b>Phase 2</b>  | <b>Time frame</b> |
|---|---|-------------------|
| Exploring the potential ideas for the study - wide reading<br>Discussions with Kidney patients association                            |   | Oct 2011          |
| Gather information resources for website  | Scoping and realist review of the current evidence (steps 1-4)<br>Review existing web resources | Oct 2012          |
| Funding grant awarded from British Renal Society – to buy Ipads, Internet access, moderation and patient involvement, web development |   | Jan 2013          |
| Development of GMKIN<br>First prototype<br>Incorporated patient and staff feedback / Development of young adult section               | Develop theories/propositions   |                   |
| Organize GMKIN Launching Event<br>Patients invitations, visit to units, advertising of launch   | Evaluation proposal refined and Ethical Approval obtained                                       | Sept 2013         |

|   |   |          |
|---|---|----------|
| Live GMKIN site<br>Moderation, posting, activation,<br>increasing and refining site information<br>Refining technology operating<br>mechanisms<br>Advertising the site to patients and<br>different units | Realist evaluation (step 5)<br>Patient recruitment and training<br>Interviews (0/6 months)<br>1 <sup>st</sup> level of analysis (baseline and 6<br>months activity for each patients) |          |
|   | 2 <sup>nd</sup> level of analysis and compilation of<br>findings  | Oct 2014 |
|   | Final analysis, revision and extension<br>of theories/propositions (step 6)   |          |
| Produce final report - Refine and submit complete Thesis  |   | Mar 2015 |

## Thesis Structure

The thesis is structured to mirror the Realist Synthesis six steps approach (Table 2), the complexity of the approach and progression of the chapters and study is depicted in Diagram 1.

Chapter 2 is a scoping chapter, setting the scene and exploring the known theories surrounding the study topic and the three core underpinning elements social media, engagement and the need for health information. Social media in the context of Consumer Health Informatics was explored and clarity on existing tools, their power in solidifying the social online movement and social engagement constructs identified. The physical, cognitive and affective user experience was examined, to identify the key factors that influence user engagement with a system. Linked to engagement was information seeking and information need. The scoping of the theory known for all three elements with respect to context, mechanisms and outcomes enabled initial study theories to be generated.

Chapter 3 reports the realist review which explores the current research evidence base of the use and influence of social media to satisfy patient information provision, communication and networking, for people with a long term condition. This chapter explains the process and principles of a realist review, following steps 2, 3 and 4 of the realist synthesis clarifying the search for evidence, the appraisal strategy, and the synthesis of the findings alongside the initial theories generated in Chapter 2.

Chapter 4 draws on the realist review theoretical evidence base (Chapter 3) and operating constructs for social media, engagement, and information need (from Chapter 2) to develop a purpose built Social Hub (GMKIN) for Hope Kidney Patients Association and to use as the research environment to test out and evaluate theory. The chapter explains

and describes the format and development of GMKIN, the operating mechanisms, moderator roles and social media tools activated and introduced within the site.

Chapter 5 presents the theory driven realist evaluation methodology, step 5 of the realist synthesis. The study methodology was founded on the realist paradigm and the fact that technologies have social implications and the design process is linked to social organisation and societies. Existing methods are critiqued and the best planned evaluation approach identified. Longitudinal patient interviews, alongside quantitative measures explore and analyse the context, mechanisms and outcomes that influence patient real life experiences of social media engagement, information provision, and the impact on their self-efficacy. Ethical considerations with respect to the patient involvement in study are reviewed.

Chapter 6, 7 and 8 form three findings chapters; exploring the data and theories related to patient engagement and networking within GMKIN, identifying and exploring what works for whom when, and examining the influence and impact of the social hub on an individual's self-efficacy, satisfaction with information need, and communication. Findings presented test out and challenge the theories generated within the realist review and current evidence.

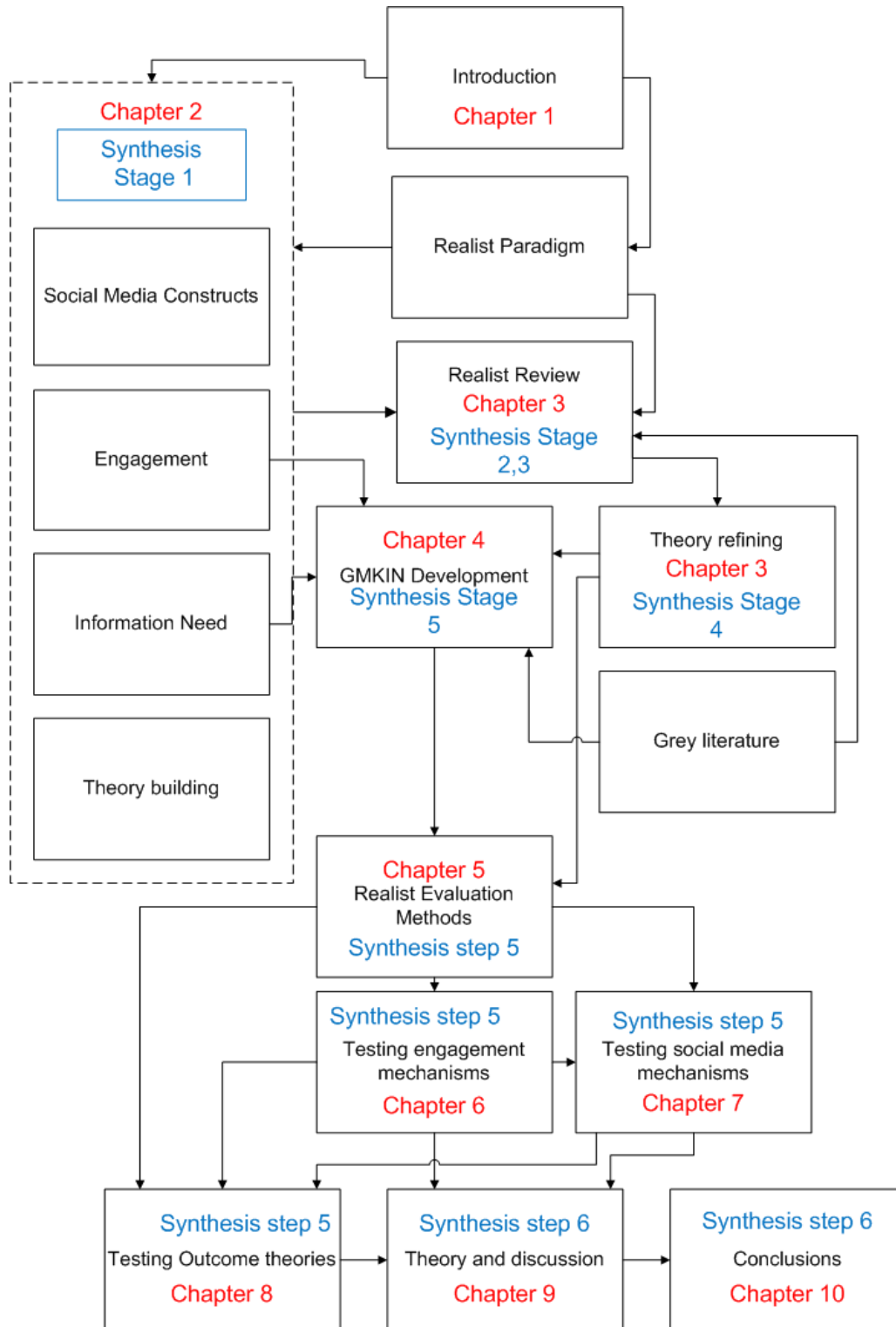
Chapter 9 explores and discusses the findings in the context of the theories generated throughout the thesis. The theories are refined and new theory developed that reflects the new knowledge gained from the realist synthesis. The limitations and strengths of the study are examined. Recommendations and conclusions are drawn from the new evidence and presented in Chapter 10 to bring the thesis to a close.

## **Chapter Summary**

The chapter introduced the research topic, and the fundamental approach of a realist synthesis that was adopted, making explicit from the outset the underpinning philosophy of both the researcher and an overview of the research strategy. It was important to establish a clear understanding of the flow of the thesis from the outset to better understand the focus of subsequent chapters. The principles of realist synthesis will be used to underpin the causal relationships of patients engaging with social media mechanism in the context of health, to influence outcomes. The aim of the synthesis is to generate theories and test these, in the context of a purpose built patient social hub (GMKIN), using realist evaluation methodology.

The next chapter begins the realist synthesis process by scoping out the core constructs and theories related to social media, engagement, and health information.

Diagram 1: Structure and flow of the thesis



## **CHAPTER 2: CONSTRUCTS AND THEORIES: SOCIAL MEDIA, ENGAGEMENT, AND HEALTH INFORMATION**

### **Introduction**

The modern perception of healthcare includes information technology and consumer health informatics as core elements of public health (Eysenbach, 2000). Online access to health information is one of the most remarkable changes that the internet has achieved (Kiley, 2002). The use of these mediums has enabled health professionals to reach consumers and patients via the internet to address the issues of information provision (Davis, et al., 2005; Snyder et al., 2011) yet satisfying information need remains a challenge (Ormandy, 2008; Schinkel et al., 2013). The field of consumer health informatics is further strengthened with the addition of social media technologies (such as Social Networking Sites and online communities). These technologies enable faster, wider, and open access to many different forms of information (Kaplan & Haenlein, 2010) complementing traditional ways of information provision such as leaflets and face to face (Coulter, 1998).

With the rise social media, many patients no longer rely on information just being given; they like to be part of the information production process, known as crowdsourcing by offering solutions to problems, comments and sharing their experiences (Adams, 2011). This generates an online form of information historically only gained from face to face discussions with other patients, often in clinics and treatment waiting rooms or sometimes through patient forums. In a healthcare context, it has been shown that patients can become activists by promoting practice, endorsing protest movements and general advocacy by integrating and sharing personal, professional and illness information with health care networks (Lober & Flowers, 2011). This form of interaction enables patients to make informed choices and feel empowered (Van De Belt et al., 2010).

However, the use of technology comes with inherent ethical issues. There is the danger that patients will no longer call health services; instead they will access online health information that can be inaccurate and misleading (Kiley, 2002; Hughes, et al., 2008). To address this problem, health professionals have to become internet aware and guide patients to accurate resources (Kiley, 2002). Yet clinicians are under great pressure within their work to adopt technology, and they find it difficult to understand why they should invest extra time in the patient– doctor relationship (Bacigalupe, 2011). However, when

information provision matches the information needs of patients the outcomes are generally reported positively (Ormandy, 2010; Davies, 2010).

This chapter provides a context for the study, with a scoping review of different theories surrounding three core themes: patients' information need and seeking patterns, the current role and impact of social media in health and consumer engagement. This forms the first step in the realist synthesis to explore the underpinning constructs of the research topic.

The three core themes will be examined to scope out the important; context, mechanism and outcome (CMOs) components of the research study, to take forward within the synthesis. Contextual factors may include individual or collective beliefs, structure, culture, agency and relationships; mechanisms could exist as practises associated with roles, resources and processes (De Souza, 2013); in this study outcome may be the use of social media to satisfy an information need or increase self-efficacy. The various forms that social media takes will be examined from not only a healthcare perspective, but also from a wider adoption in education and business, seeking to critically analyse the concepts around these technologies.

The CMOs provide a framework and the scoping review facilitates the recognition of relationships among the concepts reviewed, named as propositions (Pickett et al. 2014). Propositions are drawn together to take forward into the next chapter, to refine and eventually test as the synthesis builds.

### **Patient seeking information to satisfy a need (Context)**

Information provision for patients often occurs as a result of a problem or symptom as well as dependent on the specific needs of the patients. Effective provision of information is a determinant factor in helping people to self-manage their own illness (Astin et al., 2008). When information provision matches the needs of patients the outcomes are generally positive (Ormandy, 2008). However, research suggests that health professionals have not got sufficient time to respond to patients queries during a typical interaction (Haase, & Loiselle, 2012) therefore meeting the needs of different cohorts of patients remains an issue for the healthcare agenda (Ormandy, 2008; Schinkel et al., 2013).

Early patient information need research was undertaken from the perspective of clinicians' opinions on patient education resources, computer based education materials and patients opinion of their needs. Patients acknowledged that their information need was not

met, they required more tailored information to manage their illness, and ideally the response should be provided at the time of question formulation and not during the encounter (Tang et al., 1997).

Since then a shift was noted from the paternalistic model towards a partnership model, which encouraged patient autonomy and collaboration with physicians (Mills & Sullivan, 1999) to satisfy communication, decision making and self-management needs (Mayer et al., 2007; Ormandy, 2008; Astin et al. 2008).

### ***Information need***

The investigation of information need remains prone to problems partially because it is difficult to study users, within a complex context shaped by the physical and abstract universe of knowledge. Cole (2011) argues that information need was often a misunderstood concept, with researchers focusing on two main streams (1) empirical studies focusing more on needs assessment (Case, 2007), (2) associated with informational systems that enable users to type a question and the system offering a factual response. In his view the context of user is crucial to satisfaction of information need (Cole, 2011).

An overarching view of user's context is seen as a summary of experiences focused on the individual as an information user (Wilson, 2006), which is different from patient to patient (Ormandy, 2008) and determines the information need and the care plan required to manage their illness (Asadi-Lari, 2004). An informed patient will be able to distinguish and manage symptoms, use treatment effectively, understand professional advice, access services needed, manage work and cope with the psychological implications of the illness (Department of Health [DH], 2005). Indeed, effective provision of health related information to patients in long term conditions could improve self-care, health behaviour and overall quality of life (Coulter & Ellins, 2007).

A further difficulty arises by the confusion created by information and human needs shaped by (1) physiological needs (food, water), (2) affective needs (emotional needs) and (3) cognitive needs (learn, plan) which are interrelated. In this equation (1) can trigger (2) and (3), (2) influences (3) as well as not being able to satisfy a cognitive need (or disclosure of a need) can result in an affective need (such as fear) (Wilson, 2006).

Patients have information preferences and priorities, which are influenced by context, education, race and medical status (Mayer et al., 2007; Ormandy, 2008); and expressed

needs, preceded by searching information (Timmins 2006). However they may also defer the need, by choosing to ignore or postpone the process of finding information. Unconscious information needs exist when individuals are unaware of information deficits (Ormandy, 2008). According to Ormandy (2008) chronic kidney disease patient's main priorities are related to information about illness self-management, complications, and physical symptoms. Information concerned with the illnesses impact on daily activities, treatment available and coping with life were less important than psychological concerns and coping strategies which activated other information needs. For example knowledge on physical symptoms arose because patients needed to gain reassurance, reduce anxiety and overall feel in control. The cause of the illness, treatment options and side effects impact on coping with life came as a medium priority to patients.

The lack of information on social life and activities, work and finance was again a cause of concern for patients. Appropriate information available around these topics would reduce the number of patients having to make major lifestyle changes. The experiences of other patients were ranked lower with the evidence pointing that information from peers is a useful source rather than a direct information need (Ormandy & Hulme, 2013). The information need study developed by Ormandy (2008) provides evidence of why kidney patients are looking for information and how finding or not finding the right information influences their quality of life. The need to find information is often triggered by an event, encounter or physical/psychological experience with overlaps between the three concepts (Ormandy, 2008).

The findings of Ormandy (2008) are reinforced by research on information need across other types of chronic conditions, including coronary heart disease (Astin et al. 2008), and cancer (Van Weert et al., 2013; McNair, 2013). Astin et al. (2008) identified that patients were largely satisfied with the level of information received but indicated a need for more information on risks, medication, physical activity and diet. Cancer patients consider information, mainly related to prognosis, justification of treatment, quality of life after treatment and physical appearance important (McNair, 2013). Older cancer patients unmet needs were identified as treatment, rehabilitation, effective communication and realistic expectations (Van Weert et al., 2013), findings that were echoed in other cancer studies (Rutten et al., 2005; Franssen et al., 2009; McNair, 2013).

Cole (2011) conceptualises an information need as a black box underpinned by three categories: (1) information behaviour, (2) context and (3) human condition, the latter is seen as a holistic approach to information need. Information behaviour being concerned with information search, information seeking and information use. Information search is



the phase in which the user formulates a question to a system to respond. To formulate the question the user must have an information need, translate this into searchable terms, and identify the right keywords to retrieve information that is satisfactory. Information seeking is more than a user-system focused search accounting for complex human information behaviour.

To define information use, Cole uses Wilson's (2000) view that is the physical and mental activity of using the information found including reading, making a note, thinking and any other mental actions (Cole, 2011). The context is associated with the user context given by their problem whereas the human condition is made by sense making and evolutionary adaptation of information. Cole's theory of information needs aims to link information access to construction of knowledge. According to the theory, the user performs a task in stages, as in Kuhlthau's (1993) model: a pre-focus stage, a focusing stage, and a post-focus stage. The search begins with an uncertainty or gap in understanding, and then contours a frame of information need by bringing existing knowledge from different areas of memory up to a point when the information need is transformed into an information use event. This will focus the user on an information search pathway being introduced to problem-goal, problem-solution, or task formulas and adaptation of information to serve own need. The process of searching for information is metaphorically seen as going through a tunnel to position within the existential and survival world. This has implications for designing systems to provide information to patients, the theory mandating strong aesthetic and effective system components (Cole, 2011).

### ***Information seeking***

Patients seek information to self-manage, ensure independence, self-esteem and live a normal life as possible (Davies, 2010) which coupled with symptom management and aspects of treatment prevent further complications, leading to survival (Ormandy & Hulme, 2013). Patients with a long term condition may engage in the information seeking process to find information at different points of their illness trajectory however a longitudinal approach is needed to outline the underlying benefits of information seeking self-efficacy to understand how patients seek information in long term conditions (Anker et al., 2011). Information seeking is the process of searching information, generated by a need, which then satisfies a goal (Wilson, 1999). Wilson (2005) developed a model focusing on the continuity of the seeking process; the user behaviour is initiated by recognition of a perceived need. The behaviour materializes in different forms from information systems to other people; the latter involving information exchange recognised by sociologists and social psychologists as reciprocity. This aspect of human interaction can either have a

weak implication for example asking information from a senior colleague, or stronger implications inhibiting the seeking process (Wilson, 2005). The model does not explore the factors that determine when an individual should stop the search (Prabha et al., 2006). Whereas, Kuhlthau's (2005) model of information seeking presents the process as a sequential set of stages: initiation, triggered by acknowledging the lack of knowledge; selection of a problem area; exploration of resources; formulation of an exact problem, collection of information to fulfil the gap and finally presentation of knowledge. Kuhlthau's information seeking model was developed initially in 1993 as a six-stage Information Search Process (ISP) Model, before Wilson (1999) made the distinction between information seeking and information searching, the latter referring to a user system interaction (Cole, 2011). The information seeking process is sometimes considered ended when the user involved makes sense of the situation involved and solves the problem but this does not explicitly address the behavioural factors associated with the stopping behaviour (Prabha et al., 2006).

Patients have benefited from the influx of internet technologies to access healthcare information, and it has provided new opportunities for information provision. Further to the informational web, the rise of social media has provided digital tools that enable patients to share and rate their experiences of health care, and actively access information (Rozenblum & Bates, 2012). Although patients trust medical institutions and healthcare professionals as the main source to find information (McMullan, 2006), online technologies have become a popular resource to access health information (Beaudoin & Hong, 2011, Song & Chang, 2012), improve patients-provider communication, and enhanced use of health services (Gruzd et al., 2012). It is acknowledged that 80% of internet users are seeking to find information online (Gruzd et al., 2012). Patients search the web to find information related to nutrition or diet, medication side effects, symptoms, alternative treatment options, and second opinions. Social media, in particular popular networks such as Facebook and Twitter, are seen as beneficial in reaching a wider patient population, from different ethnic backgrounds to provide education, enable social engagement and change behaviour (Shaw & Johnson, 2010).

The internet movement was divided by Tufekci (2008) into social and non-social uses or in other terms the expressive internet and the instrumental internet. The instrumental web as opposed to the expressive web is the web of information seeking and non-social communication (Tufekci, 2008). In the online context search engines and social media provide different values to the user seeking experience (Morris et al., 2010); the rise of

social media sites is a potential informational resource for finding information (Thackeray et al., 2013).

### **Social Media in the context of Consumer Health Informatics (Mechanisms)**

This theme unveils the social media mechanisms, as the new addition to Consumer Health Informatics (CHI), then placing the information need within the context of the informational and social web.

In 1960 the benefits of technology to patients was predicted (Eytan et al., 2011) and since this time the medical care field has become transformed by digital innovations (Reiner 2011). These are in the form of bioinformatics applications, imaging informatics, research informatics, public health informatics, health information management and consumer health informatics (Hersh, 2009). CHI is concerned with satisfying patients' information needs and providing access to information using digital mechanisms based on consumer's experiences, which is believed to improve patient health outcomes (Eysenbach, 2000; Sullivan & Wyatt, 2005).

In the modern health care era, patients are expected to collaborate with health care professionals to share key medical decisions and undertake self-care, both of which are impossible without appropriate information (Holmes-Rovner et al., 2001; Forkner-Dunn, 2003). Moreover patient's lack of knowledge and physician's lack of support and time impose more barriers to collaboration hence improved communication amongst both groups is required (European Commission [EC], 2012).

The increased application of digital technologies facilitate a radical transformation of health care by enabling patients to access health related information and feel empowered (Atkinson & Castro, 2008; Van De Belt et al., 2010). If years ago most communication happened face to face the advances in mobile and online technologies provide new communication channels (Atkinson & Castro, 2008).

Previous online services include NHS Direct, a 24 hour telephone based service introduced in 1997, complemented by the NHS Direct website developed in 1999. The website was closed from March 2014, but prior to closing, NHS Direct encountered 1.5 million visits every month (NHS Direct, 2013). Now, NHS Choices, the most popular health website in Europe, has seen continuous growth since its launch in 2007. The platform remains very popular alongside other health platforms such as BBC Health, MedicineNet, and Patient UK. Traffic to NHS Choices has increased to 27 million visits per month, half of the users acknowledging that the site helps them manage their symptoms

and plan visits to a GP (NHS Choices, 2013). In 2014 the existing NHS Choices website was replaced with a new self-care portal named the Integrated Customer Services Platform. The vision of the new platform is to use digital technologies to empower the public in being more responsible for their wellbeing (Tyer, 2013). Patient Online is the route to electronic access, launched in 2013 in the UK, by the Royal College of General Practitioners (RCGP), in a movement to offer patients the option to access their health records and medical services by 2015, aiming for a paperless service by 2018. The overarching aim is to provide healthcare services with a framework that addresses the principles of enabling patients' access to healthcare records, training, education, and provides support to embrace information technologies in order to engage patients in better care (RCGP, 2013).

The introduction of new online technologies and increased consumer movement may be a drive towards the next generation of patient self-care, although further evidence is needed to examine the value of the internet for improving health outcomes (Forkner-Dunn, 2003). E-Health technologies are believed to enable access to a wealth of health information (Hardiker & Grant, 2011). Evidence suggests that having access to a wide variety of qualitative information, and personal health records enables patients to better self-manage their illness (Atkinson & Castro, 2008).

Although it was and is assumed that new web technologies will bring fundamental change in health, no major changes have yet occurred (Van De Belt et al., 2010). Robust studies are reinforcing that engagement and attrition are acknowledged as determinant factors in the online interventions efficiency (Glasgow et al., 2007; Christensen et al., 2009; Archambault et al., 2012). Public engagement with E-health continues to be a problem; although it is expected that social media will address the fundamental issue of patient engagement with health technologies (Hardiker & Grant, 2011).

### ***What is social media?***

Social media was developed initially as an entertainment tool thereafter it has become a marketing phenomenon because of its advantages: time, cost, social relationships and bigger audience (Kirtis & Karahan, 2011). The social media concept is evolving fast in the digital world; however researchers have not yet reached a clear definition of the technology (Merolli et al., 2013). According to O'Reilly and Battelle (2009) social media is a web built on the Web 2.0 fundamentals: sites that create social systems to harness collective intelligence. Oxford University Press (2013) defined Social Media as associated with *'websites and applications that enable users to create and share content or to*

*participate in social networking*'. Social media emerged from two areas of research; communication science and sociology: communication, as a mechanism to share and store information; sociology, social media is formed by a set of social groups with a dynamic interaction amongst them. In essence social media are '*communication systems that allow their social actors to communicate along dyadic ties*' (Peter et al., 2013: p282).

Kietzmann et al. (2011:p243) revealed the diversity of social media platforms through a compilation of seven components: (1) identity: the degree to which users expose their identity, (2) conversations: the amount of conversation amongst users, (3) sharing: the level of information exchanged between users, (4) presence: users awareness of others' availability, (5) relationships: users connections to one another, (6) reputation: users knowledge of successful profiles and content produced, (7) groups: users are part of organised form or communities.

Hoffman and Novak (2012) has undertaken two large scale studies (study 1, 340 participants; study 2, 208 participants) exploring use of social media as a result of which they indicated that social media's fundamental strength is given by its core functionalities: connect, create, consume and control, simplified as 4Cs. Social media interaction enables people to connect (Hoffman & Novak, 2012) revolutionising the way they communicate and engage with each other (Schneiderman et al., 2011). These connections that occur in online social environments generate content creation (Hoffman & Novak, 2012) and facilitate more than a friendly chatter providing a new way for people to share and convey information (Weber, 2011). These usually take the form of personal stories, opinions, reviews, geo-tagging, which combined to the social web mashup (information from multiple sources) become powerful tools (Boulos et al., 2010), when information produced and shared is then consumed by users.

Whilst social media is often seen as ground breaking technology, the current trend is merely an evolution of the initial World Wide Web, developed to enable information exchange between users (Kaplan & Haenlein, 2010; Grindrod et al., 2013). The emergence of social media shifted the focus towards a Web where information is created, shared, modified and repurposed rather just consumed (Kaplan & Haenlein, 2010; Adams, 2011; Kietzmann et al., 2011). This is known as the expression web and refers to technological developments used to socially interact, create self-profiles, public performance, and the creation, maintenance and increased social ties, further portrayed with the rise of social computing (Tufekci, 2008). Indeed, social media is a social revolution that happens through participation and engagement (Downes, 2005).

The domain of social media is constantly growing, with Facebook achieving 1.4 billion of users since 2004, 11% of the global population (StatisticBrain, 2013a). Facebook has become a pioneer of social communication, engagement and relationships. Approximately 55% of teenagers 12–17 years, 75% of adults 18–24 years, 57% of adults aged 25–34 years, 30% of adults aged 35–44 years, 19% of adults aged 45–54 years, 10% of adults aged 55–64 years, and 7% of adults over 65 engage in Facebook social networking (Jent et al., 2011). Twitter, a microblogging platform (enabling 140 written characters only) emerged as a new powerful technology after news events, when the plane crashed in the Hudson River, and a US student was taken to prison in Egypt (Kwak et al., 2010). Today, Twitter has 554 million users, and 135,000 signings daily, who share on average 58 million tweets per day (StatisticBrain, 2013b). It has been calculated that 35 hours of video are uploaded to YouTube every minute (Schmidt, 2010). LinkedIn, another social media platform has reported 238 million users, with more than two members signing up per second (LinkedIn, 2013). These are only some of the most popular social media platforms according to published statistics.

For the purpose of this study, social media is seen as a Web 2.0 technology that encompasses various mechanisms based on whether or not the user would like to reveal their identity, the type of communication, relationships and reputation they want to achieve through sharing information and networking. In essence Social Media is seen as an online technology and a social revolution (Downes, 2005; Kaplan & Haenlein, 2010; Schneiderman et al., 2011). To achieve a closer insight on social media it requires pinpointing two other concepts namely Web 2.0 platforms and User Generated Content, and how social relationships influence engagement with the technology (Kaplan & Haenlein, 2010).

### **Web 2.0**

The term Web 2.0 was mentioned in 2004 to set up the boundaries of a new technology, which encompassed platforms continuously updated by users, who created mashups (a mixture) from one or multiple sources, whilst providing own knowledge and perspective creating a network effect (O'Reilly, 2005). The definition of Web 2.0 is problematic, and its semantic is derived from predecessors like Web 1.5 and Web 1.0 (Kata, 2012). In many circumstances, the technology and the type of social interaction of the second generation of Web ideology are understood differently (Nijland et al., 2011; Stellefson, 2013). The push towards the different fields' derivation of Web 2.0, such as Medicine 2.0, Health 2.0, is seen more as a commercial gain (Adams, 2010). Consensus acknowledges that the difference between the Web 2.0 and predecessors (Web 1.5 and Web 1.0) rely on the

level of interaction and content generated as a result of the interaction amongst users (Kata, 2012; Van de Belt et al., 2012). Web 1.0 principles were based on one way interaction, provided generally by the site administrator (Kata, 2012; Betsch et al., 2012). In contrast Web 2.0 despite being developed on the same technical language as Web 1.0 (Kaplan & Haenlein, 2010), allows users to interact and create information, known as user generated content (UGC) (Betsch et al., 2012; Van de Belt et al., 2012). Practical examples of UGC are online communities such as PatientOpinion, Facebook groups, YouTube and Twitter. Although Web 2.0 does not bring specific technical updates, it requires specific functionalities such as Adobe Flash used for interactivity and animation; web feed formats (RSS), and AJAX (method used to retrieve data from web servers) (Kaplan & Haenlein, 2010).

To further differentiate between the two main Web types, Weber & Rech (2009) introduced the concept of the information Web (which refers to Web 1.0 and 1.5), and the social Web (which including Web 2.0 and Web 2.5). The information Web includes features such as content viewing, onsite commenting, a combination of static and dynamic pages, no interaction or form based interaction and advanced search. In contrast, the social Web allows users to edit, upload and download content, onsite commenting, dynamic pages and scalable interface, and content Mashups (Weber & Rech, 2009) which is why it is known as the expressive web (Tufekci, 2008).

The existing social media types built on the Web 2.0 technology vary in terms of scope and functionality (Kietzmann et al., 2011). There are social networking sites (SNS) that allow friendship creation like Facebook, professional networking sites such as LinkedIn or media sharing, YouTube, Flickr and Vimeo. The blogosphere is increasing, platforms like Blogger and Tumblr allowing people to blog whereas micro-blogging is a new phenomenon developed by Twitter, which allow tweets each consisting of 140 characters (Kietzmann et al., 2011). Facebook and Twitter seem to be the mainstream social technology mechanisms that enable information to be shared and shaped, engaging users through information communication technologies (Bacigalupe, 2011; Kata, 2012).

Social media is a powerful resource yet health executives are reticent to allocate resources towards use of it (Kietzmann et al., 2011). One reason is the lack of understanding of various forms it takes and which tool should be adopted (Kaplan & Haenlein, 2010). This study seeks to clarify which social media tool work and in which context for patients with chronic kidney disease. An overview of social media types is given below in an attempt to identify what tool works best, when they are adopted by whom and why in the healthcare context.

### *SNS used for health purposes*

Social Networking Sites (SNS) are powerful networks of networks that bring together millions of users, who adopt the technology as part of daily practices. SNS are online services that enable users to develop a public profile on a platform, connect with other users and create friendship lists, view and share friendships within the system (Ellison et al., 2007). The term social networking is often used interchangeably with the term social media and although there are similarities, the two concepts are different (Moorhead et al., 2013). SNS are distinctive in allowing users to create and make visible their social networks, which in many circumstances reflect their offline friendship ties (Ellison, 2008), and for this type of social interaction, face to face contact is not needed (Sato & Costa-i-Font, 2013). SNS are functionally rich applications; that entail creation of visible profiles unless steps are taken to make the information shared private to oneself, friends or just the group (Ellison, 2008).

The spread of SNS enable knowledge construction and management at an unprecedented rate (Cole et al., 2013). However, evidence suggests that only 1% of US adult population using the internet (85% of the total population) started the search for health information at a SNS (such as Facebook) (Pew Internet, 2013).

SNS enable communities' growth to achieve their own identity, become integrated and stabilized. Sustainability and growth of the online networks are achieved by a balance between dynamics of the networks and stability (Zhou et al., 2011). However, the study of SNS is yet to be developed; few studies analyse the individual profile of social networkers, and research is needed to understand the patterns of how people engage with SNS, and how they manage privacy (Sato & Costa-i-Font, 2013). Other concerns related to social networks, similar to other types of online tools (online communities, blogs) are; information accuracy (Hughes et al., 2008; Fernandez-Luque et al., 2012), de-humanisation of interpersonal relationships with decreasing face to face interaction (Demiris, 2006), misleading information and security (Kata, 2010).

Despite the concerns, patients are motivated to use social networking; for diagnosis, self-management and monitoring of treatment (Griffiths et al., 2012), to gain greater understanding and reassurance of certain illness aspects, find a second opinion on treatment because it can save time, be more convenient, wider coverage and maintain anonymity (Powell et al., 2011).



Popular SNS applications used in health vary from Facebook, Twitter, LinkedIn, Ning, YouTube, to PatientOpinion, PatientsLikeMe, each network being developed or shaped based on users interests and technological affordance (Ellison, 2007). Facebook is the most prevalent website (Tufekci, 2008). The cultures that emerge from SNS are varied with most sites connecting users with similar interests, political views or activities (Ellison, 2007). The content developed is innovative, generated from the individual's interest and knowledge on the topic (Adams, 2011), which triggers users' engagement in both creation and consumption of messages (Moreno et al., 2010). Amongst the SNS healthcare news and information, OrganisedWisdom is one of the most highly regarded being named the top website for 2008 for innovation in medical care (Nursing Assistant Guides, 2009). The platform converts crowdsourced (generated by a crowd) content into a Wisdom Card to close the gap between existing web information and a visit to the doctor. Health professionals are able to generate lists with curated links pointing towards health information (Health 2.0, 2011). Users can book appointments, receive health alerts, integration with social media and access to information that is both trusted based on patient need (OrganisedWisdom, 2012).

In contrast to OrganisedWisdom which enable patients to receive health information from doctors, PatientsLikeMe is an activist type system, significant in bringing together patients to share their personal data in the idea that the information can change their illness. Research on PatientsLikeMe has revealed perceived benefits to patients, such as greater understanding of treatment, involvement in treatment decision, and better communication (Wicks et al., 2010). Similarly, in the UK, the Patient Opinion platform enables patients to share their personal experience of health services to improve UK practice. There are approximately 42723 stories told and 2132 members of staff that listen. These existing SNS, exemplify the power of such intervention in healthcare to enable patients to share and access information.

### *Blogs*

Blogging, although available in different forms in the previous Web, has become a highly regarded feature of Web 2.0, and a powerful medium used by individuals to express themselves (O'Reilly & Battelle, 2009; Kaplan & Haenlein, 2010; Kietzmann et al., 2011; Neal & McKenzie, 2011). Blogs are online frequently updated content pages outlining individual's circumstances in a chronological order (Nardi et al., 2004; Lenhart, 2005; Bacigalupe, 2011). Different software companies attempted to define blogs (Boyd, 2006), and in 2004 the term blog was introduced as a noun and verb in the Oxford English Dictionary (OED). According to OED, blogs encompasses daily updates about different

topics such as news, dating, marriage, politics, other topics or no conclusive topic (OED, 2003). The verb 'to blog' is to be part of a community of literate and technical savvy individuals (OED, 2003).

The blogging phenomena began to expand with the introduction of Blogger and Pitas platforms in 1999, which in the first few months after release, achieved 10 to 20 new users per day (Herring et al., 2004). Blogger, a free publishing platform enables multiple users private or public blog entries, noticed an increased usage in 2002 which eventually led to being bought by Google in 2003 (Blogger, 2013). Blogs continue to expand in popularity and impact (Lenhart, 2005), and currently, 6.7 million people blog on blogging designated platforms and 12 million blog on SNS (SocialMedia Today, 2013). The most active population age group is 21 to 35 years, who account for 53.3% of the total blogging population (Sysomos, 2013). As more individuals start to blog, more people rely on the blogosphere information, then the audience engages in the creation of more blogs, although it is evident not every reader is a blogger (Nardi et al., 2004; Baumer et al., 2008; Neal & McKenzie, 2011).

In order to make the blogging process accessible, usable tools such as Blogger Wordpress, Tumblr have been developed (Nardi et al., 2004; Lenhart, 2005), which permit connection of different media genres including interactive elements such as video or audio streaming, graphics and visual materials (Adams, 2008). The rhythm of blogs varies widely in content, and whether they are an online diary or a different genre, one general characteristic of blogs is that they are expression sites (Lenhart, 2005).

A wide variety of activities and interaction occurs in blogs (Baumer et al., 2008). The three prominent types of blogs are individual created entries or journals, selection of commentary and information from other sources and knowledge entries (Herring et al., 2004). The motivation behind blogging is often to inform others about activities, share and seek opinions, reflection and release of emotional tension (Nardi et al., 2004). An important aspect of blogs is that they allow dialog between users via comment features, which enable the author to refine and better articulate their ideas (Bacigalupe, 2011) adding a social community dimension for blogs, which makes it different to diaries (Nardi et al., 2004; Lenhart, 2005; Adams, 2008). In a health related context, blogs can take different forms from coping and self-managing a chronic disease to providing evidence on a short term illness trajectory or supporting achievement of specific goals (Adams, 2008). The diversity of blogs is a result of readers engaging with the blog, their intent and the perceived message from a blogger (Baumer et al., 2008). Patients are involved in blogging because of their ability to share personal stories and emotional support rather

than gain medical knowledge (Gruzd et al., 2012). This activity is often underpinned by motivational factors such as life experiences, share expertise to influence others, seek feedback from participants, to focus own thinking by writing and release emotional tension (Nardi et al., 2004).

In mental health, engagement with blogs can be as a result of patients being utterly alone and powerless (Marcus et al., 2012). Potential therapeutic outcomes include expressing emotions, decreased feeling of loneliness, engaging in meaningful communication, emotions management and finding satisfactory information (Chung & Kim, 2008; Marcus et al., 2012). In cancer care, the emotional reactions shown by blog writers are found to be primarily positive (Savolainen, 2011). Providing information is another characteristic of blogging, however not all information available in blogs is credible or reliable, and patients could be misinformed by outdated information (Savolainen, 2011; Gruzd et al., 2012),

The blogs written by patients are useful for physicians to gain a deeper understanding of their patients (Wiesenthal, 2014). However, despite a high number of patients and physicians engaging in blogs, further research is needed to understand the process of providing health information via blogging and understand the information seeking behaviour (Gruzd et al., 2012).

Unlike other social media tools, the relationship between the blogger and reader is asymmetrical, the blogger not discussing directly with someone yet addressing an audience, who might choose to comment on certain aspects or give feedback through other channels outside the blog, which then makes the engagement less interactive (Nardi et al., 2004). Indeed in blogging the reader and the author relationships are lacking usual non-verbal signals, causing authenticity issues (Lenhart, 2005). The content authenticity arises from how the information is perceived by the reader and writer after they engage in an active process of interpretation, the constructs depicted being a result of interaction between the two parties, readers and bloggers, process enabled via the technology functions such as commenting, linking, tagging (Baumer et al., 2008).

### *Online communities (OC)*

One of the most regarded features of social media is the widespread of online peer to peer communities enabling users with similar interest to virtually share experience, information and emotional support (Eysenbach et al., 2004; Buchanan & Coulson, 2007; Coulson et al., 2007; Malik & Coulson, 2010). This activity can empower participants (Coulson et al., 2007; Chung, 2013), ease the decision making process (Gheorghe & Liao,

2012) and contributes to better quality of life (Wicks et al., 2011). OC are forms of networks of people who share similar values, whose interactions are bounded by policies and forms of tacit values (Preece, 2000). They existed prior to the social media expansion, in the form of bulletin boards, Usenet and discussion forums (Eysenbach et al., 2004; Bonnett, 2010). In 1985, Well (Whole Earth 'Lectronic Link) was established, a pioneer of OC (Rheingold, 1993). Almost 20 years on 16.7% of Internet users are members of an online community and now 68% search for information (Cole et al., 2013).

Popular examples of current OC include RareConnect.org, a platform with 40 disease communities available in English; French; German; Italian; and Spanish. Isolated patients and families engage in discussions, share articles, patient stories, and coping strategies. The service is managed by the European Organisation for Rare Diseases and the American non-profit organisation, National Organisation for Rare Disorders (Evenstad, 2013). In UK existing initiatives include the 56 Dean Street, Gaydar, and DrThom, use the online marketing strategies to diagnose HIV. The population targeted via Gaydar, resulted in over 4500 invitations who requested 132 HIV tests and the overall positive tests were 2% (Carrell, 2013).

OC have become popular amongst patients and are believed to have positive health outcomes. However research suggests mixed results, confounded by a lack of consistency between terms used to define different types of communities; the most common being online communities, online environments and online discussion boards (Gallagher & Savage, 2013). A systematic review outlined the different use of OC in healthcare services, weight loss and management, change behaviour for diabetic patients, and smoking cessation (Eysenbach et al., 2004). The studies highlighted contradictory results: one study found significant improvement in patients with diabetes behavioural change (Gustafson et al., 1999), whereas another stated that OC were less efficient compared to offline to reduce weight (Harvey-Berino, 2002). Many of the studies encountered methodological issues, including low patient engagement (Eysenbach et al., 2004).

Since 2004, online patient support groups have increased in popularity. Richardson et al. (2010) found that the study intervention with an online community decreased attrition and increased engagement in an Internet-mediated walking program. Participation is influenced by satisfaction of a perceived need, confidence in using the community and computers in general, trust of resources, awareness of their existence, and dissatisfaction with offline social support (Bender et al., 2013; Chung, 2013).

Users have various motivations for joining the groups; the two main reasons are informational support and socio-emotional support (Buchanan & Coulson, 2007; Mo & Coulson, 2010; Welbourne et al., 2013). Informational support include exchanges in health related information and advice on treatment and symptoms; socio-emotional support refers to compassion and encouragement on health issues correlated with greater posting (Welbourne et al., 2013). Thus, those who seek mainly informational support were likely to avoid posting, their engagement is often passive, and they are known as lurkers (described later) (Welbourne et al., 2013), although they often remain engaged for a longer period of time compared to active users (Lawlor & Kirakowski, 2014).

It is acknowledged that OC only create weak ties between communities with users not emotionally connected (Park & Lee, 2012). Although, receiving support and relationships between patients create strong bonds and a sense of belonging, which increases the benefits of being part in an online group (Wicks et al., 2011; Welbourne et al., 2013)

Access of communities has been shown to contribute to the alleviation of stress facilitated by social capital, the greater the social capital the better health outcomes (Beaudoin & Hong, 2011). However, other findings have found that posting support is associated with increased levels of stress given by the focus on oneself and the negative aspects of the illness (Shaw et al., 2006, Welbourne et al., 2013). An alternative explanation suggests that participants with increased level of stress are more likely to post and receive support which has positive outcomes on stress (Welbourne et al., 2013). Moreover factors such as altruism (caring and concern for others) and universality (realisation of the fact that others have similar health issues) are believed to contribute towards better mental health outcomes (Shaw et al., 2006). An online community facilitates anonymity, enhancing self-disclosure which may not be possible in a real community because of fears over stigma contributing to high levels of emotional expression (Setoyama et al., 2011; Lawlor & Kirakowski, 2014).

Internet based communities are not without disadvantages, there is a heavy reliance on online support correlated with a reduction of offline help making recovery harder (Chung, 2013; Lawlor & Kirakowski, 2014). However, it is argued that active participation and stronger online sense of belonging contributes to better connectivity with the outside community (Welbourne et al., 2013). Another potential risk associated with online communities is giving patients access to data.

Online communities can serve as new communication mediums for healthcare organisations thereby reducing costs and increasing the quality of services (Hajli, 2014).

Health professionals, patients and caregivers are increasingly using online communities (Richardson et al., 2010), however the technology is only an enabler and a successful community is influenced by strategic management (Young, 2013). Millington (2012) building on Iriberry & Leroy's (2009) model identified that a community is developed in four stages: Inception, Establishment, Maturity and Death. During the inception stage the community manager builds relationships with users, initiates discussions to maintain activity, establishes a community rhythm, and recruits community ambassadors. A community is considered established when members generate 50% of the activity. At this stage the role of the manager is to nurture and support members, continue the growth strategy and add new community tools. When members' posts reach 90% activity then the community is considered to be at a mature stage, and often successful communities remain at this stage and many never die (Millington, 2012). Examples to reinforce the importance of the community development stage are the online communities of Health Care Social Media (Canada), and Virtual Hospice's online community. The Health Care Social Media community was established in 2010 and has achieved a mature community of over 6000 members. The Virtual Hospice was initially established in 2004 but after initial phase the network had little or no activity, however, a management strategy introduced in 2011 generated unprecedented community growth (Young, 2013).

### ***User Generated Content***

User generated content (UGC) was formed as a concept in 2005 to encapsulate the various forms of digital content created by Web 2.0 users (Kaplan & Haenlein, 2010). The social media technical and social developments blur the boundaries between reception and production of information (Betsch et al., 2012) and UGC relates closely to the concept of word of mouth in an electronic context (Smith et al., 2012). UGC is a result of users being social and takes a variety of forms including tweets (Twitter) status updates (Facebook), videos (Youtube, Vimeo) and consumer posts, comments and reviews (Smith et al., 2012). UGC fulfils three basic requirements; it should be publicly available to a group of people, the content must be innovative and not copied directly from a different source and, it should be created separately from professional routines. The scale, dynamics and decentralization of UGC with the user being continuously exposed to new waves of videos and content, generates an unpredictable behaviour (Cha et al., 2007).

The vast majority of UGC is produced by users either individually or collaboratively (Kaplan & Haenlein, 2010) on the basis of self-expression, prestige within the group and with no expectations to remuneration (OECD, 2007). The level of content creation in social technologies varies by individual and level of connectivity. The diffusion of UGC is

associated with consumer intrinsic social skills, who voluntarily choose to, or not to share content, and in general does not involve high risks and costs (Thompkins & Rogerson, 2012). The size of the network and the first level connectivity of the user affect the diffusion of UGC, for example, in the case of YouTube the author subscriber list and past experience has a positive influence on the success of the video. The flow of information initially rises with network connectivity up to a certain threshold then decreases. To overcome this issue, users need to not join only for a direct network but target different OC (Thompkins & Rogerson, 2012). Entertainment and educational value, content value (of blogs), and author's age (content published by the younger generation is diffusing faster), perceived credibility, endorsement, accuracy, and similarities between subjects are factors seen to affect that spread of UGC (Thompkins & Rogerson, 2012; Flanagin & Metzger, 2013). The main benefit of UGC is the opportunity given to people, who are experienced and knowledgeable to become proficient profiles with social media networks without being an official authority, but the challenge then is the recognition of expert sources (Flanagin & Metzger, 2013). Indeed with the rise of social technologies, users are not only consumers but they become part of the creating process (Bruns, 2008), which then raises concerns on the information quality and the real value of UGC (Thompkins & Rogerson, 2012) and impact on different characteristics of consumer behaviour such as awareness, information acquisition, opinions, attitudes, use, communication and evaluation (Mangold & Faulds, 2009).

An important characteristic of UGC is the speed and size of production scale compared to other methods of content production, involving less effort. For example on YouTube 65,000 new videos are uploaded daily. This compared to IMDB (largest online movie database), which has 963,309 movies and other TV production since 1888, outlines that Youtube produces the same amount of information in only 15 days (Cha et al., 2007).

### ***The users and their online behavior***

The users of social media contribute to a varying degree to online activities; evidence from different domains categorise users' roles based on the level of engagement. The most common groups are referred to as passive known as lurkers, and active or posters; their motivation of engagement is very different (Preece et al., 2004; Rau et al., 2008; Petrovcic & Petric, 2014). Lurkers are defined as passive members who do not post or post fewer messages and learn by observing (Gray, 2004; Petrovcic & Petric, 2014). Users lurk either because their informational gap is fulfilled without posting or they consider that by posting their socio-emotional needs are not fulfilled. They visit social networks because of friendship element and the majority of PGI posted refer to personal life (Rau et al., 2008).

In health online communities lurkers form over 45% of the users (Nonnecke & Preece, 2000). They do not engage in the community yet they are familiar with the content, community norms and values turn them into active users (Schneider et al., 2013). Their main reasons for lurking are associated with: no immediate need, need to know the group better before posting, thinking that they are helpful by not posting, not knowing how to use the software; disliking the group dynamics and community was not meeting their needs (Preece et al., 2004). Moreover lurkers may refrain from posting because of having contradictory views, are afraid of being criticised or judged by other members of the community (Guan, 2006).

A more complex classification is given in the Social Technographics Ladder (Li & Bernoff, 2008) where the ladder represents in hierarchical order user participation within social media, the most active individuals are creators, followed by critics, collectors, joiners, spectators and inactive. Participants can fulfil one or more roles on the ladder (Li & Bernoff, 2008). Brodie et al. (2011) brand online communities' user engagement as sub-processes, which take different forms: sharing, co-developing, learning, socialising, and advocating. Sharing is a behavioural and cognitive engagement sub-process, in which users actively generate (co-create) information from personal knowledge and experience, along with learning and acquiring new knowledge from the information. Co-developing is associated with engagement to assist in the development of new products, services, brands or brand meanings. Users are socialising because of the benefits of two-direction interaction, in which they develop attitudes, social norms and common purpose, and advocate and recommend the community to others. Schneider et al. (2013) identified the role of expert members, who contribute to the welfare of the community, actively engage and need new information, to discover new ideas, but not necessarily actively seeking new knowledge.

According to Lai & Chen (2014) different factors affect the knowledge-sharing intention of posters and lurkers. Whilst lurkers may see mutual exchange as an influencing factor in their intention to post, posters expect reciprocity, alongside gaining enjoyment in helping others and new knowledge which motivate them to post. The enthusiasm of moderators, offering enjoyable experiences will influence the information sharing and increase participation of both poster and lurkers (Lai & Chen, 2014). Rau et al. (2008: p2761) exploring the impact intimate relationships found that both '*verbal intimacy*' and '*affective intimacy*' positively influenced posting frequency. Both lurkers and posters relished the online community, reporting similar benefits in terms of self-care and self-efficacy (Mo & Coulson, 2010). However, posters were more likely to have higher feelings, a sense of



companionship and emotional attachment; although there was no difference in terms of intrapersonal empowerment and being active did not necessarily empower users (Petrovcic & Petric, 2014).

Online behaviour is perceived to be different to offline norms (Mesch, 2012). It was identified that members join communities because of functional, entertainment and social values. The functional value is correlated with information and advice gained from online communities, whilst entertainment refers to the element of having fun (Dholakia et al., 2004). The social value focuses on friendship, emotional support, self-esteem, social status and social enhancement (Palazón, 2008), with trust as an important factor in online communities. Trust is interlinked with the concept of privacy. Mesch (2012) identified a level of consensus that privacy is about personal information, how that is controlled and the level of disclosure. Users with increased level of trust in the community feel more comfortable to disclose more personal information (Taddei & Contena, 2013). Previous research identified that the process of establishing online trust is onerous but once established it aids to alleviate the perceptions of risk, uncertainty and vulnerability influencing greater disclosure of information (Mesch, 2012). The norm of reciprocity is also believed to influence online behaviour (Posey et al., 2010), associated with the community moral code or the sense of duty to offer something to the community and those involved (Mathwick, 2002). In addition, the sense of belonging to the group, which has emotional values (such as developing affection) and self-worth of being part of the community fosters loyalty and commitment to the group (Dholakia et al., 2004).

### ***The role of social media tools in communication, information seeking and sharing***

The rise of social media applications enables health communication amongst patients (Kata, 2012), between patients and healthcare professionals (Vennik, et al., 2014) and facilitates strategies for patient engagement (Qualman, 2011). For example in the US, during the H1N1 outbreak in 2009 the Centers for Disease Control and Prevention (CDCP) used Twitter to communicate with clinicians, the Twitter feed was followed by over one million users (Eytan et al., 2011). The improved social media communication triggers positive clinical outcomes (Bacigalupe, 2011) such as increased interaction with others, availability of more tailored information, wider access, peer to peer support (mainly via blogs), public health surveillance, and influence on policy (Moorhead et al., 2013).

The Internet has become an important medium to gain knowledge, information seeking and sharing being the main activities of online communities, and less for emotional support (Meyer et al., 2008; Park et al., 2014). Information sharing is an action to provide

information whilst information seeking is the process of retrieving information that fits with personal need (Park et al., 2014). Patients use social media tools such as blogs, forums, wikis to seek information to prepare or decide on treatment; manage symptoms, adverse effects, reduce uncertainty, fulfil a knowledge gap (Bender et al., 2013; Schneider et al., 2013; Vennik et al., 2014). It enables them to make informed choices, which then initiate patient empowerment (Van De Belt et al., 2010). To create a sustainable system that will generate information the task must not be one sided, members having to provide information and not only search (Park et al., 2014; Vennik et al., 2014).

Often a person seeks information from another person if the interlocutor is knowledgeable and can share timely information. Patients indicate that participation from healthcare professionals, as experts, is preferred but they also acknowledged that they will contribute as long as the experts will check the information (Vennik et al., 2014).

An individual's pre-social characteristics including: age, gender, ethnicity, education, literacy, control, prevalence to other illnesses, satisfaction with provider, desire and intention to find information, are associated with information seeking behaviour which in return can trigger positive health outcomes (Zhao, 2009; Anker et al., 2011). Although ethnicity is an important determinant in the information seeking process, it is not an important factor when searching online information via social networks, thus social media engages a wider patient population (Shaw & Johnson, 2010). Indeed, young, highly educated females from wealthy backgrounds were more likely to seek health related information (Anker et al., 2011; Beaudoin & Hong, 2011). Older adults who are active information seekers live longer, better and do not rely only on information provided by healthcare professionals (Manafa & Wong, 2012). Well informed cancer survivors have been shown to experience fewer side effects, have better social and cognitive functioning, and treatment compliance (Jung et al., 2013). However, information availability and accessibility influences health information seeking (Manafa & Wong, 2012).

It is also common for carers or other known family members to seek information online. This group have a different pattern for seeking information and they use the internet as a tool, often looking for an explicit piece of information on illness, treatment or a hospital, to support them in their care giving activities (Haase & Loiselle, 2012; Sadasivam et al., 2013). Providing information online gives power to patients to access relevant information at a time that suits them, at their own pace and home privacy, whilst videos of individuals in similar circumstances provides a real and more personal approach to information provision (Ormandy, 2008; Haase & Loiselle, 2012). Despite the power and complexity of relevance ranking algorithms in some circumstances the vast amount of information

available online can harm patients (Ormandy, 2008; Manafo & Wong, 2012). Therefore, the depth of information should be a balance established by patients, with the view that an excess of information may increase anxiety (Ormandy, 2008).

In terms of information, patients connect the information available from different social media sources and some contribute by posting the information further (Adams, 2010). Patients prefer to gather online information by engaging with healthcare professionals and other patients to gain a wider view of their illness; expert information from physician and experiential information from peers (Vennik et al., 2014). Healthcare professionals need to be active in using social media to improve the quality of health care information, engage patients, promote collaboration and improve relationships with patients, and avoid the pitfalls (Van de Belt et al., 2012).

Social media is a dynamic domain that can instantly change; therefore organisations must implement a series of usage guidelines, and choose the language, moderation, integration and tools carefully for the targeted population (Kaplan & Haenlein, 2010). There are guidelines in place to avoid misuse of information, including refraining from posting content regarding patients or colleagues, online bullying, personal relationships with patients, ensure confidentiality and privacy (Nursing and Midwifery Council, [NMC], 2012).

Patients with long term conditions place importance on learning about the experience from other individuals with a similar health condition (Ormandy, 2008). It is hoped that the social characteristics of social media are adopted by patients and will overcome engagement issues (Hardiker & Grant, 2011).

Social Media tools enable users to become producers of content and sharing of information freely or using relatively inexpensive platforms, (Kaplan & Haenlein, 2010). Therefore, the judgements made by a health communicator become an issue mainly in the social web, where user generated information in the form of blogs, wikis, and online communities are its defining characteristics (Heath, 2005; Robins & Holmes, 2008). Information reliability, credibility and trust seems influential to patients engagement in retrieving information from social media sources.

Information reliability is often a cause for concern within social media communities (Hughes et al., 2008; Adams, 2008; Fernandez-Luque et al., 2012; Moorhead et al., 2013). Reliability of online information relates to different aspects: the system design and functionalities, information content factors such as quality, credibility, trustworthiness, and accuracy and user behaviour (Adams, 2010). Social media user generated content

escalates the issues of information overload (Adams, 2010) that can harm patients (Ormandy, 2008; Manafo & Wong, 2012). However not all reliability issues are a cause for concern, social media networking and information sharing in the form of images and interactive information are believed to influence understanding of health, communications amongst patients (Adams, 2010).

Factors used to evaluate the quality of information include satisfaction with content and structure, alongside agreement, emotional support, attitudes, humour, effort and taste (Liu & Agichtein, 2008; Kim & Oh, 2009). More recently Oh & Worrall (2013) proposed ten criteria to identify how experts and users recognize the quality of health answers: accuracy, completeness, relevance, objectivity, source, credibility, readability, politeness, confidence, and empathy. Their findings also identify the differences in perceptions amongst experts and users. Users' focus on source credibility (health expertise, experiences, or URLs in answers), readability, and confidence in providing health information and appreciated the efforts of creating answers compared to the experts (Oh & Worrall, 2013). The most important quality aspect for users is the ability to identify the source of information either via crowd consensus or links to source with literacy less important (Lederman et al., 2014). In addition, the health websites with enhanced functionalities, which convey a clear message and provide easy navigation and links to other information, are considered more credible and those with a coherent message are more influential and engaging (Betsch et al., 2012). Moreover, location and a clear policy on privacy indicate that a site is a legitimate source of information (Rains & Karmikel 2009).

Users' anonymity enables anyone to post information on social media, which in turn facilitates greater openness and expression of telling contributing to intimate relationships (Chung, 2013). Anonymity does not have a negative impact on the perceived credibility of a blogger (Chesney & Su, 2010) but it can be linked to online (cyber) bullying, freeing the cyberbully from the social implications of their behaviour (Patchin & Hinduja, 2006). Often users of social websites keep anonymous profiles and are multi-user's making it difficult for the reader to assess the reliability of information (Moorhead et al., 2013).

Users control social applications the information they share, and their privacy, although online privacy and confidentiality remains a serious concern associated with social media (Demiris, 2006; Adams, 2011; Thompkins & Rogerson, 2012; Sato & Costa-i-Font, 2012; Hoffman & Novak, 2012). For example, Path, a social app allowed children under 13 to sign up and retrieved personal data, which triggered a fine of \$800,000 by Federal Trade Commission (FTC) (Arthur, 2013). Facebook admitted privacy breach for 6 million users;

on Twitter 250,000 accounts were hacked; 6.5 million accounts were stolen from LinkedIn in 2012 and published online (Rigoli, 2013).

Trust in social media is achieved if the sources showcase relevant expertise in the area, have experience and are impartial not vesting other's interests. Content with high visual design and aesthetics are reported as more credible sources (Robins & Holmes, 2008) and affinity with social media sources is often triggered by similar values, interests and whether or not the source is recommended (Heath, 2005).

### ***The role of social media in social support***

The evolution of social technologies brings in a new dimension of social support, which may provide a solution to continuous user engagement and retention in online interventions, increasing access to information and patient self-management (Poirier & Cobb, 2012). Previous studies revealed that long term engagement is an issue associated with web based interventions (Eysenbach et al., 2004); engagement being acknowledged as a determinant factor in online intervention efficiency (Glasgow et al., 2007; Christensen et al., 2009; Poirier & Cobb, 2012; Archambault et al., 2012). The social aspect of social media may be a potential solution to improve the weak engagement of patients in web based health interventions, but it must engage users on a daily basis (Strecher et al., 2008; Poirier & Cobb, 2012; Parkinson, 2012).

Social support, a theme discussed widely in social media, is the transfer of knowledge (advice, information and resources) to help an individual cope with an uncomfortable situation (Mikal et al., 2013). Social support usually encompasses four domains, mainly related to (1) informational support (transfer of information), (2) instrumental support (actions, resources), (3) socio-emotional (esteem support and companionship), and (4) embedded support (wellbeing, identity) (Mikal et al., 2013: pA46). Among social media mechanisms, SNS are greater sources of social support through presence of users and information richness (Lee & Kvasny, 2014). Social support requires active engagement of users. The attributes of online support known to influence participation and retention are interactivity, expert presence, sharing of similar experience, social distance and wider expertise, share at a favourable time, access to educational resources, privacy and anonymity (Hwang, 2009; Paterson et al., 2013). Moreover, patients' level of motivation is needed to engage in social support, which is given by the volume of information shared and non-judgemental discussion (Hwang et al., 2009).

Computer mediated social support is a growing model of communication and support using online technologies, which if matched to the right type of transition can trigger social capital and support reducing stress (Mikal et al., 2013). They can bring new dimensions on the concept of social capital expressed by Putman (2000) altering the concept weak ties and boundaries of private/public information (Tufekci, 2008). Communities with a higher sense of social capital have high quality of life due to social trust, networking and norms (Kavanaugh et al., 2005). Social capital has been studied in different online formats: social networking sites and online communities (Littau & Thorson, 2009; Phulari, 2010). According to Putman's theory of social capital, societies are successful if horizontal bonds, long term interaction and relationships that generate group cohesion are created amongst users, enabling users to work together, socialise and eventually create communities (Putman, 2000). This theory is reinforced by Littau & Thorson (2009) studying one local social community, to outline how involvement in virtual communities influences the health outcomes of that online community, assessing social capital from a global perspective. They found that use of information and connectivity were positively correlated to engagement, whilst entertainment was seen as a negative motivator (Littau & Thorson, 2009).

Putman (2000) introduces the concept of bridging and bonding social capital. Bridging is linked with weak ties, which refers to connections between individuals who share useful information but are not emotionally engaged (Granovetter, 1982 cited by Putman, 2000). Bonding social capital exists between family and close friends who are emotionally engaged (Ellison et al., 2007). Social support alongside internet use has the potential to increase the numbers of weak social ties (Kavanaugh, 2002; Tufekci, 2008). Users become members of different groups creating bonding amongst each other, although, Hampton (2002) argues that local online interventions create weak social ties and community involvement. Asynchronous discussions (instant exchange of information) establish social bonds due to their role in generating spontaneity and sense of someone else's presence, whilst the non-synchronous interactions influence learning (Smithson et al., 2012). A study on relationships between Facebook and social capital found that social networking maintained relationships between users mainly bridging type generating social capital accumulation unlike Facebook (Ellison et al., 2007).

The social dimension of social media appears to create social ties and social bonding amongst users although users primarily remain content consumers of health information rather than engaging in the process of posting (Thackeray et al., 2013). For example, a telephone survey of 1745 users to determine individual's use of SNS for health purposes,

find reviews of medical services, and contribute with content creation in the form of service reviews and enquiries revealed users as consumers of information and not creators, and the social influences did not change an individual's behaviour (Thackeray et al., 2013). These are not unexpected findings. Research by the Pew Internet & American Life Project, indicated that 6% American patients tagged online information and contributed to online discussions, 5% posted health information on a blog, reviewed a doctor online, and only 4% posted a review on a hospital or shared video or audio content (Pew Internet, 2009). Another study on the level of UGC on Youtube highlighted that the active level of user engagement in creating comments and star rating was low, the summative ratings accounting for 0.22% of total views (Cha et al., 2007).

### **The role of social media on Consumer Engagement**

Consumer engagement is an important factor in online adherence and sustainability of interventions (Christensen et al., 2009; Calder et al., 2009). Despite the technological advancements, policy and wider changes on social perceptions maximising consumer ehealth potential is yet to be achieved (Ricciardi, 2013). Patients engaged in seeking information to self-manage their health are more likely to get positive outcomes. They are more equipped to take part in clinical appointment, discuss healthcare issues with medical professionals and change behaviour to improve their health (Ricciardi, 2013). Furthermore, community engagement is acknowledged to positively impact on more access to interventions and achieve more social cohesion (O'Mara-Eves, et al., 2013).

Often there is confusion associated with defining consumer engagement, the field encompassing various streams of research, which is transformed into disbelief that investment in the area is worthwhile (Hurley et al., 2009). Given this reason although the focus of this research is on patient engagement using social media, the literature examined the wider context of consumer engagement.

### ***Engagement concepts***

The broad conceptualisation around engagement follows four main streams: behavioural, psychology, multidimensional and social being applied to various contexts such as '*organizational behaviour, education, informatics, psychology, sociology, management, health communication and political sciences*' (Javornik & Mandelli, 2013: p2). Behavioural studies focus on actions occurred as a result of motivational factors (Van Doorn et al., 2010) within the field of social media often this involves different levels of engagement in creating and distributing content. Psychological studies identify '*emotional and cognitive*

*process mainly antecedents to the behaviours'* (Javornik & Mandelli, 2013: p7), suggesting the multidimensional aspect of engagement involves both, behavioural and psychological change as well as a result of user experience with the medium. The social dimension is a complex phenomenon concerned with interaction among individuals involved in the community, and individuals and context (Javornik & Mandelli, 2013).

Given the multi-faceted nature of user engagement, there is no consensus definition of engagement, but it often associated with involvement, adherence, and participation which trigger positive human-computer interaction (Quesenbery 2003; Christensen et al., 2009; Calder et al., 2009; Brodie et. al, 2011; Sarrami-Foroushani et al., 2014). Involvement is a result of users expressing interest towards a community that has resonance with personal preferences and goals (Hollebeek, 2011). Whereas adherence refers to how users experience the content of Internet interventions (Christensen et al., 2009). Participation measures the frequency and length of time spent within the community (Poorrezaei & Heinze, 2014). In the healthcare context, engagement is used concurrently with patient activation (Mittler et al., 2013). Engagement involves behavioural, emotional and cognitive functions that construct a positive user experience, which is enhanced by the addition of social web. In this context, O'Brien & Toms (2008: p949) definition of engagement provides a wider outlook where engagement is a positive experience *'characterized by attributes of challenge, positive effect, insurability, aesthetic and sensory appeal, attention, feedback, variety/novelty, interactivity and perceived control'*. Indeed the level of information generated and shared is intrinsic to engagement (De Valck et al., 2009).

### ***Consumer engagement theories***

Engagement is a term associated with behavioural usage, for example, often viewing and spending substantial time on a website, but to achieve successful behavioural change users need to actively engaged (Calder et al., 2009; Schwarzer & Satow, 2012). The Technology Acceptance Model (TAM) and Theory of Planned Behaviour (TPB) are part of the group of theories assessing behavioural usage. TAM was initially introduced by David (1989) as a theory used to assess consumer engagement, but has since been developed to include social and cognitive influence processes (Padilla-Meléndez et al., 2013). The combined hypotheses identify that relationships between perceived usefulness, perceived ease of use, attitude toward using, and behavioural intention to use, influenced by a goal to use the system, and the user's internal beliefs, attitudes and intentions, underpin technology acceptance and use (Padilla-Meléndez et al., 2013). The theory has been previously investigated (Yang et al. 2005; Liao & Tsou, 2009), but the Turner et al. (2010) study was unable to highlight the accuracy of perceived usefulness and perceived ease of



use and identified more contextual research was needed. However, TAM does not measure the benefits of using a technology rather it outlines the factors that influence satisfaction and user perception of quality of information (Pai & Huang, 2011; Padilla-Meléndez et al., 2013).

TBP was developed by Ajzen (1991) to encompass the relationships between perceived behavioural control, attitudes and subjective norms on a person's behaviour intention. Although the theory has been extensively applied to healthcare interventions to predict behaviour it has not been found reliable within longitudinal studies, with measures often objective and not self-reported (Sniehotta et al., 2013). Studies report that TBP when tested can be misleading and measures seem to be more conclusive amongst young, healthy and affluent users, suggesting cohort bias (French & Hankins, 2003; Sniehotta et al., 2013). There is limited focus within both TAM and TBP on external factors that may influence engagement, such as the flow, aesthetics, and social factors.

A review by O'Mara-Eves et al. (2013) compiled a health specific conceptual framework encompassing various types of community engagement which could trigger positive health impact. The community engagement models varied based on whom initiated the intervention (public service or community); the level of engagement (consultancy, collaborative or leaders); and the type of engagement (individual basis or community). O'Mara-Eves and colleagues suggested that engagement could be initiated when the community were included in activities such as consultations, peer support, service development, human resources in local projects and community tier government. As a result of being engaged in communities members could experience benefit at an individual level (personal development), community level (social capital), enhanced service development and delivery and better health (O'Mara-Eves et al., 2013). Sarrami-Foroushani et al. (2014) expanded the work of O'Mara-Eves et al. (2013) on consumer engagement with the addition of nine further themes: decision making, self-management, health care systems, health promotion, enable access to health care, rehabilitation, participation in research, collaboration in research design and conduct, and peer support. Although the combined frameworks explain the various types and processes of interventions there remains limited evidence on how to develop, manage, and sustain interventions (for example what works for whom and why). There is very little understanding of the factors influencing the process of engagement, reinforcing the need for a more comprehensive engagement strategy which identifies the influential factors and strategies for developing and sustaining users over a longer period of time.

The Engaging Consumers in Health and Health Care in Communities (EHC) framework introduced by Mittler et al. (2013) differentiates between the concepts of consumers and patients, similarly among activation and engaged behaviours. The notion of consumer refers to personal informed decisions which maximise welfare, whereas patients traditionally are associated with individuals relying on healthcare providers to make decisions on their behalf. Activation is the capacity and the motivation to action, which is used synonymously with engaged behaviour. Indeed, the EHC framework identifies self-management, self-care encounters, shopping and health, which manifest at individual, group and community level, are influenced by a variety of key characteristics (Mittler et al., 2013). Despite the complexity of the model drawing on wider inclusion of contextual factors and behaviour, its application on the AF4Q initiatives provided subtle evidence of impact on improving consumer engagement (Mittler et al., 2013). However, the intricacy of the model and the omission of user experience triggers constrain the framework. In the context of online communities, built on the technological developments of Web 2.0, the user experience, alongside cognitive, affective and social experiences are important influential engagement triggers.

Fundamental to engagement is to understand the various experiences consumers have with a platform, O'Brien & Toms, (2008) theory combines physical, cognitive and affective users' experience, to study human information interaction. Experience is defined as users' perceptions and beliefs of how the site meets their needs (Calder et al., 2009; O'Brien & Toms, 2013). The experiences of a user are tangible (use the computer to write a post), intangible (feeling connected with the audience) and process outcomes, similar with usability (O'Brien & Toms 2013). The theory is based on human-computer interaction studies, suggesting that usability of the system is not the primary factor in engagement, but draws on elements from other major theories, such as: Flow Theory (Csikszentmihalyi, 1990), Aesthetic Theory (Beardsley, 1982), Play Theory (Stephenson, 1967) and Information Interaction (Toms, 2002). The theory brings together previous associations of consumer engagement with cognitive functioning, motivation, and behaviour (Laurel, 1993; Kappelman, 1995; Hutchins et al., 1996; O'Brien & Toms, 2008).

Flow is a situation achieved by a total absorption where people are involved because of the sheer enjoyable and rewarding activity (Csikszentmihalyi, 1990). Specific to the flow theory is that there should be a balance between an individual's skills and challenges, where both are high stimulus for an activity (Csikszentmihalyi, 1990; Ghani & Deshpande, 1994). An activity will flow if the experience is characterised by pleasure, control, concentration, experimentation, and challenge (Ghani & Deshpande, 1994). The theory

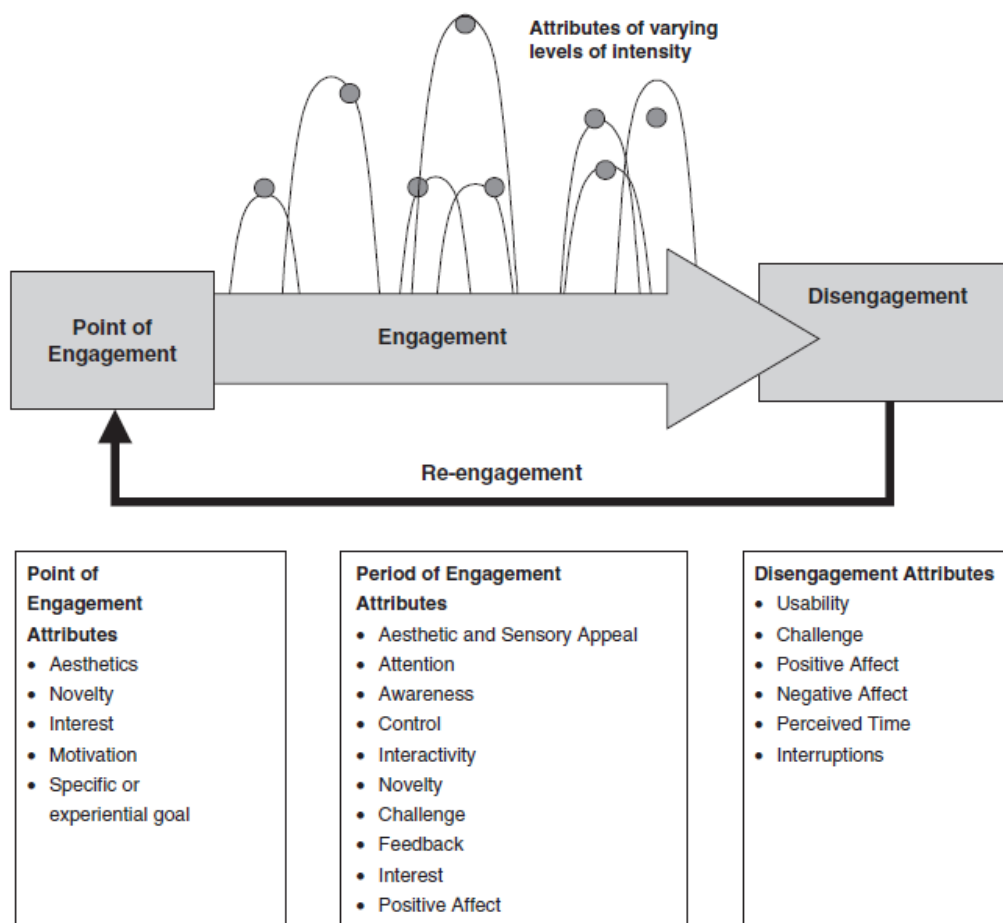
has been applied to games to describe the enjoyable subjective experience with focus on cognitive aspects such as challenge, concentration, goals and feedback (Boyle et al., 2012). It was recognised that the flow theory factors could be applied to SNS (Kwak et al., 2014). Aesthetic theory is an object characteristic, focusing on functional quality and positive experience with the design, maybe the simplicity or meaningfulness of a design that stimulates emotional quality and a pleasurable experience (Beardsley, 1982; Wang et al., 2010). An issue with aesthetics is that individual users have different tastes and preferences, designing web pages for various users' taste is recommended but difficult to achieve (Tractinsky et al., 2006). Users will determine the relative attractiveness of web pages rapidly (Lindgaard et al., 2006). Aesthetics is an elusive and confusing construct, which can be closely associated with concepts such as symmetry, balance, emphasis, harmony, proportion, rhythm, and unity (Beardsley, 1982) design layout and colour (Lindgaard et al., 2006), clarity, originality, creativity, richness and usability of the design (Tractinsky et al., 2006). Indeed a visual layout and graphics have high impact on website aesthetics to capture users' attentions and visual focus (Lin et al., 2013). Playfulness is another factor associated with engagement defined as the capacity of drawing players' attention and involvement during engagement with a device (Webster & Martocchio, 1992). Play to everyday reading, viewing and listening was a concept seen as an interlude from work and it functions as an involuntary and necessary decision (Stephenson, 1967). Play characteristics are similar to a compelling construct in flow and the relationship of challenge, skill and playful enjoyment; when an interaction with a device attributes to increased motivation and challenge it affects fundamental elements of engagement (Woszczyński et al., 2002; O'Brien & Toms, 2008).

The O'Brien & Toms (2008) model focuses on the process of engagement with inherited elements at each step of the process. The main steps are point of engagement (first contact), engagement (period of engagement), disengagement and re-engagement, each step having specific attributes (O'Brien & Toms, 2008: p949) (Figure 1).

At the initial point of engagement, the user has a specific or experiential goal in mind, triggered by motivations and interest, and is attracted by the aesthetic appeal or novelty of the system. In some circumstances users are motivated by social reasons and therefore it is believed that social media is a good mix of technology and social elements to trigger engagement (O'Brien & Toms, 2008). Throughout the period of engagement users' attention and interest on the object is maintained by interaction and positive emotions. Users are looking for an interface that is suitable to their needs, easily customisable and responsive. At this phase users can lose perception of time but keep touch with others in

the case of social interaction. Disengagement is a result of users deciding to stop the activity or due to external factors, and technical and usability issues influence users' decisions to disengage (O'Brien & Toms, 2008). Users' decisions to disengage do not necessarily mean the end of engagement, users can return if the past experience is positive (O'Brien & Toms, 2008). An explanation of the concept of disengagement, as opposed to engagement, is offered by Cheyne et al. (2009), who tested three states or concepts; task inattention (state 1), going through motions (state 2) and decoupling (state 3) from the task environment.

Figure 1: Model of engagement (O'Brien & Toms 2008: p949)



Task inattention is influenced by stimulus and it can be affected by incidental factors, performance errors and near-misses. Errors will influence novice task attendees, whereas complex tasks require monitoring and situational changes. The near-misses often occur at early stage of inattention, and attention is sufficient to notice the errors in advance. At state 2 the user enters an automatic routine resulted as loss of sensitivity to moment to moment stimulus. At state 3 the user disconnects from the online stimulus and attention is triggered by thoughts and feelings. The three states of engagement/ disengagement are

interconnected, with individuals moving from state to state (Cheyne et al., 2009). Whereas non-engagement occurs when the web experience is not enjoyable and there are barriers in place such as application content and poor usability (O'Brien & Toms, 2008).

Whilst other theories neglect the aesthetics of design (Lindgaard et al., 2006), O'Brien & Toms' (2008) model explores in detail the user engagement, the underlying causes such as look and feel of the hub (aesthetics), interactivity, motivation and goal to engage or disengage, which are also influential factors to patients information seeking to satisfy an informational need (Cole, 2011).

In addition to the factors identified by O'Brien & Toms (2008) other factors are proposed as influencing engagement. Quality is another measure of web design correlated with usability, usefulness of content, adequacy of information, accessibility, and interaction that further affects engagement (Yang et al., 2005). Accessibility is another factor that plays an important role in web engagement and the Web Content Accessibility Guidelines (WCAG) were developed to ensure that people with a disability can access the web (World Wide Web Consortium [W3C], 2004; Kreps, 2007). Types of impairments range from people with physical and sensory impairments (diabetes, disfigurements, heart disease and epilepsy), although not all types of disabilities pose a barrier to internet browsing. When it comes to web accessibility, people with visual, hearing, motor and cognitive impairments are most affected, but a similar attention should be drawn to all impairments. In web design, the cause of disability is the system designers' failure to implement accessible systems for all by default (Kreps & Adam, 2007). W3C aims to achieve Web interoperability so as to make the most fundamental Web technologies to be compatible with each other. This will allow the software and hardware implicated in any process to access the information on the Web without any barriers and, therefore, accommodating the growing diversity of people, hardware, and software (W3C, 2008). Following these guidelines the information presented on the web is optimised to work on a variety of devices and meet different personal needs and preferences (Matausch et al., 2012).

Patient engagement with online health services is triggered by health status and information needs, factors outlined as either motivators or inhibitors of engagement (Hardiker & Grant, 2011). Indeed information interaction is the bridge of engagement between user and a system aesthetically designed, enabling flow and playfulness which then influences user engagement or disengagement with the system (O'Brien & Toms 2008; De Valk et al., 2009). The principal motivators of parents of young patients involved in online interventions were the level of social support that contributed to satisfaction of information need and communication with others in a similar reality (Paterson et al.,

2013). The need for information was an important determinant of engagement enabling them to locate resources, understand the healthcare system, make decisions and develop coping strategies (Paterson et al., 2013). Engagement emerges from compositional or data from user engagement experience, complemented by sensual (cognitive functions), emotional (pleasure), and spatiotemporal (searching, browsing, communication) experience (O'Brien & Toms, 2008).

### ***Summary of theories reviewed***

The majority of current models of engagement focus on user behaviour, they are linear and do not necessarily capture the dynamic nature of social media. Researchers often extend existing models such as TPB, which is not necessarily helpful in advancing knowledge, given that the underpinning theory has been tested and expanded beyond recognition, therefore a new approach is advocated (Sniehotta et al., 2013). O'Brien & Toms' theory, although not focusing merely on behaviour, proposes a model of engagement that involves behavioural elements such as motivation, experiential goals, and interactivity combined with spatiotemporal, emotional and sensual experiences. The process of engagement takes place in different phases (point of engagement, engagement, disengagement, and reengagement) each phase being influenced by particular factors (O'Brien & Toms, 2008). The addition of social media would bring a new dimension to this engagement theory with more emphasis on social aspects.

### **Social media influences on Self-efficacy (Outcomes)**

The new digital technologies enable people to take collective action and strong personal efficacy and collective efficacy will determine active engagement with online technologies (Bandura, 2002). Self-efficacy beliefs determine how people feel, think, motivate themselves and behave (Bandura, 1977). Indeed, self-efficacy is a cognitive mechanism that influences behaviour, how an individual overcomes certain situations and engages in adopted behaviours, the effort and determination to succeed and finally master the behaviour (Bandura, 1986). Effects or outcomes of high self-efficacy can be positive related to increased self-satisfaction, pride, self-worth, whilst low self-efficacy influences self-dissatisfaction (Bandura, 1997). Bandura (1994) identified four sources that influence self-efficacy (1) mastery experience (individuals can overcome obstacles and build on successful experiences); (2) vicarious experiences (seeing people in a similar situation would increase belief oneself and abilities to master activities); (3) social persuasion (people who are persuaded that they possess the capability to perform influences their self-efficacy and beliefs that they can succeed); (4) somatic and emotional states like

mood, illness symptoms, reaction to stress and by reducing the effects emotional distress and interpretation will increase self-efficacy.

Evidence indicates that patients with long term conditions develop enhanced knowledge about their health from the internet and forums (Smithson et al., 2012). In the social context people learn by observing each other's behaviour, the factors that influence effective learning are attention, retention, reproduction, motivation (Bandura, 1977b). Patients often engage in the social aspect of social media if they have a specific goal in mind (O'Brien & Toms, 2008), for example information needs and social engagement. The social support in online interventions relies on motivation, information, shared experiences but also some unique aspects such as anonymity, convenience, non-judgemental discussion (Hwang, 2009). Healthcare organisations could use these mediums more effectively to engage with patients; providing appropriate information, increasing knowledge and meeting information needs improves functional adjustment, reduces stress and facilitates coping, creating more knowledgeable and competent patients (Timmins, 2006; Ankem, 2006; Lambert & Loiselle, 2007). Research has shown that patients who seek support online have a different profile to the offline seeker, generally lacking support from family and physicians (Paterson et al., 2013).

Engaging patients and providing the information needed improves well-being and personal control (Hepworth & Harrison, 2004); increases self-management, self-efficacy (Harrison et al., 1999; Lorig et al., 2001; O'Mara-Eves et al., 2013) and reduces dependency on health services improving well-being and personal control (Hepworth & Harrison, 2004), although there is very little evidence to support this (Griffiths et al., 2007). The existing evidence provides mixed views. Shaw & Johnson (2010) acknowledged that patients actively engaged in self managing their illness are predisposed to manage their chronic condition more effectively. This has a positive effect on their quality of life (Health Foundation, 2011). A systematic review by Pitt et al. (2013) on consumer led mental health interventions indicated that existing evidence was of low quality; however it reported a small reduction in use of emergency services. Similarly, it was identified that motivation, self-efficacy, and self-regulation skill contributes to positive health outcomes (Teixeira et al., 2015)

Griffiths et al. (2007) within a systematic review of peer led self-management education in the context of chronic conditions highlighted a very small, clinically unimportant effectiveness on their health status. The evidence suggested the positive influence of two health behaviours: increased activity and cognitive symptom management, and increased self-efficacy to manage symptoms, although the increase in self-efficacy may not

necessary improve other health outcomes. Similarly, Olander et al. (2013) identified that change in behaviour (more physical activity) was not directly correlated with increase in self-efficacy.

Whilst health outcomes often are the focus of such studies social outcomes are often overlooked. Merolli et al. (2015) introduced the concept of social health reporting positive outcomes such as enjoyment of life and positive relationships with others. Given that social support is a dominant component of social media, it would be interesting to explore potential social outcomes resulted from consumer engagement with social media.

### **The theoretical study approach**

The use of Web 2.0 technologies in healthcare is expanding rapidly, with researchers showing an increased interest in technology, searching for evidence of its usage in long term conditions. Social media is a relatively new domain and encompasses a series of tools, which have not been fully evaluated to determine impact.

The examination of existing theories exploring the nature and context of social media identified fundamental conceptual elements to engagement required to satisfy information need. Social media encompasses a wide variety of tools (mechanisms), which are used differently by each user (context), indeed SNS, blogs and online communities have been explored in detail to understand use, role in user generated content and outcomes. The realist synthesis seeks to provide evidence of the role of social media in patient engagement, information provision, networking and communication. Drawing on the key theoretical concepts identified by Ormandy (2008) for patients with a long term condition (chronic kidney disease) and the engagement theory developed by O'Brien & Toms (2008) the underpinning study CMOs pertinent to social media are exposed (Table 4).

The realist synthesis approach is used to find CMO relationships that will provide evidence of the role social media plays. The synthesis looks at the combination of characteristics that a Social Hub (a platform with a variety of tools) must have in order to be effective, the different explanations, potential for transferability by determining the links with existing knowledge (Pawson & Tilley, 2006). There is an assumption that the relationships exist amongst, social media, engagement, information need and self-efficacy. It is the purpose of this study to examine how the social element of social media influences engagement and satisfaction of information need. Throughout the study these relationships are modelled using the Logic Model (Figure 2) to offer a clear road map of an intervention and provide a clear visual picture of the intervention operations (Knowlton

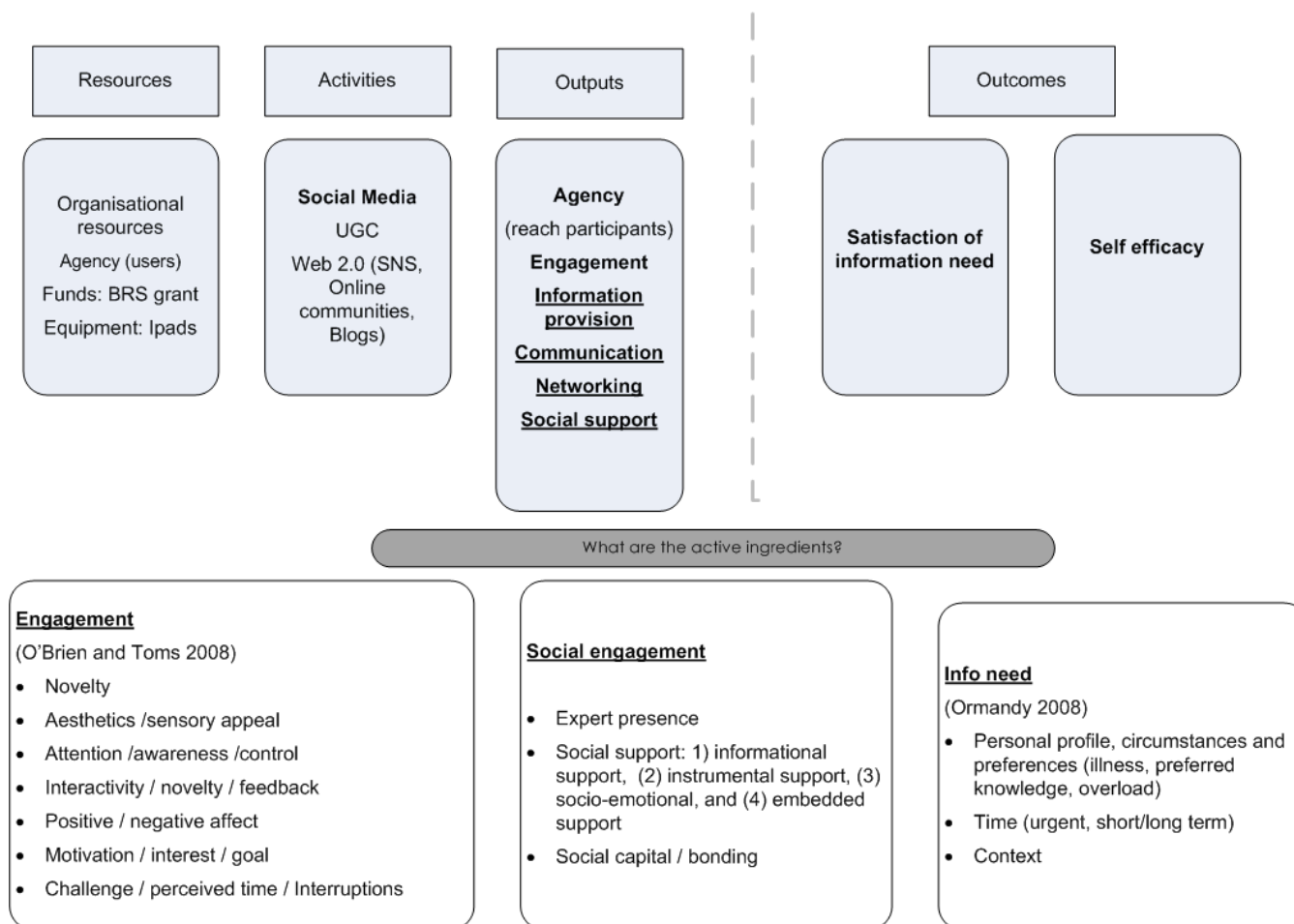


& Phillips, 2009). This working framework will develop throughout the thesis based on emerging evidence and theory testing to examine what social media interventions work for different patients when and how; which tools influence which outcomes. The key conceptual elements of the logic model include (1) resources, (2) activities, (3) outputs and (4) outcomes (Knowlton & Phillips, 2009). The map (Figure 2) summarises the findings of the theory scoping review that underpin existing social media constructs and factors that influence social engagement to satisfy information need.

Table 4: The study CMOs

| Realist Synthesis                                    |   | C   | M | O |  |
|--|---|---|---|---|--|
| Users (Patients)                                     | age, sex, race, education, literacy, control, and prevalence to other illnesses, satisfaction with provider, desire and intention to find information | X   |   |   |  |
| Information seeking and need                         | Content   |   | X |   |  |
|  | Purpose/Goal  |   | X |   |  |
|  | Profile   | X   |   |   |  |
|  | Time  |   | X |   |  |
|  | Context   | X   |   |   |  |
| Social media   | Social Networking Sites (e.g. Facebook, Twitter)  |   | X |   |  |
|  | Online community  |   | X |   |  |
|  | Blogs   |   | X |   |  |
|  | Forums  |   | X |   |  |
| Engagement   | Overall Experience of using resources   |   | X |   |  |
|  | Patient Engagement /Activity with the Social Media Hub  | Aesthetics, sensory appeal  |   | X |  |
|  |   | Novelty   |   | X |  |
|  |   | Interest, attention, awareness, control, interactivity                    |   | X |  |
|  |   | Motivation, specific or experiential goal (link to information need goal) |   | X |  |
|  |   | Positive /negative effect, feedback                                       |   | X |  |
| Usability challenges (Perceived Time, Interruptions) |   | X   |   |   |  |
| Social impact  | Motivation  |   | X |   |  |
|  | Shared experience   |   | X |   |  |
|  | Convenience/Time  |   | X |   |  |
|  | Anonymity   |   | X |   |  |
|  | Non-judgmental  |   | X |   |  |
|  | Privacy   |   | X |   |  |
|  | Expert presence   |   | X |   |  |
|  | Support   |   | X |   |  |
| Social capital                                       |   |   |   |   |  |
| Self-efficacy  | Pride, Self-Worth, Self-Satisfaction / Dissatisfaction  |   |   | X |  |

Figure 2: Logic Model version 1



## Hypothesis

Drawing on the theory synthesised, on how social media provides health information, communication and networking, embedding an understanding of use, context and outcomes the preliminary study hypothesis and propositions were refined. The context was established around patient information deficit, preferred knowledge and personal significance; mechanisms identified with engagement with social media, with the outcomes focusing on satisfaction of information need and self-efficacy. However it was difficult to identify papers that studied social media as a collection of tools, rather than how individual tool's (such as SNS or blogs) impact on health care. Combining aspects of the theoretical scoping review, exploring social media beyond a healthcare context, the hypothesis generated was:

*Social Media contributes to the engagement of patients in long term conditions to provide instant (rapid) information that responds to a specific goal, within a context that increases self-efficacy and facilitate self-efficacy. More importantly, the social add-on will enable networking and communication amongst patients and patients, and staff.*

Two main propositions identified from the scoping review were:

***Proposition 1: Engagement with social media tools enhances networking, communication and generation of health information to satisfy patients information need***

***Proposition 2: Engagement with social media mechanism and satisfaction of information need increases self-efficacy***

These propositions based on engagement and social media in various contexts, such as health informatics and marketing were taken forward and tested in the next chapter within the specific context of health and patients managing a long term condition.

## Chapter Summary

This Chapter presents the theoretical scoping review to set the context of the study. The nature and content of social media in a healthcare context were explored and key operating concepts identified. The different social media tools (SNS, OC, blogs) are built on the technological advances of Web 2.0 and dependent on UGC. The large amount of UGC is a result of users in a social context who produce and share content moving from the status of consumer only, to consumer and producer. The speedy evolution of UGC

and social media offers a new dimension of social support assumed to be the potential response to previous issues with user engagement (Putman, 2000; Littau & Thorson, 2009) and positively correlated to self-efficacy (Mo & Coulson, 2010).

Patients' network and communicate on social media to create, share and access information (Kata, 2012; Van de Belt et al., 2012; Betsch et al., 2012) to satisfy an information need, which may influence self-efficacy. Patients engage in the social aspect of social media if they have a specific goal in mind (O'Brien & Toms, 2008), for example information needs and social engagement.

Evidence is provided about each social media tool outlining what is known about when, why and for whom each tool works. For example, information from SNS is used to diagnose, self-management and monitoring of treatment (Griffiths et al., 2012). Whereas, blogs are associated with coping and self-managing to providing evidence on a short term illness trajectory or supporting achievement of specific goals (Adams, 2008). Online communities are efficient communication methods amongst users to seek and share information (Oprescu et al., 2013). What is not evident from the theory and evidence is which of these tools are more efficient to trigger patient engagement to access health related information. More importantly whether access to online health information influences healthy behaviour or improve an individual's self-efficacy, is unclear (Thackeray et al., 2013) and additional research is required on consumer-led services (O'Mara-Eves et al., 2013). Based on the initial theoretical constructs found to influence engagement with information using social media a CMO representation was designed and represented in the logic model (Figure 2). Two propositions were developed from this theoretical review and will be explored and applied within a focused realist review in the next chapter within the context of people managing a chronic health condition.

## **CHAPTER 3: REALIST REVIEW: INFLUENCE AND USE OF SOCIAL MEDIA FOR PEOPLE WITH A LONG TERM CONDITION**

### **Introduction**

This chapter takes forward the theories and constructs underpinning engagement, information need and social media, synthesised from the previous chapter theoretical coping review within the context of health. Evidence is examined and critiqued using the principles of a realist review to gain a deeper understanding as to the relationships between the context (managing a long term condition and health), mechanisms (engaging with social media tools for communication and information provision) and outcomes (satisfying information needs, improving self-confidence and self-management).

The chapter is shaped into two parts. Part one presents and describes the process of the realist review, the principles, search strategy and analytical method used to explore the operating constructs and examine relationships in the current literature. Part two presents the findings of the review collated in the first instance under the emerging propositions from chapter 2, which are refined and/or confirmed from the evidence critique. The realist review findings are presented under themes of individual tools (SNS, blogs) to begin to explore gaps in evidence exposed in the previous chapter; which of these tools were more efficient to trigger patient engagement to access health related information. For a web developer and further deployment this framework appeared logical to identify the tools as overarching mechanism within the realm of social media (which is not particularly a true mechanism), but supports various mechanisms which identify what is about each tool that work or does not work.

This chapter draws together and examines the current research evidence on engagement, information need and social media with focus on long term health condition. In a comprehensive realist review, grey literature and other sources would be explored simultaneously to inform theory. In this realist review the grey literature and other sources of evidence consisted of a critique and review of current web applications, which directly informed the development of the Social Hub, presented separately in the next chapter alongside the description of the development of GMKIN.

### **Differences between realist and systematic review**

An integral part of a realist synthesis is a realist review, the main aim of the review is explanation building to highlight and refine underlying programme theory after

interrogating existing evidence. Therefore primary research identified is scrutinised for their contribution to theory building. It is important to understand the difference between realist review and a systematic review, to comprehend the review process and findings. A systematic review aims to identify and summarise all available and good quality resources fitting a defined criteria. It focuses on interventions that are successful; the inclusion has a high emphasis on methodological rigour and transparent process to minimise bias (Khan, 2003). Realist review unlike systematic review goes beyond examining the vocabulary of intervention terms, explaining interventions as objects and undertaking an explanatory and iterative rather than a judgemental process (Table 5).

*Table 5: Realist review versus systematic review*

|                             | <b>Systematic review</b>   | <b>Realist review</b>   |
|-----------------------------|--|---|
|                             | Simple programmes  | Complex interventions   |
| Stage 1                     | Identify question  | Scope: Identify question, refine review purpose, identify theories  |
| Stage 2:<br>Search          | Meticulous and compressive predefined search closely related to an established specification                       | The search stretches from identifying the question to synthesis, refine inclusion criteria as new findings emerge |
| Stage 3:<br>Appraisal       | Use of a predefined check list (appraisal tool) strictly correlated to research question and methodological rigour | Quality is appraised using researcher judgement including evidence that is fit for purpose                        |
| Stage 4:<br>Extraction      | Standard items using extraction matrix   | Interactive extraction from different studies   |
| Stage 5:<br>Synthesis data  | Synthesis of data  | Obtain information to refine theory to determine 'what works for whom, how and other what circumstances           |
| Stage 6:<br>Recommendations | Indicate if findings are definitive or further research is required  | Refers to contextual issues   |

Realist review is methodologically different to the systematic review. The latter, is focusing on a specific type of intervention developed for a specific subject and seeking that type of outcome (Pawson & Tilley, 2004). Researchers use systematic reviews to identify, justify and synthesise results to support a question; estimate the sample size; appraise the quality of studies and identify accuracy and gaps (Mulrow, 1994). In a simpler view, the review provides an overview of research responding to a specific question (Parry & Land, 2013), but a systematic review does not respond to why intervention may or may not work, in what circumstances and how (Pawson & Tilley, 2004). Moreover at the search stage, a systematic review often excludes papers based

on rigour whereas this type of exclusion would reduce the quality of a realist review (Pawson et al., 2005). Whereas the usefulness of a realist review in this sense is juxtaposing the evidence to identify, for example, if one study provides explicit evidence of process to understand the outcomes generated in another, or adapting the search based on findings throughout the process (Pawson & Tilley, 2004; Pawson et al., 2005). Where studies outline contradictory results, the reconciliation of findings is attempted by examining the contextual differences, or dissimilar accounts of impact may result in identifying rival explanations, or multi-layered explanations (Pawson & Tilley, 2004). However, the flexible methodology of a realist review is not without limitations, the lack of guidance in conducting a realist review makes it time consuming and not a straight forward task (Pearson, 2012) the various layers of applications that need to be studied are often difficult for a novice researcher (Greenhalgh et al., 2011) and it was certainly a challenge.

### **The realist review approach**

Pawson et al. (2005) describe seven key underpinning assumptions that form the basis of a realist review, with the exploratory approach creating a model of how, whether and why interventions are effective (Table 6).

*Table 6: Realist review assumptions (Pawson et al., 2005: p24)*

- |   |
|---|
| <ol style="list-style-type: none"><li>1. Interventions are theories constructed on hypotheses assuming that the delivery of a programme this way will trigger an improved outcome;</li><li>2. Interventions are active, based on individual's input, reviewers identifying part of the justification through reasoning and personal choices of participants;</li><li>3. Interventions are followed over a long period of time, the interventions being passed from designing onto participants, different groups and relationships influencing the outcomes;</li><li>4. Implementation chains are non-linear, the review would aim to underpin the relative influence of different project stakeholders;</li><li>5. Interventions are embodied social systems, the same intervention can be a success or a failure depending on the context applied and the differences between organisational culture, leadership, resources and other factors should be noted;</li><li>6. Interventions are prone to be adopted in different environments after refining and adaptation to local circumstances;</li><li>7. Interventions are open systems that reshape themselves after changing the context that made them successfully in the first conditions.</li></ol> |
|---|

The starting point of a realist review is more complex with more iterative, overlapping stages and sub-stages, for example the search stage can influence the question refinement and vice versa (Pawson et al., 2005). The strengths of a realist review is the fact that it explores from a philosophical and social science perspective what works for

whom, in what circumstances, as well as what does not work, enabling lessons to be learnt from failures (Rycroft-Malone et al., 2012).

With these realist assumptions and core operating principles in mind the challenge remains on how best to conduct the review of evidence, particularly in the complex environment of social media interventions and health. The quality of the review is often influenced by the researchers' experience, philosophical basis (Greenhalgh et al., 2011), which in this case was influenced by the orientation to realist evaluation. There are different layers to explore and clarify within the review, more than just identifying a particular social media tool utilised but looking closer as to how users interact with the tool, how the system components respond to interaction, which tool is more efficient and when. For example questions such as is an open Facebook group more efficient compared to close group, when and why.

### ***Review method***

There are six steps to a complete realist synthesis (Chapter 1, Table 2) of which step 1 involved the theoretical scoping for the hypothesis (Chapter 2), identifying the question and then extracting key social media, engagement and information need theories. This chapter within the realist review takes forward steps 2, 3 and 4, which applies the emerging theories to the field of long term conditions, and seeks out, appraise and synthesise current evidence. Often the lack of a framework to check the quality of journals makes the process harder; therefore different strategies and frameworks were introduced to complement the process and guide the researcher (Pearson, 2012) but the fundamental task of the realist review was thinking, reflecting and interpreting (Greenhalgh et al., 2011).

- Step 2: Search for evidence. This step focused on the use of social media within the long term illnesses in an attempt to find further evidence on what works for who and when. The exploratory search included two parts, one concerned with searches via databases to find rigorous evidence; and the second search exploring online platforms.
- Step 3: Appraising evidence. The journals were appraised using adapted programme theory concepts by Pearson (2012) to examine '*conceptually rich*' sources and identify theories and supportive evidence to strengthen them (described later in the chapter). Fundamental to realist synthesis is the inclusion of studies without concerns about



rigour; although all studies were considered, those with a clear methodological approach were considered candidates to be '*conceptually rich*' evidence.

- Step 4: Synthesizing and drawing conclusions on current evidence. The findings were used to refine the theories developed in the previous chapter, draw conclusions and generate CMO relationships. To achieve this, the evidence from different papers were categorised into CMOs and subsequent relationships. The identified concepts and theories from this step would then be further tested through the subsequent realist evaluation (Chapters 5-8).

Employing the principles of a realist review enabled the analysis of why, when and how different social media tools works to engagement and information provision of patients with a long term condition (Pawson & Tilley, 2004).

### ***Searching for evidence***

To develop a conceptual framework of how social technologies are used by patients with a long term condition, the review seeks existing information on '***what social technologies works for what types of patients, in what circumstances and why***'.

The search was initially undertaken between in June-July 2013 and re ran and theory refined in July 2014 (diagram 2). The research began by formulating a search strategy to focus on use of social media for people with long term conditions; influenced by the findings of a systematic study on the use of social media in long term conditions (Merolli et al., 2013). The search query was tested on different databases and included all terms related to Web 2.0 applications, its predecessors, information provision, networking, communications and self-care applicable in long term condition (Appendix 1). The databases were chosen to cover subjects from science, medical and social science, arts and humanities, technical, clinical and biomedical information, nursing and allied health literature to explore wider information, and included:

- Web of Science
- Scopus Science direct
- Pubmed
- Medline via EBSCO
- Cinhal via EBSCO

The search included manuscripts from 2005 to 2014 (English only language). The 2005 timeframe was considered based on the increased popularity of Web 2.0 applications from this time onwards.

#### *Grey literature and relevant sources*

A realist review does not rely on a finite set of relevant papers indeed many search strategies are used to identify relevant sources (Pawson et al., 2005). This principle was of a particular interest because in order to develop an evidence based resource for renal patients, existing online interventions have to be identified. Therefore a supplementary search using '*chronic kidney disease*', '*chronic kidney disease websites*', '*Web 2.0 patients' websites*' was performed to establish complementary evidence, on existing social media web applications. The search was intended to retrieve valuable evidence, which could not be identified through the research papers; on what applications exist, what is their purpose (provide information or/and networking) and how patients use the sites. Each website was analysed in detail seeking to understand its' functionalities, content and social media strategy, the findings were analysed and used to develop the social media hub intended for patients with a chronic kidney disease explained in the next chapter.

#### *Inclusion of evidence*

The realist review inclusion of evidence was an iterative process with theoretical decisions being made based on findings (Pawson et al., 2005), the overall process of screening and inclusion of studies is shown in Diagram 2. The combined search of six databases provided a total number of 923 manuscripts. After removing duplicates 879 abstracts were reviewed. The realist review did not follow a strict methodology and decisions were made throughout the process until a structured inclusion criteria was formed (Table 6). The 143 manuscripts were read and papers, a structured inclusion criteria developed, with focus on E-health only (no social element) being excluded, resulting in a total of 32 manuscripts being retained for detailed appraisal.

The inclusion criteria were developed following a series of decisions. Firstly, the exploration of social media (chapter 2) identified that the complex social media mechanisms were unclear and poorly defined, with blurred boundaries between Web 2.0 and its predecessors (Merolli et al., 2013). The predecessors, Web 1.5 and Web 1.0, incorporate social interaction elements mainly in the form of discussion boards (Weber & Rech, 2009), which makes it difficult to define a boundary between the two technologies.

Therefore, the first inclusion rule would be to include all Web 2.0 applications, Web 1.5 and 1.0. Predecessors of Web 2.0 would include any online applications with a social element (such as a discussion boards). A second rule was that study elements such as engagements, communication, networking, information need, long term conditions and challenges, were other decisive elements of inclusion (Table 7).

*Table 7: Inclusion criteria*

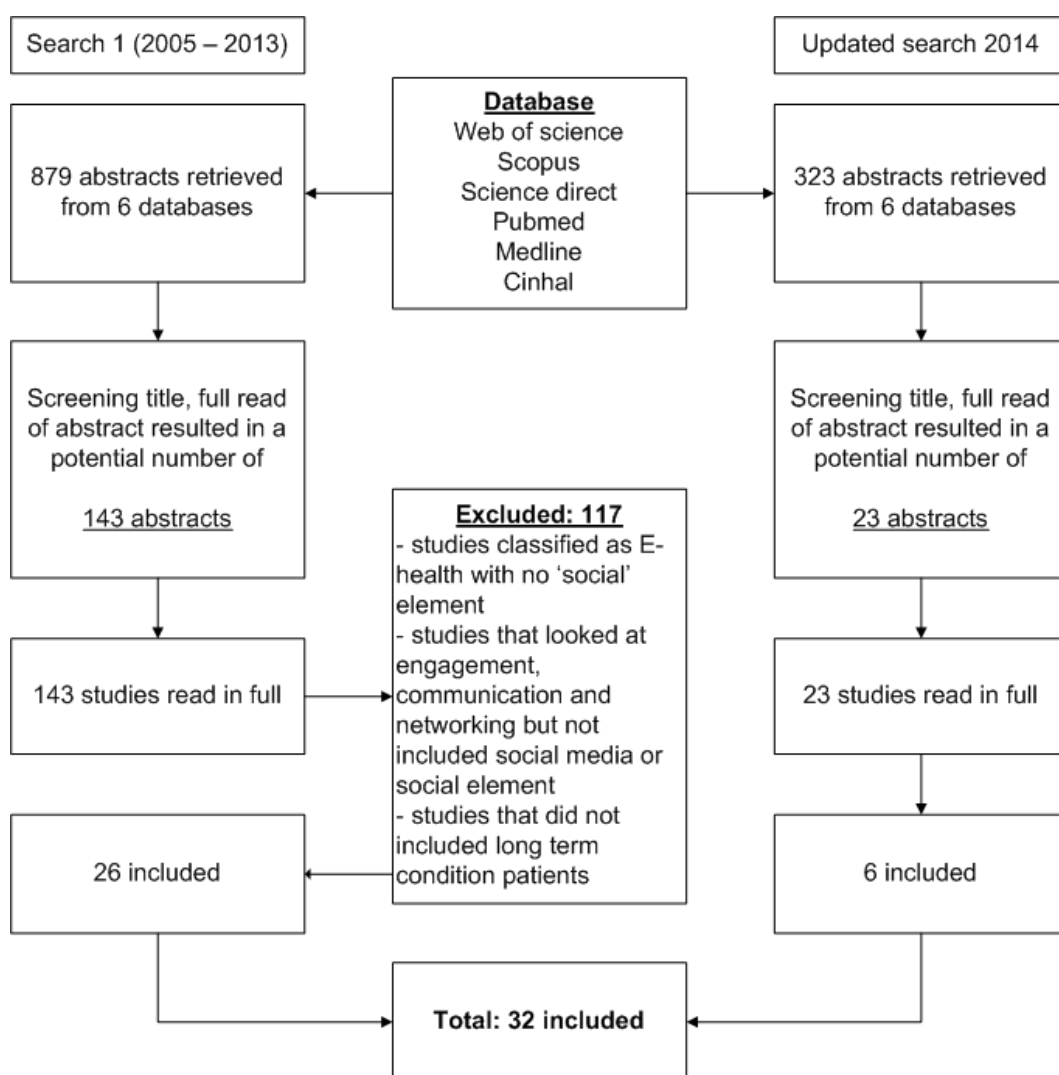
| Social Technology  | Other elements   |
|--|--|
| <ul style="list-style-type: none"> <li>• Web 2.0 (general)</li> <li>• Blog</li> <li>• Twitter (TT)</li> <li>• Facebook (FB)</li> <li>• Online communities (OC)</li> <li>• Social Networking Sites (SNS) (general)</li> <li>• Applications/interventions with social element</li> </ul> | <ul style="list-style-type: none"> <li>• Engagement</li> <li>• Communication</li> <li>• Networking</li> <li>• Long term condition health outcomes (motivation, self-care, self-efficacy)</li> <li>• Challenges and benefits</li> <li>• Information need</li> </ul> |

The studies focused on different social technologies, health information, engagement, communication, peer support, health related outcomes, challenges and benefits. The studies were divided into categories, an overarching Web 2.0 group and individual applications to enable mapping the theories related to each application in order to understand what tool works best for what patients and why. The focus on long term condition identified studies which included mapping different patient groups (Table 8).

*Table 8: Patient groups mapped during inclusion process*

| Group (other terms)   |  |
|---|--|
| <ul style="list-style-type: none"> <li>• Post-Traumatic Stress Disorder (PTSD; Pathological Grief, PG; Adjustment Disorder, AD )</li> <li>• Diabetes</li> <li>• Primary Biliary Cirrhosis</li> <li>• Chronic Physical and Mental</li> <li>• Cancer</li> </ul> | <ul style="list-style-type: none"> <li>• Chronic Pain</li> <li>• Psychosis</li> <li>• Bulimia nervosa (BN)</li> <li>• Spina Bifida (SB)</li> <li>• Paediatric (Teens with chronic disease)</li> <li>• Chronic Illness</li> </ul> |

Diagram 2: Inclusion process



The original search undertaken in 2013 (Jun-July) identified the evidence that generated the underpinning theories that informed the development of the study. In July 2014 it was considered necessary to review and re-run the initial search to capture additional evidence within the previous 12 months. The same search strategy was performed on the same databases; identifying a further 323 manuscripts, 23 of which were included for full appraisal, only six of which were considered relevant to the theory generated (diagram 2). Two were particularly conceptually rich (Magnezi et al., 2014; Swallow 2014) and confirmed the theory generated others added thicker descriptions (de Jong et al., 2014; Lawlor & Kirakowski, 2014) whilst none of the additional papers changed the developed theory they all added a deeper understanding of the context mechanism and outcomes.

## ***Appraising evidence – Using Programme theory***

To reinforce and guide the decisions concerning evidence quality and generate evidence on the impact of social media engagement on information provision and ultimately self-efficacy, a complex programme theory approach was selected (Greenhalgh et al., 2011). Programme theory was employed to appraise the theoretical evidence on interventions with multiple components suitable then for understanding Web 2.0 mechanisms, such as blog, Twitter, social networking site, Facebook, online communities and forums. Programme theory as a concept refers to a process of developing programme causal links amongst activities and underlying theories that influence the intended or unintended outcomes (Rogers, 2008; Pearson, 2012).

For the purpose of this study programme theory is linked to the causal result of using social media to engage patients in the process of information provision in terms of:

- what works or does not work
- what are the underlying causes'
- what can be changed

Pearson (2012: p25), within a realist study, was inspirational in deciphering the programme theory based on a criterion of conceptual richness, three categories (Table 9) which clarified the judgement as to whether evidence was:

- '**conceptually-rich**' theory based on evidence
- a comprehensive or '**thick**' description without explicit theory
- weaker '**thin**' description sources with no theoretical underpinning

To understand the difference between the theoretical framework categories examples are provided in Table 9. Conceptually rich documents provided evidence on social media programmes, was meaningful in a context and transferable. A programme was any tool or intervention (such as Facebook) with a process described in detail to provide clear contextual evidence (users' exposure to peers, system easy to use), which triggered an outcome (such as continuous engagement). The results were transferable to similar interventions (social networking sites, easy usable). The thicker description resources provided a comprehensive description of the programme but no clear understanding of theory (for example detailed evidence of development of an intervention based on decisions believed to be applicable specific to the sample involved). Thinner description resources included were mostly articles and reviews which were used only to reinforce theoretical decisions.

Table 9: Conceptual category framework (adapted from Pearson, 2012: p25)

| 'Conceptually-rich'   | 'Thicker description' but not 'conceptually-rich'   | 'Thinner description'   |
|---|---|---|
| Social media intervention   | Social media component  |   |
| The sources, underpinned by theoretical concepts related to social media, networking and communication to satisfy information need are clearly defined and described to be useful to the study. | Social Media theoretical concepts are described with not much depth; it only provides enough information to be surfaced.                | The journals provided an overview but no information on the theoretical aspects are exposed |
| Clear evidence on causality links amongst concepts of engagement, provision of information and self- efficacy   | The social media context in which the programme took place is described but no causality links are stated                               | Not adequate information of the social media context sounding the project                   |
| The theories are defined in great detail to be used by readers with no direct experience with the topic.  | Discussion of the differences in the intended outcomes and final outcomes.  | Limited or no discussion of programme intended outcomes and final outcomes.                 |
| Concepts are evidence based, the study's methodology was clearly outlined   | Strengths and weakness are evaluated in detail; methodology was outlined  | Limited or no evaluation of the strengths and weaknesses; no clear methodology              |
| Concepts are parsimonious (greatest generality)   | Unusual results are explained with reference to context and data  | No attempt to explain unusual results   |
|   | Description of the factors affecting implementation   | Limited or no description of the factors affecting implementation                           |
|   | Typified by:<br>Terms - 'model', 'process' or 'function'<br>Verbs - 'investigate', 'describes', or 'explains'<br>Topics - 'experiences' | Typified by:<br>Mentioning only an 'association' between variables                          |

## Results and findings

The findings of this review were grouped and regrouped. Initially, papers were grouped to include overarching Web 2.0 and individual tools (such as blogs, Twitter, Facebook). This identified studies exploring: online communities, social networks and blogs, which were included in the Web 2.0 group. Four research papers reported on Web 2.0 predecessors, namely bulletin boards, questions and answer forums. An initial analysis was formed of each individual tool, how it worked and why, thereafter, papers were conceptually

analysed to seek overarching theories and to reflect main topics. Five studies were found to be rich in conceptual explanation, 17 presented a thicker description but lacked conceptual depth, and ten provided only limited thinner theoretical descriptions (Table 10).

The findings were grouped to identify and expose the relationships between the CMOs in an attempt to refine theories. The identification of theories was a lengthy process; many papers did not provide a clear identification of the theory, what triggered the process and what was the evidence base to support the statements. Moreover, it was difficult to form a judgment in separating outcomes from context and mechanism. De Souza (2013) CMO's elaboration framework; where contextual factors may include individual or collective beliefs, structure, culture, agency and relationships; mechanisms could exist as practises associated with roles, resources and processes; (Chapter 2) was used to ensure a consistent approach and clarify the concepts behind CMOs and to enable extraction of each theory.

Table 10: Summary of review paper characteristics and conceptual richness

| Author   | Patient Group<br>(n=)      | Social<br>technology type | Information | Engagement | Communication<br>/Networking<br>peer support | Self –efficacy,<br>coping, QOL,<br>Decision,<br>Empowerment | Data collection           |
|--|----------------------------|---------------------------|-------------|------------|--|---|---------------------------|
| <b>Conceptually rich</b>                             |                            |                           |             |            |  |   |                           |
| Merolli et al. (2013)                                | Chronic                    | Web 2.0                   | X           | X          | X  | X   | Review                    |
| Magnezi et al. (2014)                                | Chronic                    | SNS                       | X           | X          |  |   |                           |
| Ressler et al. (2012)                                | Chronic Pain               | Blog                      |             |            | X  | X   |                           |
| Swallow (2014)                                       | CKD stages 3-5             |                           | X           |            |  |   |                           |
| Zhang & Zhao (2013)                                  | Diabetes<br>(n=2565 posts) | Forum                     | X           |            |  | X   | Analysis of Yahoo Answers |
| <b>Thicker description but not conceptually rich</b> |                            |                           |             |            |  |   |                           |
| Alvarez-Jimenez et al. (2013)                        | Psychosis<br>(n=20)        | Forum, SNS                |             |            | X  |   | Online interaction        |
| Armstrong & Powell (2008)                            | Diabetes<br>(n=16)         | OC                        |             |            | X  | X   | Focus group               |
| Chan & Dicianno (2011)                               | SB (n=59)                  | SNS                       |             |            | X  | X   | Survey                    |
| Demiris (2006)                                       |                            | SNS                       |             |            | X  | X   | Review                    |
| Griffiths et al. (2012)                              |                            | SNS                       | X           |            |  |   | Review                    |
| de Jong et al. (2014)                                | Chronic                    | OC                        |             |            |  | X   | literature search         |
| Lawlor & Kirakowski (2014)                           | Mental health              | OC                        | X           |            |  |   |                           |
| Lasker et al. (2005)                                 | Biliary cirrhosis          | OC                        |             |            | X  |   |                           |
| Neter & Brainin (2012)                               | (n=1289)                   | Web 2.0                   |             | X          | X  |   | Telephone based survey    |
| Nordfeldt et al. (2010)                              | Diabetes (1 site)          | Web 2.0                   |             |            | X  | X   | Qualitative Analysis      |
| Nordfeldt et al. (2012)                              | Diabetes (1                | Web 2.0                   |             |            | X  | X   | Qualitative Analysis      |



|                          |                   |                  |   |   |   |   |                                  |
|--------------------------|-------------------|------------------|---|---|---|---|----------------------------------|
|                          | site)             |                  |   |   |   |   |                                  |
| Pretorius et al. (2009)  | BN (n=101)        | Pre Web 2.0, BB  | X |   |   | X | Survey                           |
| Walton and Rice (2013)   | (n=3751 tweets)   | Twitter          |   |   | X |   | Analysis                         |
| Richardson et al. (2010) | Fitness(n=324)    | Pre Web 2.0 – OC |   | X | X |   | Survey                           |
| Roblin (2011)            | Diabetes          | SNS              |   |   | X | X | Review                           |
| Scanfeld et al. (2010)   | (n=971)           | Twitter          | X |   | X |   | Observation                      |
| Stellefson 2013          | Chronic           | Web 2.0          |   |   |   |   |                                  |
| Thinner description      |                   |                  |   |   |   |   |                                  |
| Applebaum et al. (2013)  | Chronic (n=20,33) | SNS              | X |   | X | X | Focus group participants, Survey |
| Chorbev et al. (2011)    | Diabetes          | SNS, Forum       | X |   |   |   |                                  |
| Liaw et al. (2010)       |                   |                  |   | X |   |   | Review                           |
| Lober & Flowers (2011)   | Cancer            | Web 2.0          |   |   | X | X |                                  |
| Pulman (2010)            |                   | Web 2.0          |   |   |   | X | Review                           |
| Rogers et al. (2011)     |                   | SNS              |   |   |   | X | Discussion                       |
| Schatell 2013            | CKD               | X                | x |   |   |   | review                           |
| Sarasohn-Kahn (2013)     |                   | Web 2.0          |   |   |   | X | Article                          |
| Seeman (2008)            |                   | Web 2.0          |   |   | X | X | Review                           |
| Timpka et al. (2008)     | Diabetes          | Web 2.0          |   |   |   | X | PAR                              |

## Refinement of propositions

The two propositions identified during the scoping review (chapter 2) were taken forward to situate social media used in information provision, networking and communication within the context of long term conditions.

**Proposition 1:** Engagement with social media tools enhances networking, communication and generation of health information to satisfy patients' information need

**Proposition 2:** Engagement with social media mechanism and satisfaction of information need increases self-efficacy and social outcomes

Each proposition was tested using the evidence identified from reviewing the literature on long term condition, using conceptually rich evidence, reinforced by studies with thicker description (but not thinner description).

### **Proposition 1: Engagement with social media tools enhances networking, communication and generation of health information to satisfy patients' information need**

Social media expanded rapidly across different fields, from personal to social, professional and healthcare, across ages, education, and ethnicity (Lober & Flowers, 2011), providing interactive learning and reflection on personal experiences (Pulman, 2013). The expansion is a result of a powerful technology that enables access and turns communication into dialog and user generated content (Lober & Flowers, 2011).

The difficulties with social media were concerned with the variety of forms and functionalities they takes, making them difficult to categorise, and assess the impact on chronic disease. For example online communities, forums and discussion boards were restrictive in presenting user profiles and have limited interactivity (Merolli et al., 2013). Practitioners were apprehensive about the use of social media and despite the lack of quality and evaluation of patient generated information patients continue to seek and produce information using these mediums (Lober & Flowers, 2011).

The notion of affordance (such as the option to create online identity, flexibility in terms of time and location) is gaining increased attention in the field of social media in an attempt to gain knowledge of different outcomes for various users. It indicates that user perceptions of object within their environment were not necessarily related to what it is, but the potential use of it. Analysing social media from an affordance perspective required

a holistic approach taking into consideration the features of social media (profile, commenting, sharing) as well as a selection of other affordances including identity, flexibility, structure, narration and adoption. Merolli and colleagues (2013) identified that patient identity or self-presentation ('who' and 'what') refers to the ability of social media to enable patients to create profiles on social media sites (such as Facebook), enhancing credibility; or anonymous platforms such as blogs and virtual communities where users can disclose more taboo and stigmatised topics. Social Media offered a level of flexibility (when' and 'where') which was influenced by factors such as group size, time of the day, geographical location. These factors influenced the effectiveness of social media tools in chronic disease. Furthermore social media has the ability to enable people to connect, share information, assisting and guide patients with their self-management. This can be self-guided (blogs) or fostered through peer to peer support or directed by professionals. The social media mechanisms enable patients with chronic conditions to narrate their stories through blogging, their information and support needs require adaptability and social media offered this potential. Although initial contact with a social media medium was usually to address an information need, over time relationships started to consolidate (Merolli et al., 2013)

## **Mechanisms: Social media tools used in chronic conditions**

### ***Social Networking Sites (SNS)***

Social networking sites or '*network of networks*' or '*system of support*' (Rogers et al., 2011: p3) unlike other online communities were designed mainly; to enable users to create a public profile, connect in social networks as well as a person to person manner, build relationships between and amongst themselves, and initiate new connections, reflecting more accurately, real life connections. People with chronic physical disabilities affected by cognitive and behavioural impairments experienced high risks of both peer and social rejection, therefore virtual socialisation enables them to be part of a social community (Chan & Dicianno, 2011).

The evidence generated from the conceptually rich literature indicated that social networking sites such as Facebook or bespoke designed sites allow patients with a long term condition to find social support, which in turn engage them in online interventions to fulfil needs unmet in real life (Merolli et al., 2013). Facebook was reported to have the most active users engaging in a variety of tasks. For example patients with type 1 diabetes have used the community set up on Facebook to share and retrieve information, and offer support; the latter being the most regarded feature amongst other conditions as

well (Merolli et al, 2013). In addition, a thicker description by Chan & Dicianno (2011) highlighted that patients' with Spina Bifida, improved their social interactions by using social networking sites like Facebook. An increase in QOL for patients was noted for the four domains: physical health, psychological health, social relationships, and environment (Chan & Dicianno, 2011) and increased self-efficacy in self-management of blood glucose (Roblin, 2011).

Twitter and Facebook offered interactivity on seeking and sharing healthcare information, personal experiences, treatment and symptoms for those living with a chronic condition, contributing to communication, and networking amongst patient groups and illness specific communities (Griffiths et al., 2012). Facebook groups were a potential source of information and social support; nevertheless there were concerns about misinformation in non-moderated groups. Twitter could be an informal outlet for information sharing with high potential reach and dissemination, but similarly information misuse and misunderstanding were acknowledged (Scanfeld, 2010). The increased access to these platforms via mobile technology contributed to increased self-efficacy (Roblin, 2011). Moreover, constructs such as an individual's direct network motivated patients to adopt positive behaviour (Ba & Wang, 2013). The users with a high number of friends reported higher socialisation, although further research was needed to explain causality of the relationship and the impact of online social friendship on quality of life (Chan & Dicianno, 2011). Previous research outlined correlations between the number of motivators and number of achieved goals, indicating that motivators from social networking were linked to people's exercise level (Ba & Wang, 2013). SNS enabled patients to create a personal profile, access a network of networks, to access information and find social support. However, users feared the use of SNS because of service quality including privacy, reliability, security, connectivity, performance, appeal and usability (Applebaum et al., 2013).

**CMO 1-3**

- 1. SNS reflects real life relationships enabling patients to create a personal profile, access a network of networks, connect person to person in order to access information and social support.*
- 2. Facebook is a source of information and social support having the potential to engage more active users.*
- 3. Twitter is used as an outlet for satisfying information needs with high potential reach.*

## **Blogs**

Traditionally, patients communicated their experience with illness either orally or on paper and claims suggest that the process of writing may have therapeutic benefits (Ressler et al., 2012). In the digital era the use of internet tools such as blogs enable patients to share emotional experiences of the illness implication in real time and get immediate support from others in a similar situation (Ressler et al., 2012). Conceptually rich sources highlighted that blogs were positively correlated to information and experience sharing, problem solving, alleviating emotional distress and helping to understand own health conditions and illness challenges (Ressler et al., 2012; Merolli et al., 2013).

In particular, a study by Ressler et al. (2012) of chronic pain patients identified that bloggers took the initiative to post and share with friends and family, and deciding to blog could be an indication that patients already had self-care mechanisms in place. Bloggers revealed a sense of accountability in their actions of developing online relationships with other patients and demonstrated a deeper knowledge of oneself through the insightful process of blogging, caused by a sense of responsibility, purpose and understanding of illness, and support. Although blogging was time and energy consuming, patient bloggers were less isolated by engaging in online connections and the reflexive experience via the process of reading, writing and commenting. The concerns around posting blogs were associated with judgement of feeling and behaviour, privacy, editing, negative opinions, and lack of interest from healthcare professionals (Ressler et al., 2012).

A source classed as 'thin' description acknowledged that for patients with renal disease blogs were possible informational resources outlining dialysis life implications, care needs and involvement in renal communities (Schatell, 2013).

### **CMO 4**

*4. Blogs allow patients to narrate emotional experiences and contributes to information sharing, problem solving, alleviating emotional distress. Blogging is energy and time consuming.*

## **Online communities (OC)**

Conceptually rich evidence suggests that OC (discussion forums, bulletin boards and virtual communities) are among the preferred social intervention in chronic disease management, generating better engagement and health outcomes such as improved symptoms in depression and self-efficacy (Merolli et al., 2013). Questions and answers

logs continue to attract users in the process of seeking information being particularly tailored to individual needs (Zhang & Zhao, 2013; Merolli et al., 2013).

The evidence generated from the literature classed as 'thicker description but not conceptually rich' highlighted the role of OC to foster engagement of users in the process of creating and sharing information. For example, an OC part of an intervention to increase walking (Stepping Up to Health) had not increased the daily steps of participants but was seen as an efficient tool to reduce attrition (Richardson et al., 2010). The study identified that users with less social support reported frequent community visits, posting and reading information (Richardson et al., 2010). Whereas patients with Auto-immune liver disease using a message board identified that they engaged with the community mainly to discuss and share with peers the medical information gained from personal experience or news (Lasker et al., 2005). Three communication dimensions were identified from information shared within an online discussion group for breast cancer: information sharing, social support and personal empowerment (Demiris, 2006). Finally, a platform developed to display clinical outcomes on Bulimia Nervosa, including online sessions and message boards among other functionalities, showed significant improvement on behaviour and cognition (Pretorius et al., 2009).

Conversely, a study by seeking to highlight the efficiency of an OC to reduce self-stigma reported deterioration in self-stigma recovery as a result of frequent visits to the community (Lawlor & Kirakowski, 2014). It was presumed that by accessing the community, patients became more socially excluded therefore the community was used to avoid the offline world, instead of recovering from the illness (Lawlor & Kirakowski, 2014). Although those users who were more active appeared to seek more offline support (Lawlor & Kirakowski, 2014).

The majority of patients who engaged in discussions online showed a high level of empowerment, felt better informed and had confidence in treatment, improved well-being, could cope well with the illness and were self-efficient (Merolli et al., 2013). Richardson et al. (2010) found those who engaged better with internet mediated interventions, those who were active posters within the community of an online exercise intervention, increased exercising compared to those who did not post and did not demonstrate a positive behaviour change. Alternatively, Magnezi et al. (2014) suggested that less active users of an online community for chronic conditions perceived higher usefulness of the community compared to active member. The similarities between the social media mechanisms highlighted the difficulty in generalising the evidence: one studied type 2 diabetes patients, who used a portal with social media as an add-on (Richardson et al.,

2010); the other platform incorporated blogs, forums, support groups, email, chats and health information (Magnezi et al., 2014).

Synthesis of evidence suggests that OC increase patient engagement with healthcare interventions (Richardson et al, 2010; Merolli et al., 2013). Within an online community patients generate and share information (Lasker et al., 2005; Richardson et al., 2010). In addition, OC foster high social support, sharing of patients' experiences, self-regulation strategies (Richardson et al., 2010), emotional support, access, 24 hours availability (Lasker et al., 2005, Pretorius, 2009). Patients with a long term condition report better health outcomes as a result of using such communities, (Merolli et al., 2013). Features less regarded by patients within OC include technical issues, unhelpful posts and minimal use (Pretorius, 2009).

**CMO 5**

*5. Online communities are among the preferred social intervention in chronic disease management increasing patients' engagement with health interventions. The access to information and support influence positive health outcomes.*

**Communication and patient generated information (PGI)**

The evolution of technology creates new communication channels, which influence the delivery of health care. Through the use of social media patients form online groups focused on one condition or more, protest movements, cultural discussions or to share general interest and advocacy. Patients' online activities, such as the right to choose their own doctor, and the general consumer who has the right to choose a product, overlap in some cases with general consumer roles. The patients were searching for illness relief where as consumers search to meet certain personal goals (Lober & Flowers, 2011). It was recognised that communication via an online platform is more standardised, with the asynchronous messaging system allowing access at a convenient time. In a study based in the UK focused on diabetes, health professionals found that this type of communication was time saving (Armstrong et al., 2007).

Patients enrolled on social media sites influenced by the idea of the 'we' feeling which connects users one to another building relationships between themselves and the website. Social technologies have re-shaped patients roles. A study with patients suffering from cancer outlined that patients not only create and share content they also look for patients with similar conditions (Lober & Flowers, 2011). The factors that

influence their use were attentive to the nature of the disease, background and cultural needs, personal needs and internet use. The new patient roles identified in the process of online interaction enables them to create personal, professional and health specific content, use the knowledge to make decisions and share knowledge with their created virtual networks (Lober & Flowers, 2011). Internet technologies were enablers of an exchange of information between patients as well as patients and healthcare professionals (Armstrong & Powell, 2008).

The rise of technology has created the tech-savvy boomers, who are inclined to manage their own and family health using social technologies (Lober & Flowers, 2011). Patients indicate that managing their own care is an important aspect of living with a condition (Applebaum et al., 2013). Health information has the potential to contribute to decision making (both to patients and provider) and generate evidence from patients on self-management, which then enable healthcare professionals to develop educational and engagement strategies (Roblin, 2011). Social media is potentially an efficient mechanism to enable access to information through peers, who generate and share information (Merolli et al., 2013; Applebaum et al., 2013).

A study with young adults' readiness to progress to adult care indicated that subjects scored low on self-care as they ignored early symptoms and only report to parents or school nurse if pain was experienced. Moreover teenagers felt that they needed more information on the disease, symptom management and when to call a doctor (Applebaum et al., 2013). Adolescents may prefer to find information via less formal sources because of embarrassment and reduced illness knowledge, which complement the support received (Pretorius et al., 2009). Armstrong & Powell (2008) in a study involving patients with diabetes identified key themes in developing a website resource: (1) communication amongst patients, patients and professionals, (2) patients records, (3) peer support, (4) a question and answer facility, (5) connections with existing care, (6) consider that it will not work for all those involved. Timpka et al. (2008) using participatory research action method defined the core design of a platform for children with chronic disease; the main characteristics being inclusion of resources to manage the disease, learning through peer to peer education and accreditation of learning materials.

An online communities for liver disease study acknowledged that users at an early stage of illness or recently diagnosed were more likely to search for biomedical information, compared to those who had experienced the illness for a longer period of time posting more messages (Lasker et al., 2005). Evidence that individuals searched for online



information was provided in Zhang & Zhao's (2013) study, which analysed Yahoo Q&A's to understand patients seeking terms on diabetes. The categories which emerged were cause and pathophysiology, sign and symptoms, diagnosis and tests, organ and body part, complication and related disease, medication, treatment, education and info resource, affect, social and culture, lifestyle, and nutrients (Zhang & Zhao, 2013). Often users had the expectations of being part of interactive systems with high activity levels and trustworthy sources (Nordfeldt et al., 2012).

In the context of chronic conditions, patients collate information and share their opinion on illness, treatment, experiences and services using blogs, social networking sites, support groups and so leading to improved care, user generated content (Lober & Flowers, 2011). For the purpose of this study the term used for user generated content is 'patient generated information' (PGI). There are tensions amongst PGI mostly associated with the characteristics of unrestricted information: quality, privacy, liability for disclosing sensitive information in the case of staff, digital divide (Demiris, 2006), and health literacy (Magnezi et al., 2014).

**CMO 6**

6. Social media is potentially an efficient mechanism to enable access to information through peers, who generates and share information.

***User engagement behaviour***

Online communication to exchange information and support was directly influenced by user engagement behaviour. The measurement of engagement behaviours was focused around two broad categories, 'interactive' or 'active' and 'non-interactive' and frequency of visits.

The first approach, interactive and non-interactive behaviour, was often associated with posting or lurking. Whilst posting was associated with users who post, lurking was identified as a passive role of observing (Demiris, 2006). Patients were more active if the portals were regularly updated and reminders were regularly sent to emails (Nordfeldt et al., 2010). Active users might benefit more from online communities by seeking formal support, however active participation was not directly linked to positive effects on illness but rather underlying factors (Lawlor & Kirakowski, 2014). Patients with reduced social support were more prone to engage in posting behaviour (Richardson et al., 2010). However, an important aspect revealed was that lurkers remained engaged for a longer

period of time compared to active users and therefore more research was needed to understand the factors underlying longer participation (Lawlor & Kirakowski, 2014).

Frequency of posting was part of a larger category of engagement associated with 'visit frequency' and 'visit duration', dominant elements in establishing connectivity. However there were mixed results as to whether or not frequency of visit improves recovery. A study of online communities acknowledged that for patients with mental health problems, frequency of visits reduces recovery; potentially because it may be correlated with greater withdrawal from society (Lawlor & Kirakowski 2014). Although further research was needed, negative impact occurs via two routes: '*loss of multiple identity*' (multiple identity enables individuals to move between identities as opposed to their stigmatised one) and '*stigmatised dominant role identity*' (visiting online communities will focus behaviour on the stigmatised identity) (Lawlor & Kirakowski, 2014: p158).

### ***Social and peer support contribution to engagement***

Social networks have a role in assisting individuals to go through changes. Friends, colleagues, acquaintances, and family members provide social capital and support to manage their transition through life changes. Transition was influenced by factors such as emotions (stress, low well-being, depression, anxiety, uncertainty and low self-esteem), individual's roles identity and expectations, relationship change and environmental implications (such as finance) (Merolli et al., 2013). Social interaction enabled peer support, empowerment and exchange of health related information, which enhanced problem solving skills (Merolli et al., 2013). It has been acknowledged that individuals who overcome illness issues were equipped to provide valuable support, inspiration and advice (Alvarez-Jimenez et al., 2013).

Seeman (2008) review sought to implement a theoretical framework on how to improve long term conditions using Web 2.0 highlighted social theories and their significance on human wellbeing. It highlighted the Social capital theory by Putman (2000) and its association with health, and acknowledged that social capital gained in an online network increased both physical and mental health (Seeman, 2008). Indeed, social interactions and subsequent benefits determined users' engagement with social technologies (Merolli et al., 2013). To achieve a sense of social community with a collective purpose there was a need for clear goals, member roles, policies and guidance to foster interaction. Each community was unique with an unpredictable development and a common purpose achieved by clear communication strategy and guidance (Demiris, 2006). Social peer

support and access to illness related information instilled in patients the need to efficiently manage certain aspects of living with the condition (Roblin, 2011). Alongside access to emotional support, recognition, exchange of information and having fun, the functionalities and usability of the application and access to information contributed to patients' empowerment and continued system usage (Lober & Flowers, 2011; Nordfeldt et al., 2012). It was recognized that building online communities and supportive relationships took time (Richardson et al., 2010).

### ***Contextual factors influencing PGI***

#### *Patient profile*

Neter & Brainin (2012) strengthened the view of previous research that age, socioeconomic status and health status influenced the level of health literacy, whereas gender was not influential. However, a study of a social media website in the Hebrew language for chronic conditions reported that men were using the website more than women (Magnezi et al., 2014). On Twitter, women seem to reveal more emotional and nurturing information compared to men who have a greater need to manage their professional life (Walton & Rice, 2013). In online self-presentation patients chose how much to disclose depending on their needs. Despite the ability to control some information, certain personal information was available (for example profile photo on Facebook) which enabled perceived credibility and enhanced networking but on the opposite side makes SNS less suitable for support for a stigmatizing condition (Merolli et al., 2013). Blogs and online forums were anonymous and more private, allowing the user to decide what personal information to disclose in order to post embarrassing and taboo topics, otherwise not discussed in an open environment, online or offline (Merolli et al., 2013).

The younger population from higher socioeconomic backgrounds and with digital access reported higher E-health literacy skills (Neter & Brainin, 2012). Nordfeldt et al. (2010) explored young patient's aged 12 – 21 views on a Web 2.0 diabetes hub identifying that it was considered a good source of information, because they found answers to their health questions, which contributed to satisfaction of information need. Another study with a similar age group but with a rheumatologic condition sought participant preferences and adoption of technology to manage transition. Respondents were reluctant in using social media to access health information and communicate with professionals mainly because of privacy concerns and feeling less comfortable in talking with people they do not know (Applebaum et al., 2013). It seemed that web portals providing healthcare information

verified by healthcare professionals were perceived as reliable by young people in contrast with social networks. Regarding message boards, adolescents with bulimia nervosa appreciated the benefits of being part of an easy accessible group, sharing personal experiences, and anonymity but disliked the lack of participants, technical problems and unhelpful information (Pretorius et al., 2009). Nonetheless, children up to the age of 19 with a CKD condition agreed that they would like to use social media to gather health information, but their parents and healthcare professionals presented mixed views (Swallow et al., 2014). One study reported that user's aged between 20-29 years perceived that using online interventions, because of difficulties in accessing information, more useful compared to older adults (Magnezi et al., 2014). Individuals aged 30-39 years and 50-64 years were predominantly online information seekers, the first group being parents of young children, whereas the second group began to encounter more chronic conditions (Magnezi et al., 2014). Chan & Dicianno (2011) identified that older patients with Spina Bifida were more likely not to virtually socialise compared with those below the age of 50.

#### *Technical and health literacy challenges*

It was unfortunate that in this digital age of technology the digital divide still influenced access and outcomes (Neter & Brainin, 2012). The online preferred system would have to be secure, accessible to both doctor and patients, customisable and provide elements of fun (Applebaum et al., 2013). Although new online technologies were freely available, multimedia applications required broadband width that restricted users who had limited services or limited computer skills (Demiris, 2006; Neter & Brainin, 2012). Digital divide refers to the gap in computer and internet access and was concerned with different user particularities, including age, location, income, and educational level (Demiris, 2006). The digital divide was influenced by accessible and usable design and often applications including functionalities which were incompatible with the level of user's experience, which inevitably excluded the group users (Griffiths et al., 2012). The user group likely to be affected by poor accessibility designs were senior users, who more often were excluded from developer's perception of an accessible design. Applications developed to address health information should undergo rigorous accessibility and usability checks (Demiris, 2006).

Technical issues were classified in two broad categories: sociability and usability, and design accessibility. Sociability referred to the '*collective purpose of a community, the goals and roles of its members, and policies and rules defined to foster social interaction*' (Demiris, 2006: p185). Usability was characteristic of the design interface that enabled

intuitive and easy access to information, influenced learning and reduced technical errors. In addition, accessibility was removing the technical barriers imposed on users with cognitive, sensory and motor issues as a result of disabilities or aging (such as visual impairment) (Demiris, 2006).

Moreover the web was seen as a potential response to health sustainability and self-management, giving patients the means to seek information and link peers with peers and health professionals to share knowledge (Neter & Brainin, 2012). However, patients only used information if they could understand it, therefore patients with a higher E-health literacy were able to use more information sources, conduct focused searches, use more strategies and evaluate the resources (Sarasoehn-Kahn, 2013). The outcomes of information seeking of individuals with high literacy were associated with finding information, knowledge of health status, symptoms and treatment, self-management of need and better health insurance (Neter & Brainin, 2012). Thus those with greater E-health literacy skills were believed to be younger and educated, with people with a chronic illness having lower skills (Neter & Brainin, 2012).

#### *Information quality*

Information quality and potential risks were concerns related to the field of social media amongst professionals and patients, because there could be a high ratio of irrelevant information in absence of specific guidance and use policy (Armstrong et al., 2007; Pulman, 2010). Patients felt resurged if the information accessed was checked by healthcare teams (Nordfeldt et al., 2012). The quality of information and who was producing it made patients anxious and they acknowledged that the preferred sources were those recommended by professionals (Applebaum et al., 2013). Accuracy, no commercial links, information associated with a known organisation and the content regularly updated were contributing to trust on the source (Nordfeldt et al., 2012).

#### *Privacy*

Patients were concerned about online privacy and confidentiality; privacy lay with the patient's right to control information related to them whereas confidentiality was a tool protecting patient privacy (Demiris, 2006). Within social media patients were more concerned about privacy (Applebaum et al., 2013). The existing tensions were among the information shared, breach of confidential data, emotional distress and identity theft (Liaw et al., 2010; Ressler et al., 2012). In an online environment like any offline intervention patient consent must be sought if dealing with high sensitive patient data, ethical

guidance must be focused on fundamental ethical principles and not on national laws (Demiris, 2006).

#### *Healthcare professionals role*

Given that patients were concerned with the level of information quality shared on the social mediums, they preferred interventions that were managed by healthcare professionals (Armstrong et al., 2007; Applebaum, et al., 2013).

#### **CMO 7**

*7. The factors influencing patients engagement in the process of producing and sharing information are patient profile, technical and health literacy challenges, information quality, privacy, and health professionals*

#### **Refinement of Proposition 1**

The mechanisms and the process of how patients with a long term condition communicate, generate and share information (PGI) were reviewed to understand what worked and the underlining causes. Furthermore, the concept of user engagement behaviour and social and peer support were explored to identify the aspects related to engagement, this led to the refinement of proposition 1 (Box 1).

#### *Box 1: Proposition 1 refined*

**Proposition 1: *Engagement with social media tools enhances networking and communication of health information to satisfy an information need***

- 1. SNS reflects real life relationships enabling patients to create a personal profile, access a network of networks, connect person to person in order to access information and social support.*
- 2. Facebook is a source of information and social support having the potential to engage more active users.*
- 3. Twitter is used as an outlet for satisfying information needs.*
- 4. Blogs allow patients to narrate emotional experiences and contributes to information sharing, problem solving, alleviating emotional distress. Blogging is energy and time consuming.*
- 5. Online communities are among the preferred social intervention in chronic disease management increasing patients' engagement with health interventions. The*

*access to information and support influence positive health outcomes*

6. *Social media is potentially an efficient mechanism to enable access to information through peers, who generates and share information satisfying patient information needs.*
7. *The contextual factors influencing patient engagement in the process of producing and sharing information are patient profile, technical and health literacy challenges, information quality, privacy, and health professionals.*

**Proposition 2: Engagement with social media tools and satisfaction of information need increases self-efficacy**

***Outcomes of patient engagement with social media***

The social technologies allowed patients to connect with peers creating relationships (Seeman, 2008; Pulman, 2010) and engaged in the process of producing and sharing information starting (Merolli et al., 2013). The social interaction fostered social support, which was linked to increased positive behaviour and self-efficacy (Roblin, 2011). In addition, social media was believed to impact on psychosocial wellbeing, for example depression, anxiety, stress (Merolli et al., 2013) and quality of life (Chan & Dicianno, 2011).

***Social capital and social identity***

Social capital was seen as the benefits gained by a patient from being part of a community and it was believed that Web 2.0 had spawned a new type of collaboration, enabling people to learn from conversation in a social context (Seeman, 2008). This reinforced Putman's (2008) view that social capital gained from networks leads to improved physical and mental well-being and enhanced local connections (Seeman, 2008; Pulman, 2010). In addition, Pulman (2010) highlighted social identity emerged from memberships of groups and that groups allowed members to gain social identity. Social identity was developed to seek the psychological grounds of groups, based on the hypothesis that an individual had several selves related to each circle of the group (Pulman, 2010).

### ***Self-efficacy and other psychological outcomes***

The use of Web 2.0 technologies was positively correlated with the development of coping mechanisms and increase in self-esteem (Merolli et al., 2013). The modern approach of patient education included conveying skills including self-monitoring, self-statement modification, goal setting, self-induced relaxation, exercising, attention and emotion control, review of belief, self-efficacy enhancement, planning, coping. The review of the literature on long term condition identified mixed results on outcomes. For example, an intervention outlined modest positive impact on factors influencing pain management, attitude and belief, knowledge on the topic, depression, stress, and anxiety, albeit with difficulties in attrition rates (Ruehlman et al., 2012). A study with diabetic patients strengthened the evidence that greater knowledge on illness and peer support helped the development of emotional and instrumental support and promoted self-efficacy (Roblin, 2011). However, Richardson et al. (2010) measuring impact of online communities on individual's exercise identified no difference between those with access to the online community compared to the remaining sample who had not used this functionality in the study. The noted differences were that those in the online community used the self-regulation components more, for example participants wore and provided pedometers data more often, than the non- participants (Richardson et al., 2010).

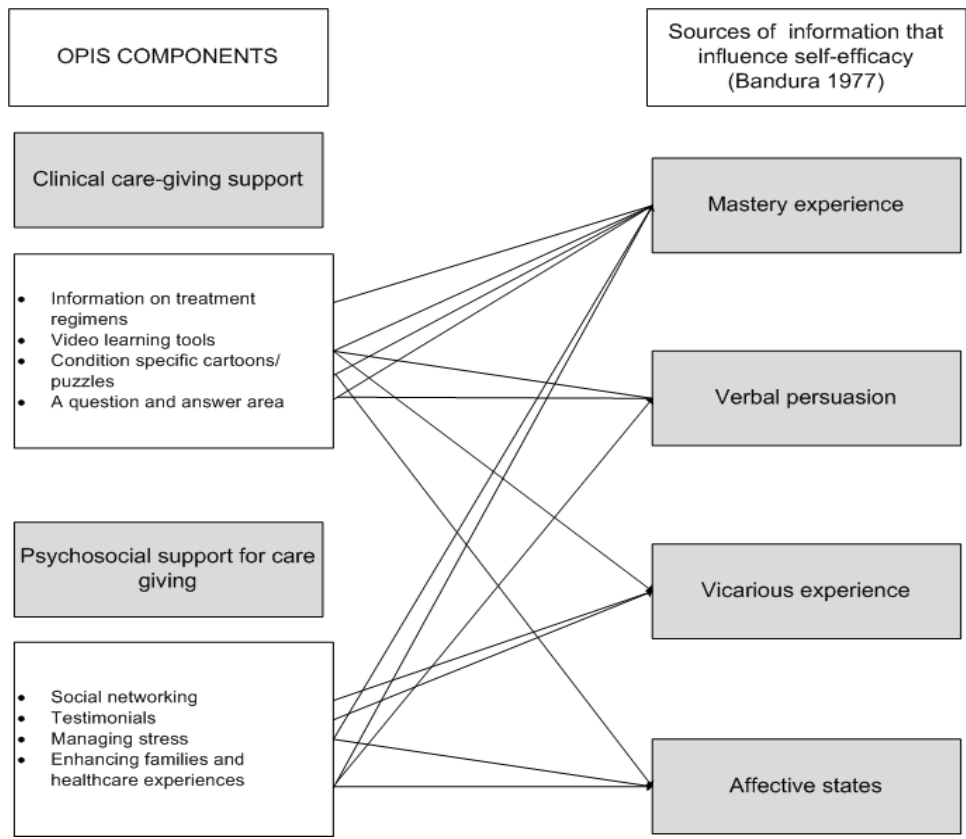
Pulman (2010) linked the concept of Bandura's self-efficacy and social learning in the context of the social web, used to assess the impact of an online community to an online walking programme on participant engagement. As did Swallow et al. (2014), who developed a model of online resources to promote parent self-efficacy for CKD caregiving based on Bandura's self-efficacy theory (Figure 3). The model was drawn from data collated with parent, young patient and renal professionals. It outlined the developmental needs of a platform and the relationships amongst the main sources of information and self-efficacy. Of particular interest were the platform specific elements, combining both informational and social resources, seen to influence self-efficacy (Swallow et al., 2014). The drawback of the model was including only 'information on treatment' (Swallow et al., 2014) whereas patients with a renal condition have different information needs and priorities (Ormandy, 2008).

Another concept acknowledged by Armstrong et al. (2007) directly linked to self-efficacy was patient empowerment. Patient empowerment was a notion often stated in health care research in recent years based on the concept that patients have the right to access health information and make informed decisions. Indeed empowerment was a process



that enabled patients or groups to control their lives and manage illness and the rise of social technologies have created new communication mechanisms, which supplement communication between health professionals and patients.

Figure 3: Model of online resources to promote parent self-efficacy for CKD caregiving (Swallow et al., 2014: p10)



The online technology that contributed to patient self-sufficiency in dealing with illness; reduced negative perceptions of being different, enabled peer support, set up attainable goals and provided rewards which were directly linked to self-efficacy in managing the condition (Armstrong et al., 2007). Patients with psychosis also reported moderate to high improvement on symptoms, influenced by social ties and empowerment (Alvarez-Jimenez et al., 2013).

**Quality of life (QOL)**

During the review, the concept QOL was reported as an outcome resulted of engagement with social media. QOL was a subjective norm referring to general well-being, including environment, physical and mental health, education, recreation and leisure time, wealth, employment, and from a patient view was the balance achieved given health circumstances and hopes and expectations. The four broad domains of QOL were

physical health, psychological health, social relationships, and environment, all related to patient context (goals, values, worries) (Chan & Dicianno, 2011). Pulman (2010) reviewed the impact of Web 2.0 on patients with a long term condition quality of life (QOL). Donald (2008) cited by Pulman (2010) provided a description of quality of life including individual's emotional, social, and physical wellbeing influencing ability to perform living related task. Its application to health was defined as health-related quality of life (HRQOL), which included constructs such as opportunity, health perceptions, functional status, morbidity or impairment, and mortality. People going through illness could still experience quality of life, and it was acknowledged that social media applications will connect people, enabling collaboration and access to health information (Pulman, 2010).

**CMO 8**

8. *Despite mixed results on the impact of social media on self-efficacy and other health outcomes, it is believed that the social capital, patient empowerment and satisfaction of information increases self-efficacy and other health outcomes*

**Refinement of Proposition 2**

Evidence from the literature on long term condition was explored to identify the health outcomes resulted after engagement of social media mechanism. The evidence produced mixed results suggesting the proposition required further testing and the proposed middle range theory will be taken forward to be tested with realist evaluation of GMKIN (Box 2).

*Box 2: Proposition 2 refined*

**Proposition 2: Engagement with social media tools and satisfaction of information need increases self-efficacy**

8. The social capital, patient engagements and satisfaction of information increases self-efficacy and other health outcomes

**Mapping CMOs and evidence using the Logic model**

During the realist review undertaken in this chapter, the nature of social media engagement to satisfy patient with a long term condition information need was examined. The CMOs were identified and findings mapped on the updated version of logic model version 2 (Figure 4). The logic model version 1 mapped the findings identified as a result

of reviewing theoretical concepts and outcomes around engagement and social engagement using social media and information needs. In this chapter, the logic model version 2 contextualises the evidence based on the conceptual findings and experiences specific to people with a long term condition. It situates the model within the realm of how patients with a long term condition communicate and generate information (PGI) using social networking (Facebook, Twitter), blogging, and online communities (activities and resources). The model maps the social relations and information provision generated as a result of engaging with the resources (outputs), and contextual factors influencing engagement, social engagement, and information needs. Finally, intended outcomes, are exposed such as satisfaction of information needs, increase in self efficacy and other positive social and health outcomes. The model will be updated in the methodology chapter 5 to include the evaluation techniques that will be employed to test the theories in the context of GMKIN.

### **Chapter Summary**

An in-depth iterative research of literature was undertaken to gain focused knowledge on how social media is used in the context of health and of people managing a long term condition. The findings revealed the use of individual social technologies, blogs, forum, SNS by patients with a specific health conditions. The two theories developed from chapter 2 were reinforced and confirmed although refined and underpinned by eight new concepts and relationships, described as middle range theories.

***Proposition 1: Engagement with social media tools enhances networking and communication of health information to satisfy an information need***

- 1. SNS reflects real life relationships enabling patients to create a personal profile, access a network of networks, connect person to person in order to access information and social support.*
- 2. Facebook is a source of information and social support having the potential to engage more active users.*
- 3. Twitter is used as an outlet for satisfying information needs.*
- 4. Blogs allow patients to narrate emotional experiences and contributes to information sharing, problem solving, alleviating emotional distress. Blogging is energy and time consuming*

5. *Online communities are among the preferred social intervention in chronic disease management increasing patients' engagement with health interventions. The access to information and support influence positive health outcomes*
6. *Social media is potentially an efficient mechanism to enable access to information through peers, who generates and share information satisfying patient information needs.*
7. *The contextual factors influencing patients engagement in the process of producing and sharing information are patient profile, technical and health literacy challenges, information quality, privacy, and health professionals*

**Proposition 2: Engagement with social media tools and satisfaction of information need increases self-efficacy**

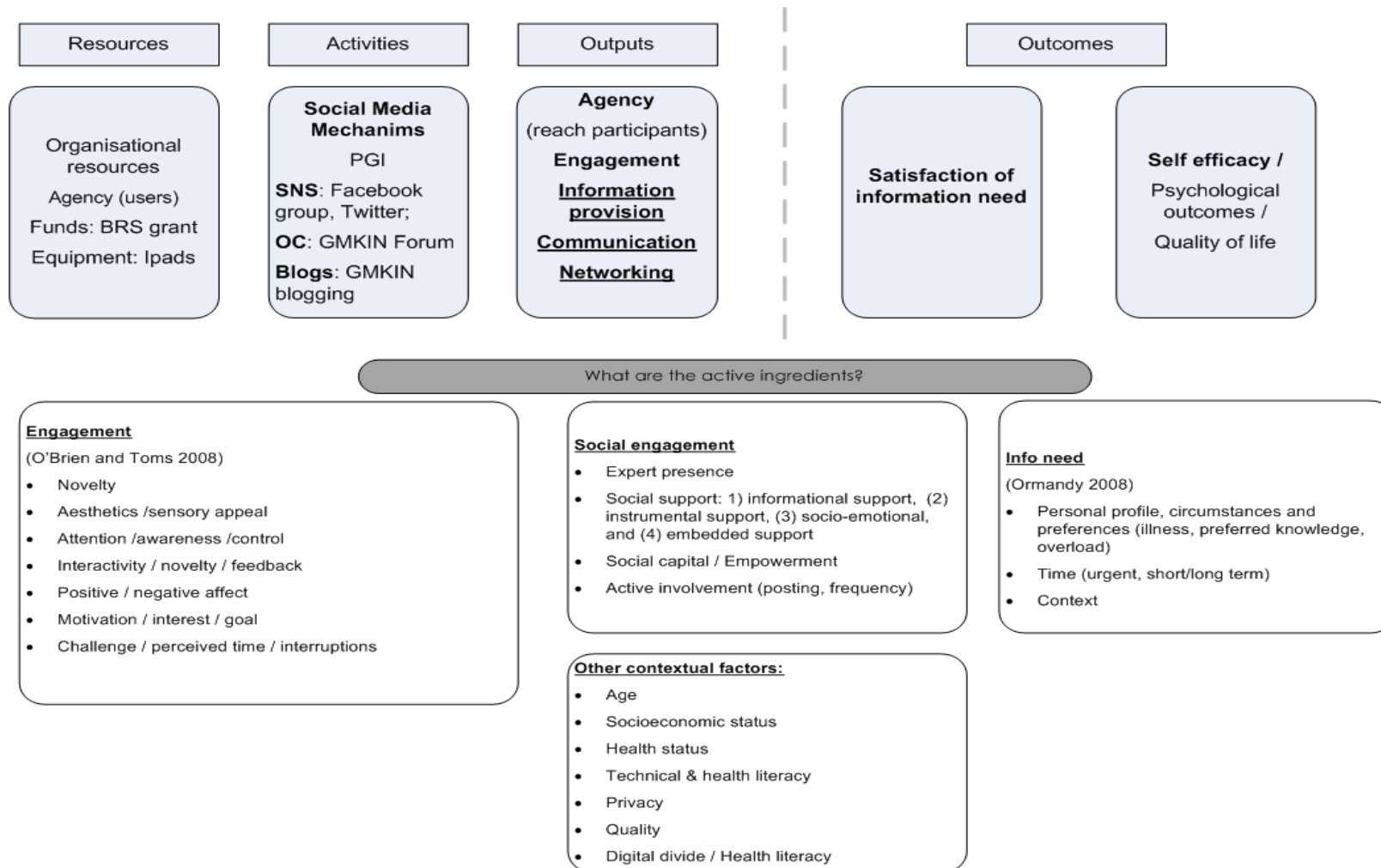
8. The social capital, patient empowerment and satisfaction of information increases self-efficacy triggering social and health outcomes

The review clarified concepts surrounding social media engagement to seek information to satisfy a need and gaining confidence to self-manage the illness. However it was evident that more information was required to understand the possible integration of these tools to engage patients, provide information, and facilitate communication and networking. Moreover, very little was known about how patients use the information retrieved to self-manage their condition. The social media domain is a relatively new and complex technology, sparingly adopted in clinical care, making it difficult to assess overall impact (Lober & Flowers, 2011). A review by Merolli et al. (2013) provided strong evidence of the gap, identifying limited evidence or clarity of what social media mechanism works for different individuals and what are the circumstances. Most findings were correlations amongst platform and outcomes, focusing on the functionalities of the platform rather than interactions and behaviours (Merolli et al., 2013). Further research was needed to: analyse the impact of Web 2.0 specific mechanisms and the context in which they are most effective (Stellefson, 2013), strengthen the evidence of the impact of blogging on psychological health, and determine the causality links of how SNS contribute to better socialisation (Chan & Dicianno, 2011; Merolli et al., 2013). Indeed the review reinforced the need to better understand the multi-facets of engagement, which currently are measured using mainly quantitative and linear models (Schultz, 2009).

Chapter 4 describes the development of the study Social Hub (GMKIN) and presents the findings of the second part of the realist review the critique of current Web based

platforms in health. Chapter 5 explains the realist evaluation methods and testing of theories approach. The middle range theories developed and refined within this realist review were tested to generate new knowledge of the impact of social media on patient's engagement, patient generated information and satisfied information need, and ultimately the impact on self-efficacy.

Figure 4: Logic model version 2 (patients with a long term condition)



## **CHAPTER 4: GMKIN DEVELOPMENT**

### **Introduction**

This chapter presents the theoretical and social development of the hub named Greater Manchester Information Network (GMKIN: [gmk.in.org.uk](http://gmk.in.org.uk)), based on the theoretical evidence drawn from the scoping review and the theory synthesised from current research evidence within the realist review (chapters 2 & 3).

GMKIN was a longstanding ambition of the Hope Kidney Patients Association; the committee were seeking to employ someone to develop a website for local people to communicate and raise awareness the activities of the association, in the first instance. Secondary aims included recruiting more people to help raise funds, identify problems patients experience and those who require help, advocating the patient voice within the service delivery.

The GMKIN system was the primary enabler of the research study, pivotal in examining social engagement, providing information to satisfy chronic kidney disease (CKD) patients' need, the source of the study cohort and research data. Therefore, GMKIN purpose within the study was twofold: to develop a social platform to enable wider patient access to social and informational resources and to test out theories developed through the scoping and realist review within a realist evaluation (described in Chapter 5). The underpinning theoretical focus was to examine the engagement of people, within a health context seeking information and social support through online activity.

From the outset the purpose of GMKIN was not to replicate existing renal platforms but to create a local social and informational resource. The new resource inherited and combined elements from other online renal resources; an information platform and information links, a place for people to post whilst being identified (Renal PatientView) or choosing to be anonymous (Patient Opinion). More specifically the GMKIN hub provided local information to renal patients, reshaping the way patients had previously received information, empowering patients to take control over the information they need, in a particular context, a specific moment in time. Based on the principles of patient generated content, an element of Web 2.0 platforms, the hub enabled patients to engage with each other, form communities of interest and collaborate using the channels (methods) they prefer. Patients often search across several websites to find information but ultimately rely

on one website considered to be most trusted (Maddock et al., 2011). It was hoped GMKIN over time would become the local preferred trusted site.

The realist review and scoping of underpinning theories was crucial to ensure GMKIN was based on current evidence and developed in an innovative way to enable the testing of emerging theory. To supplement this evidence a further synthesis was undertaken of existing web resources (grey literature) to identify online resources and elements that would be incorporated onto the new resource or used as external links. Within this chapter the web resource synthesis is presented alongside the decisions, the context, and operating processes that guided the development and implementation of GMKIN. Crucial to the analysis of existing web resources was my experience in web design and usability. The knowledge gained throughout my development work and system design in various contexts (business and health) and undergraduate dissertation (research on web accessibility and users testing of ecommerce website) influenced and informed decisions during the development of GMKIN.

### **Synthesis of existing resources**

The Web has evolved from providing static content, images and links to become a powerful tool, which encompasses elements such as user participation and interaction, openness, and networking. Participation enables users to interact with the web in different ways, by commenting, reviewing, changing, using and sharing the information creating the expressive net or the social web (Tufekci, 2008; O'Reilly & Battelle, 2009; Weber & Rech, 2009). Its predecessors (Web 1.0 and 1.5) were linked to the Informational Web. The features of both, Information and Social Web services are adopted to explore existing healthcare websites from a social and informational perspective (Weber & Rech, 2009) (Table 11).

*Table 11: Classification of Web Services (adapted from Weber & Rech, 2009: p3-16)*

| <b>Information Web</b> |                        | <b>Social Web</b>          |                          |
|------------------------|------------------------|----------------------------|--------------------------|
| Web 1.0                | We 1.5                 | Web 2.0                    | Web 2.5                  |
| Content Viewing        | Onsite Commenting      | Content Upload             | Content moving           |
| Static Pages           | Dynamic Pages          | Content Editing            | On-site commenting       |
| No Interaction         | Form Based Interaction | Content Download           | User sensitive interface |
| Insensitive Interface  | Advanced search        | Tagging                    | User sensitive search    |
| Plain Search           |                        | Dynamic Pages              | User sensitive search    |
| Off-site Search        |                        | Device sensitive Interface | Time sensitive Services  |
| Insensitive Search     |                        | Onsite search              |                          |



|                   |  |                |  |
|-------------------|--|----------------|--|
| Inactive Services |  | Content Mashup |  |
|-------------------|--|----------------|--|

**Search of Web resources**

A web search was performed to identify existing health applications specific to the renal field. A total number of 11 websites (Table 12) were selected for in depth review; four USA based and seven UK based platforms. The names were among those circulated in research papers, blogs and named by patients on social media. In addition specific social media applications were reviewed to acquire knowledge on the design, functionalities and level of social interaction. Among those there was a clear preference for the design and aesthetics of Organised Wisdom (clear, user friendly and intuitive). In terms of information the website trusted to provide healthcare information (such as EDREN) were used to link to information from GMKIN.

Table 12: Web resources (general and specific)

| General   | Kidney specific   |
|---|---|
| Organised Wisdom<br><a href="http://www.organizedwisdom.com/Home">http://www.organizedwisdom.com/Home</a> | National Kidney Federation (NKF)<br><a href="http://www.kidney.org.uk/">http://www.kidney.org.uk/</a>   |
| Everyday Health<br><a href="http://www.everydayhealth.com/">http://www.everydayhealth.com/</a>            | Life Options<br><a href="http://lifeoptions.org/">http://lifeoptions.org/</a>   |
| PatientsLikeMe<br><a href="http://www.patientslikeme.com/">http://www.patientslikeme.com/</a>             | British Kidney Patients Association (BKPA)<br><a href="http://www.britishkidney-pa.co.uk/">http://www.britishkidney-pa.co.uk/</a>   |
| Patient Opinion<br><a href="https://www.patientopinion.org.uk/">https://www.patientopinion.org.uk/</a>    | Kidney Patient Group (KPG)<br><a href="http://www.renal.org/information-resources/information-for-patients#sthash.V2ZZF6Mo.dpbs">http://www.renal.org/information-resources/information-for-patients#sthash.V2ZZF6Mo.dpbs</a> |
|   | Edinburgh renal Unit (EDREN)<br><a href="http://www.edren.org/">http://www.edren.org/</a>   |
|   | Kidney Research UK (KRUK)<br><a href="http://www.kidneyresearchuk.org/">http://www.kidneyresearchuk.org/</a>  |
|   | Renal Patient View (RPV)<br><a href="https://www.patientview.org/#/">https://www.patientview.org/#/</a>   |

**Synthesis of findings**

Amongst the news and information groups OrganisedWisdom was named top website for 2008 for innovation in medical care (Nursing Assistant Guides, 2009). The platform converts crowdsourced content into a Wisdom Card to close the gap between existing

web information and a visit to the doctor. Health professionals are able to generate lists with preserved links pointing towards health information (Health 2.0, 2011). In a similar way EverydayHealth.com compiles personalized health advice, tools, and communities for an audience of over 28 million monthly visitors (Everyday Health, 2013). Amongst the activists' sites, PatientsLikeMe brings together patients to share their personal data in the idea that the information exchanged can change their illness after being analysed researchers. Similarly, in UK the Patient Opinion platform primarily facilitates patients sharing their personal experience of health services to improve practice. There were approximately 88,712 stories told and 2676 members of staff that listen.

CKD specific resources vary from international and national origins. The National Kidney Foundation a non-profit organisation aims to prevent kidney disease and provide information to improve life of patients and families (NKF, 2013). Life Options, an American rehabilitation project, helps patients to have a good future with a kidney disease. The advisory panel of Live Options, known as Life Options Rehabilitation Advisory Council (LORAC) identified the fundamental principles of rehabilitation. Encouragement, education, exercise, employment, and evaluation or the '5Es' provides the basis of a new research paradigm (LifeOptions, 2013). The British Kidney Patient Association (BKPA) and the Edinburgh Renal Unit (EDREN) provide rich information resources to kidney patients and health professionals in the UK (EDREN, 2012; BKPA, 2013). The BKPA resources are available in the form of leaflets with option to download. Similarly, the Kidney Patient Guide (KPG) is designed primarily for UK users to provide health information for renal patients, families and carers. The information focuses not only on the physical impairments but also on emotional, social and financial aspects of living with CKD. Features such as the support forum enable information exchange and support (KPG, 2012). Kidney Research UK (KRUK) a leading charity funds research to improve kidney treatment. The website consists of kidney specific health information and case studies, and examples of current renal research, or research funding opportunities (KRUK, 2012).

Renal PatientView (RPV) provides instant information related to a patient's health, and advice on illness management. The system has improved over time with new functionalities such as patient self-reading measures, community forum and blog and now has almost 18,000 users (Turner, 2011). An initial evaluation of the system showed that only 11% of the users engage in the discussion forum to share concerns, issues and find help (Mukoro et al., 2012). Given that anonymity is one of the most regarded features of

online discussion forums (Hwang, 2009) this may explain why the RPV forum is not actively used.

The Web resources were analysed using the characteristics identifying information and Social Web conceptual elements (Table 11) and classified whether they predominantly 'information rich', 'social rich' or both 'informational and social rich' (Table 13). For the purpose of this synthesis, websites based on user generated content were classified as social rich. Information rich websites focused towards providing specific health information via onsite content or offsite links. The social rich websites shifted focus to social elements including networking, communication and sharing. The combined Information Web and Social Web platforms, met some or all of the web characteristics identified (Table 13). Informational and social web functionalities, such as Organised Wisdom and Everyday Health were identified as effective in engaging users and were included in GMKIN to provide a holistic approach. In addition those informational rich websites influenced the development of GMKIN and link to existing informational resources.

Table 13: Analysis and classification of existing online resources

| Web Characteristics                        | Website          |                 |                |                 |     |              |      |     |       |      |                    |       |
|--|------------------|-----------------|----------------|-----------------|-----|--------------|------|-----|-------|------|--------------------|-------|
|  | Organised Wisdom | Everyday Health | PatientsLikeMe | Patient Opinion | NKF | Life Options | BKPA | KPG | EDREN | KRUK | Renal Patient View | GMKIN |
|  | USA              | USA             | USA            | UK              | UK  | USA          | UK   | UK  | UK    | UK   | UK                 | UK    |
| <b>Information Rich</b>                    |                  |                 |                |                 |     |              |      |     |       |      |                    |       |
| Characteristics Information Web (Table 11) |                  |                 |                |                 | X   |              |      | X   | X     | X    | X                  |       |
| Health information                         | X                | X               |                |                 | X   | X            | X    | X   | X     | X    | X                  | X     |
| Day to day health management tips          | X                | X               | X              |                 | X   | X            |      | X   | X     | X    |                    | X     |
| Study cases                                | X                | X               |                |                 |     | X            | X    | X   |       | X    |                    | X     |
| <b>Social Rich</b>                         |                  |                 |                |                 |     |              |      |     |       |      |                    |       |
| Characteristics Social Web (Table 11)      | X                | X               | X              | X               |     |              | X    |     |       |      |                    | X     |
| Participation                              | X                | X               | X              | X               |     |              |      |     |       |      |                    | X     |
| Networking                                 | X                | X               |                |                 |     |              |      |     |       |      |                    | X     |
| Openness                                   |                  | X               | X              | X               |     |              |      |     |       |      |                    | X     |
| User generated content                     |                  | X               | X              | X               |     |              |      |     |       |      |                    | X     |
| Anonymous                                  |                  |                 | X              | X               |     |              |      |     |       |      |                    | X     |

|                                      |          |          |  |  |  |  |  |  |  |  |          |
|--------------------------------------|----------|----------|--|--|--|--|--|--|--|--|----------|
| <b>Information &amp; Social rich</b> | <b>X</b> | <b>X</b> |  |  |  |  |  |  |  |  | <b>X</b> |
|--------------------------------------|----------|----------|--|--|--|--|--|--|--|--|----------|

The synthesis informed decisions on what to include within the GMKIN platform, indeed the functions of GMKIN were directly compared (Table 13). In terms of security, it was noted that among these websites, a preference of UK sites was to be hosted on secure servers with encrypted traffic using secure socket layers (SSL) technology, unlike USA. For example PatientsLikeMe and Patients Opinion, both of the same genres (sharing personal experience) are hosted on different types of servers. PatientsLikeMe uses a non-encrypted traffic whilst Patient Opinion is hosted on a secure SSL enabled server. It was reassuring then to host GMKIN on a non-encrypted server, which was considerably more affordable, from a limited budget. It was decided that personal data (apart from user name and password) was not to be stored on the system until a SSL was purchased in the future. To strengthen the security of the site and privacy of users there was the option to create an anonymous profile.

The GMKIN platform unlike Renal PatientView forum was open to public to view the blog posts and discussions. It followed the example set by Patient Opinion. Furthermore it included links to UK renal websites in an attempt to provide medical information alongside patients' experiences to enable wider patient participation and networking, to contribute to and inform a database of local patient generated information. Each site was screened by for their policy, terms of use and other useful information to influence GMKIN development and moderation.

**GMKIN a platform designed by patients for patients**

The technical and social development was undertaken by the main researcher with the involvement of supervisors in their role as evaluators with expertise in long term conditions. Understanding the context of CKD patients, whose information needs were to be met, was considered central to developing meaningful and relevant website information (Ormandy, 2008). User-centred design (UCD) when developing informational systems is often ignored (Cole, 2011), but for GMKIN UCD was the most important guiding principle: designed by patients for patients. According to Norman (1998) the principles of UCD (also known as human centred design) requires knowledge of the needs of system users, involves them in an iterative process of system testing to enhance usability, and evaluates their satisfaction. UCD is an approach to system design focusing on developing a usable system using multi-faceted and multi-disciplinary team input to identify the context of use, user and organisational requirements, develop solutions and

evaluate the designs International Organization for Standardization (ISO, 1999). Therefore, a UCD development method was employed, eliciting informal feedback on reference and prototype versions of the hub (Norman, 1998; Losada et al., 2013).

### ***GMKIN in context***

The evidence generated from previous chapters identified that social media technologies enabled patients with a long term condition to take collective actions in a movement to construct social activism acknowledged as an essential mechanism to determine engagement (Bandura, 2002). Blogs, SNS and online communities were positively correlated to information and experience sharing, problem solving, alleviating emotional distress, acceptance and management of illness, high social and emotional support and 24 hours availability (Ressler et al., 2012; Merolli et al., 2013). However, attrition and engagement of patients in online healthcare intervention remains a challenge (Glasgow et al., 2007; Christensen et al., 2009; Poirier & Cobb, 2012; Archambault et al., 2012). It was important then, in this study, to better understand the causal relationships amongst GMKIN components (the hub, the Facebook group and Twitter) and patient generated information; to identify engagement regularities and patterns by categorising social media tools and interventions as mechanisms, and observing people's reasoning and use in a particular context.

The development opportunity originated with a vision: to help the HKPA to create new communication channels to provide local information to patients with a renal condition and enable them to communicate and network with each other. The collaborative project began in August 2012 and the concept evolved after meetings with HKPA, patients and local healthcare professionals. The stakeholders emerged as three groups: (1) Researchers (digital lead and evaluation), (2) Patient Reference Group (involvement in developing an application that suits their needs, with relevant content) and (3) Multi-Professional Information Working Group (specialist content verification).

To support the work an application for funding to the BRS/BKPA was successful and awarded in January 2013: to cover the costs of hosting, advertising, moderation costs and involvement of patients with no access to technology. Throughout the initial six months of development a series of individual and group meetings, and online discussions were held to develop an understanding of what patients expected and wanted from an online platform. The development phase was shaped by both theoretical and research evidence gathered in Chapter 2 and 3, to identify and embed successful tools and

mechanisms and social elements to meet the user needs. GMKIN developed into social and informational intervention:

- GMKIN Platform – bespoke online system (available at gmkin.org.uk) developed to enable patients to access information and/or register to post blogs, comments and/or ask questions
- GMKIN on Facebook – open patient to patient social networking group. All accepted members of the group could post and share information, make comments, upload information and ‘like’ different content

The Facebook group was developed simultaneously with the GMKIN platform, being used initially as a “*useful tool for keeping in touch with the company of volunteers helping to provide useful additions and information for the website*” (Patient)

- GMKINet - Twitter account to engage in conversations on health matters including CKD, share and build a follower base to increase patient involvement, greater access to opinions and raise GMKIN profile

### ***GMKIN platform theoretical underpinning: information need and engagement***

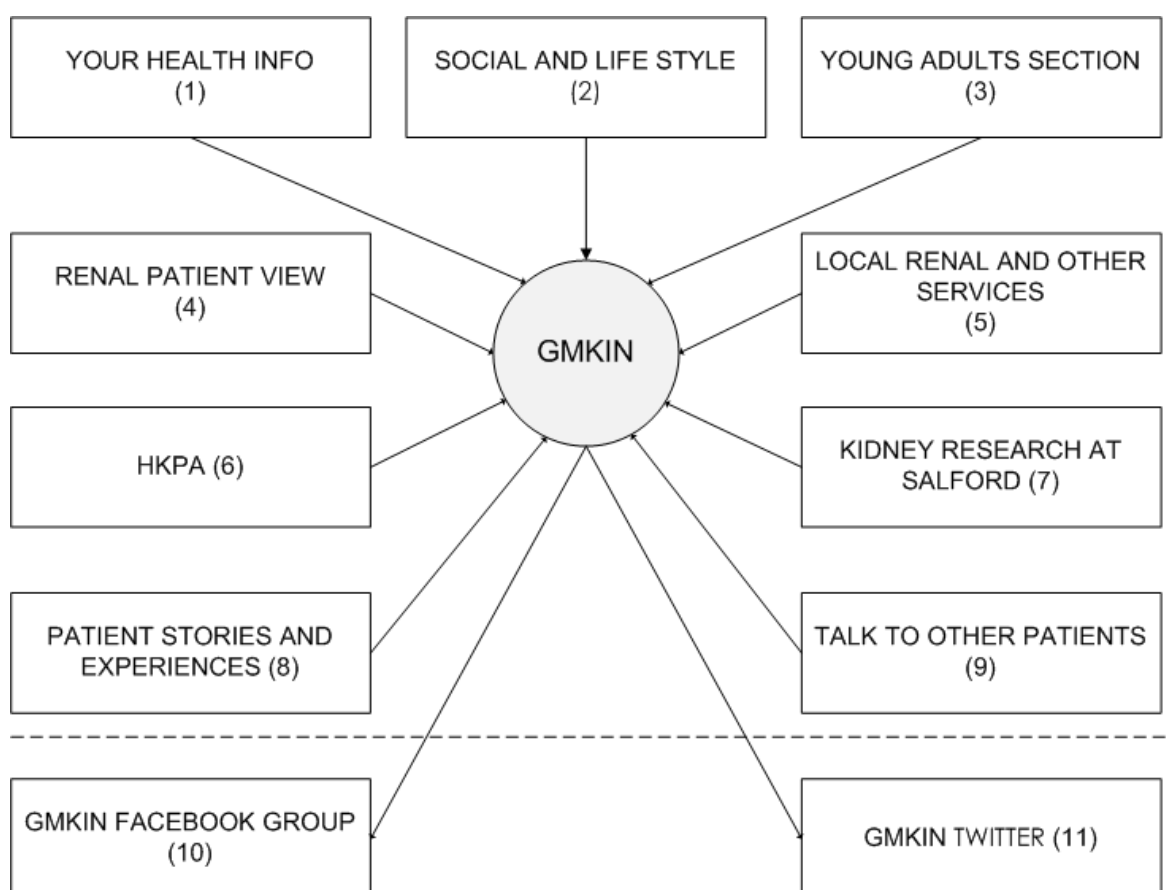
One of main objectives of the hub was to complement the information given by healthcare professionals to patients, who rely on the internet to access information related to their care (Rozenblum & Bates, 2012). As the context of each patient is different (Ormandy, 2008) GMKIN enabled users to define and determine what information needs to be added to the site and were encouraged to engage with each other by sharing information, tips and experiences of using different coping strategies. The information needs of patients with CKD (Ormandy, 2008) were reflected in the components of GMKIN, supported by evidence that when patients join a CKD Facebook community to discuss health related issues they felt less isolated (Swallow, 2014).

The system was developed using Wordpress (2013), an open source Content Management System integrated with other social components (Wordpress, 2013). The choice reflected the need to sustain the platform after project completion. Given that Wordpress supports more than 17% of the web, from basic website to complex applications, blogs, communities, it was considered an appropriate choice. Its features encounter simplicity, flexibility and scalability to continuously update the application to support stakeholders’ need, user management, and more importantly for the purpose of this project enabled easy updates and content processing.

### Information

GMKIN's main information rich components included an overview to existing resources: (1) health information, (2) social and life style, (3) young adults section, (4) renal patients view, (5) local renal and other services, (6) HKPA and (7) kidney research at Salford (Figure 5).

Figure 5: GMKIN components



(1) The health information facilitated access to a directory of resources that helps patients with a chronic kidney disease to stay healthy, bringing together CKD resources, treatment options, medication, diet and nutrition, balancing fluid intake, fitness and living with CKD. The information provided a response to information needs of *'what is happening to the physical self'*, identifying symptoms and illness complications and gain understanding of how to act on the information gained (Ormandy, 2008: p201).

(2) The social and life style section synthesises food recipes, outside meals, recommended holidays, financial tips and other services helpful in special to young adults. Holidaying whilst on dialysis was considered important to renal patients (Ormandy, 2008) and yet a criticism by a patient in a planning meeting suggested *'all dialysis*

*holidays mention cruises or caravans'* which stirred frustration as *'not all patients are retired and want to go on a retired holiday'* (patient comment). In response patient generated information presented patients' experience, suggesting places to go on the basis of self-expression (OECD, 2007).

(3) The young adult section was dedicated to young people, who can connect with other young patients, share and find information. The section was inspired by feedback received from young patients currently attending local renal services who rarely meet each other. The information section included more specific activities for young people, pregnancy/abortion services, substance abuse, sexual health, eating disorders.

(4) Links to Renal PatientView enabled patients to self-manage their illness by accessing their latest blood test results, diagnosis and treatment from any location; this is possible by a login into the system and sharing their own clinical data with appropriate medical staff.

(5) Local renal and other services sections were compiled in an alphabetical order Greater Manchester Services directory considered useful to renal patients.

(6) The HKPA section provided information about the association roles, promoting the recruitment of new members and access to an online form to join the association and direct communication to contact or share their experiences, problems, or request financial support.

(7) Kidney research at Salford is a section that connected patients with information and feedback links to research studies taking place in their Trust and unit, including the contact details of clinicians if they wish to get involved in a specific study.

The content of GMKIN was crowdsourced, obtaining information from many sources indicated by patients and identified during the synthesis of existing resources and curated (collated, organised and presented on the web) by the main researcher. The resources were then verified by the primary supervisor and healthcare professionals to ensure accuracy and trustworthiness of information. Links agreed and suggested by the patients' reference group included: All Citizens Advice Bureaus within the footprint of the Trust, Nationally Recognised Kidney Patient Associations, Medical Information Sites (such as EDREN, RPV), Renal support organisations for patients (NKF, BKPA), youth organisations, Jobcentre Plus and Specialist Driving Schools for people with special needs (dyslexia/dyspraxia).



### *Patient Generated Information (PGI)*

GMKIN brought a new dimension of social interaction, which enabled patients, to take part in asynchronous discussions, create social bonds, and generate their own information useful to their health (Smithson et al., 2012). Patients were able to post blogs on the GMKIN platform, comments on existing information rich components, use the forum facility, or engage in discussions via the Facebook group and Twitter, contributing to PGI.

(8) Patient stories and experiences appeared in the blogging section which allowed registered users to post their experiences and engage in discussions. Experiences of other patients of the disease and treatment were perceived as an important information need, certainly by new patients (Ormandy, 2008).

(9) Talking and communication with other patients took place in the discussion forum where patients could connect to other patients or carers and ask specific questions.

(10) Within Facebook, the GMKIN group took the first steps towards building a social platform. Patients started to connect bounded by local geographical settings (Greater Manchester) or connecting based on a solidarity factor (experience of renal disease), (Adams, 2011). Initially Facebook;

*'proved to be a very useful tool for keeping in touch with the company of volunteers helping to provide useful additions and information for the website'* (expert moderator patient).

The comments made by patients during this phase were related to difficulties in using the platform;

*'I am having trouble trying to register, how do I register please'* (patient); requests and guidance *'If you have tips for a good holiday please also share on GMKIN - To post use the form on the page or sign up', 'If you have any renal holiday photos or shots of fund raising events then please notify us'* (expert moderator patient).

Upon completion of the first phase of platform development, Facebook began to focus solely on sharing about their kidney illness renal, day-to-day information, raise discussions and patient to patient advice.

(11) GMKIN Twitter account was the last addition to increase the wider social community, it was interlinked with GMKIN Platform to streamline the engagement occurred via twitter

(Courtney et al., 2013). The purpose of the account was to bring together renal patients and healthcare professionals to generate conversions and sharing of information.

Apart from Facebook and Twitter, the GMKIN main platform enables users to register, create public profile, and connect with other users (Ellison, 2008). The registration process was, '*much in the same way as a Facebook account*' (patient).

The information shared by patients via GMKIN platform: blogging, commenting and forum were fully moderated and Facebook discussions are monitored.

#### *Expert moderation*

The synthesis of existing resources identified that good practice included holding comments and opinions for moderation. GMKIN moderation process followed two approaches: moderation by an expert patient or moderation by health professional.

All blog posts, forum topics and comments were held for moderation. Given that the GMKIN has multiuser blogging, the blogs were initially checked by two expert (independent) patient moderators or the main researcher. The comments on blogs were moderated by the patient blogger, expert patients' or main researcher on the basis that the blogger would know his topic and would raise any unwanted issues. Comments on the forum and website were the responsibility of the main moderators. Topics related to the social living and experiences were addressed within the group, whereas as those related to symptoms and treatments were directed towards healthcare professionals to verify or comment on accurate information.

GMKIN apart from providing patients opinions, the usual approach for the majority of SNS, had access to a multi-disciplinary group of expert healthcare professionals who guided patients with medical issues to a relevant service.

Community moderators were encouraged to identify motivated members, recognising and seeking diversity to influence community growth, and foster underlying psychological bonds amongst certain groups to keep a healthy community growing. Building community commitment was facilitated by creating an identity based on shared values, interests and goals, reaching broader audiences by informal tone and humour (Light & Ormandy, 2013).

#### ***User Interface***

Designing and building an appropriate user interface that contributed to a total absorption with an enjoyable and rewarding activity, drawing patients' attention and involvement

during engagement and be aesthetically designed were important ingredients contributing to the success of GMKIN (O'Brien & Toms, 2008). The UCD approach to the development of GMKIN provided continuous feedback during the development period and beyond regarding the aesthetics, navigation and site structure.

The initial prototype developed based on information research (Ormandy, 2008) was discussed with the first joint group of patients and health professionals that consisted of 15 members. The meeting commenced with a presentation of the hub which triggered discussion and feedback. There was a general consensus amongst the audience that an online resource would unite people in a way that could make them feel supported on their journey, and provide health professionals with a resource to signpost new patients to for support and information. During the meeting patients gave their opinion on aesthetics (colours, graphics, logo, strapline and font) and identified different opinions on graphics, font and strapline, exposing different user tastes and preferences (Tractinsky et al., 2006). There was a unanimous view that graphics should include existing patients and two patients agreed to have their photo on the home page, however different versions of the strapline were proposed '*Our Journey is Safer Together*' different iterations of '*OUR*', '*JOURNEY*' & '*TOGETHER*', and '*A Journey With Friends*'.

Following that meeting the researcher was approached to be involved and connect to three other projects: one, supporting young adult transition to adult care; the second aimed to increase patients' contribution to renal research and the third, seeking to improve patients and staff experience with the service. GMKIN was further developed based on feedback from patients to add a section for Young adults (3) including a private forum and information on health issues and services available. Similarly, information about research projects was made available and constantly updated by healthcare professionals (7).

### ***User rights and Testing***

The information on GMKIN was available to all internet users, however to blog and comment, registration onto the GMKIN platform was required. The details required to register were username, password, email and city, whereas the Facebook community was accessed using personal account, provided by simply asking permission to join. Initially, registration was only allowed for individuals from the Greater Manchester area, however as a result of further requests from patients located in wider geographical areas registration was opened nationally.

The GMKIN platform enabled the administrator (a joint role held by the researcher and the expert patient moderator) to assign users different roles on the platform (user rights). The roles were subscriber (default role given after registration), collaborator (blogging, commenting rights) and editor (editing health information).

The primary aim of UCD was to develop usable applications (W3C, 2004). Usability testing forms part of observing patients using the platform and collating information on ease of use (Dumas & Redish, 1993). Initial testing was undertaken by the expert patients group. They were asked to navigate around the website, test all links and interactive features, write/edit/submit blogs, post comments and create their own profile.

User feedback indicated that:

*'...registration with the site is very easy. All you need is your full name and email address and a suitable easily memorable user name that will identify you publicly on the site with an anonymous identification. In return by email you receive a randomly generated password that can be changed the next time you log in...'* (Patient, field note: 15 May 2012)

Technical issues appeared during registration by two patients indicated there was:

*'...a minor glitch during the early development meant that I had to re-register my details with the site' (patient), 'I am having trouble trying to register' (patient, field note: 16 May 2012)*

This triggered further development to ensure a smoother signing in process.

To perform GMKIN usability testing, 10 patients were observed using the website. They were asked to navigate through the site, post, edit and publish blogs under the supervision of the researcher. That provided an insight of how intuitive and usable the functionalities were. Furthermore, a technical forum was opened on the website enabling patients to share data on issues that occurred during use, providing instant technical feedback.

The final version of GMKIN was tested by all the administrators. A separate account for each user role was created and functionality tests completed. The functionality tests included: profile, posting, commenting, notifications, security, add photos, draft posts and posts submitted for moderation (Appendix 2). As a result of the user testing and feedback received via the log and technical forum, a refined version of the website was released.

## **Social community development – first phase**

Developing GMKIN as a social support community relies on users' interaction, however building online communities and supportive relationships takes time (Richardson et al. 2010). As a sustained process, team members developed a strategy of continuous development and increased sustainability, recognising that in online communities solidarity and social bonds contributes towards community building (Adams, 2011; Smithson et al., 2012).

The initial step to solidarity was connecting patients using the Launching Event held at a media venue (September 2013). A combination of online and offline methods were used to advertise the event, which included: minority group targeted advertising within an advert in Asian newspaper to attract the Asian population, article in the Manchester Evening News, on the University website, flyers in all local Renal Units, face to face inviting patients on dialysis at clinics, and at educational sessions for pre-dialysis patients by members of HKPA and researcher. The event location and the invitation of a magician triggered more interest from patients, mainly the young adults, indeed 50 patients with a chronic kidney condition, carers and staff were brought together to interact and get to know each other, and learn about GMKIN.

The second event was organised in December 2013 to showcase the benefits of clinical research and the necessity to get involved amongst patients. The bookings were organised via GMKIN to increase awareness of the platform as an established resource and bring patients back to feedback and engage with the community. One of the patient moderators presented an overview of the purpose of GMKIN to a 70 strong audience and we distributed business cards with the site address and GMKIN vision amongst the CKD population and healthcare professionals.

As a result of the events and promotion, more patients joined the GMKIN platform and/or the Facebook Group. Indeed, on-going recruitment naturally occurred through social media mechanisms: Facebook and Twitter. The Facebook group was initially 'open' to public (all Facebook members could see who was in the group and posts), increasing visibility amongst friends and wider network of GMKIN members. To discover more patients living with a kidney condition in the Northwest searches were performed using Facebook search engine to find renal communities and post links to the new group. Email invitations were sent to HKPA members to join the Facebook group. Twitter searches were performed using specific syntax that will retrieve users within a specified geographical location with interests on kidney. The extended Twitter activity and

interaction resulted in new users joining the GMKIN platform or creating own blogging space using a blog specific platform. In addition patients and carers joined the community referred by medical staff.

To maintain the momentum created around these events, an informal tone was maintained through the communities and a variety of topics were used to attract and sustain user interest, participation and create an enjoyable experience (Light & Ormandy, 2013; Lai & Chen, 2014). The rationale was that, long term interaction and relationships on GMKIN would create horizontal bonds amongst patients influencing positive health outcomes (Putman, 2000; Seeman, 2008).

Initially Facebook posts were initiated by the researcher in conjunction with an expert patient. The researcher posted information regarding the GMKIN platform, online safety guidance, diet, and issues with the healthcare system, in the form of statements or questions to trigger conversations. Examples included:

*'In our health system the patients are in the best position of ensuring their health care is coordinated... Do you agree?'*, *'Hi All, Can we start using this group more efficiently? For example, tell fellow patients your favourite meal and how you cook it.'* (Field note: October 2013)

The expert patient moderator posted renal specific information that he felt pertinent to the community, commenting or challenging changes in services or policies, to stimulate a response.

### **GMKIN activity**

GMKIN during the period of 01/08/2013 – 31/01/2015 moved from a zero base to the site generating 167 members on Facebook and 440 followers on Twitter and 113 registered users on the GMKIN platform (Table 14). The stats were retrieved from Google Analytics (<http://www.google.com/analytics/>), Twitter Analytics (<https://analytics.twitter.com/>) and GMKIN platform (<http://gmkin.org.uk/>).

Patients generated 134 blogs sharing information varying from CKD to emotions, fundraising, technical advances. Each blog had an option to add keywords highlighting the main aspects of the topics shared, these are then compiled onto a Tag Cloud (weighted list of keywords) (Figure 6).

Table 14: GMKIN activity overview

|   |
|---|
| <p><b>Facebook:</b> 167 members, on average 80 users viewing the posts</p> <p><b>Twitter:</b> Followers: 440 (from cities: 13% London, 8% Manchester, 2% Los Angeles, 2% Salford), Following: 973, Tweets: 2481</p> <p><b>GMKIN:</b> Users (number of people who visited the website at least once): 6082 (47.8% returning, 52.2% new visitors)</p> <ul style="list-style-type: none"> <li>• Page views (total number of page views including repeated views): 27,348</li> <li>• Sessions (a period of time a user is actively engaged with the website): 11,656</li> <li>• Pages/session (average of pages viewed during a session, included repeated views): 2.35</li> <li>• Average session duration (average time spent on each session) 3min:11sec</li> <li>• 30 days active users (unique users engaged in an least one session within the last 30 days period): 394 active users / day</li> </ul> <p><b>Contributors:</b> 113<br/> <b>Blog Posts:</b> 134<br/> <b>Comments to blogs:</b> 405<br/> <b>News section:</b> 327</p> |
|---|

Figure 6: Keywords generated from blogging



The traffic to GMKIN during the time of the study generated 11,656 sessions (Table 14), 41% of the total sessions are generated via social and referral traffic, amongst which the most significant is Facebook and Facebook mobile (app) and Twitter (Table 15). Another important correlation is that of direct traffic and visits to GMKIN, users subscribed to GMKIN had an option to receive notifications with blog posts via email, hence the direct traffic encompasses 34.86% of traffic to the site.

Table 15: Traffic to GMKIN

| Traffic source  | Number sessions (%) |
|---|---------------------|
| Direct (the source of traffic could be associated with links sent by email, accessing the site directly on the browser) | 4,063 (34.86%)      |
| Social (conversion from social channels)  | 3,811 (32.70%)      |
| Organic (conversion from listings on search engines as a result of optimization and relevancy to user searches)         | 2,815 (24.15%)      |
| Referral (segment of traffic to the website via another source)   | 967 (8.30%)         |
| <i>Most popular referral &amp; social mechanism</i>   |                     |
| m.facebook (Facebook app)   | 735 (15.38%)        |
| Facebook  | 1392 (29.13%)       |
| Twitter   | 1,307 (27.35%)      |
| Local renal hospital  | 107 (2.24%)         |

## Chapter Summary

The GMKIN project was developed with the involvement of HKPA, in a move to maximise patient reach by creating a local social and informational resource. The creation of the GMKIN Platform, GMKIN Facebook and Twitter provided a study site which enabled the researcher to examine the impact of social media tools in a context. The underpinning theory suggested that information provision would be influenced by members who engage in the process of PGI and maintain communication with others with a similar condition (Adams, 2011; Kata, 2012). By creating a research environment that resembled the typical settings in which a social media intervention was delivered could overcome some of the issues of other experimental studies (Coulter & Ellins, 2006).

GMKIN development followed the principles of UCD to meet the usability needs of patients. The resource inherited elements from existing online resources, and was developed based on evidence drawn from the scoping and realist review presented in previous chapters. More specifically it focused on how to create an informational platform that was aesthetically designed and interactive (O'Brien & Toms, 2008), addressing the information needs of renal patients (Ormandy, 2008). The social community development was equally as important to create a sustainable project based on patients' long term interaction. Meeting patients, explaining about the project, connection with medical staff, training those with no technical skills helped promote GMKIN and increase bonds amongst patients with a similar long term condition.

GMKIN was designed to enable the engagement of CKD patients, carers and healthcare professionals to network, communicate and generate health information, with the aim to



measure if such activity increases a person's self-efficacy. It was considered important to present the way the platform operated and was designed prior to the evaluation methodology introduced to measure impact, described in the next chapter.

## CHAPTER 5: REALIST EVALUATION METHODS

### Introduction

Explicit from the first chapter of the Thesis was that the method and research approach for the study was a comprehensive Realist Synthesis. The initial chapters scoped current theoretical propositions and research evidence which relate to how patients with a long term condition use social media to engage in the process of information seeking and gathering information from others to self-manage their condition. This provided a deeper understanding of the study context; the various forms of social media and their use in healthcare; the factors that are perceived to facilitate patient engagement with social technologies to find information; and the theoretical constructs that underpin the developing synthesis, that are to be tested.

This chapter takes forward step 5 of the Realist synthesis (Chapter 1, Table 2) presenting the methods of the realist evaluation to test theories and examine evidence surrounding the topic. The realist review as well as exposing overarching and middle range theories provided a critique of what methods have been used, and identified the best approach to measure and report the relationship of the CMO's relevant to core topic constructs: information provision, engagement, self-efficacy and self-management.

The decision of which method to employ was influenced by the philosophical belief, thoughts and experiences of the researcher as well as the research question. The study idea was generated from previous work undertaken to engage a patient population and the role played by social media outlined in Chapter 1. The fundamental driver was the passion to provide different communication channels to patients to enable them to choose the most suitable mechanism to find information, social support and share existing experience to improve their quality of life.

### Study aim and objectives

The study responds to the questions: ***What social media mechanisms increase information provision, networking and communication for patients, how and in what context?***

The primary aim of the study was to adopt social media to provide health information to patients with a chronic illness and measure whether it had an impact on a patient's self-efficacy and illness self-management. A secondary aim is to understand the challenges of

adopting and managing social media tools, the influence of healthcare professionals and other factors in engaging with patients via this medium and establish a series of management guidelines.

**Objectives:**

- Develop a Social Media Hub (GMKIN) that provides patient specific information and opportunities for CKD patients to communicate to each other and share their experiences.
- Train and educate patients and health professionals in the effective use of deploying and using Web 2.0 tools within the Social Media Hub.
- Explore and examine the engagement of CKD patients using GMKIN to better understand the process of engagement with social media and influential factors.
- Explore and examine the information generation practice of renal patients using GMKIN to better understand the impact social media on information need, self-efficacy and illness management.
- Add to the theory of patient information need, patient engagement and use of social media in health to inform practice and develop mechanisms that optimise the use of social media in healthcare settings.

**The Rationale of Realist Evaluation**

This project aimed to analyse the impact of social media and the changes attributed to GMKIN. In recent years the debate on various issues associated with impact evaluation have increased, namely around its definition; the counterfactual aspects (observed vs expected results) attributing changes to outcomes and application to controlled groups without being necessary (White, 2010). There are two main approaches adopted by researchers to define impact, one refers to the long term effects of an intervention and the second is concerned with *'the difference in the indicator of interest... with the intervention and without the intervention'* (White, 2010: p154). Amongst the first approach impact is defined as *'positive and negative, primary and secondary long-term effects produced by a development intervention, directly or indirectly, intended or unintended'* (OECD-DAC Glossary, 2002). Although this definition is mainly concerned with long-term effects, it was anticipated that the evaluation would present effects along the way (Department for International Development, DfID, 2012).

The designs employed with impact evaluation are experimental (randomised controlled trial), statistical (including statistical modelling), theory-based (realist evaluation, theory of change), case-based (ethnography), participatory (action research) and synthesis studies (realist synthesis) (DfID, 2012). Baker (2000) explains the difference between design methods adopted within research studies (Table 16).

*Table 16: Impact designs (adapted from Baker, 2000: p2-14)*

|  | Benefits  | Practical issues  |
|--|---|---|
| Experimental design (randomisation)                                  | Robust evaluation method; minimal bias, simplicity of results, determining the impact on outcome  | Difficult to identify hidden characteristics of participants that triggered the effect; difficult to ensure that inclusion of patients is totally random; expensive, time consuming |
| Quasi-experimental design (matching methods or constructed controls) | Draws on existing data sources; low cost and can be performed after program implementation  | Reliability due to less robust methodology; selection bias; statistical complexity  |
| Qualitative methods  | Focus on the process, behaviour and conditions perceived by individuals or groups; flexible approached tailored to the evaluation project; holistic understanding of people's perceptions | Subjectivity; lack of statistical robustness; validity is determined by evaluators' skills  |
| Mixed methods studies  | Enhanced validity using triangulation   | Increased acceptance for both methods to enhance reliability  |
| Theory based evaluation  | Early evidence of intervention effectiveness; understand 'how' and 'why' programmes are effective   | Difficult to identify the theories; difficult to measure each step of the intervention; difficult to test if the assumptions are not clearly defined; not easy to generalise        |

The whole study encompasses the realist synthesis approach, in which realist evaluation is an integral component. Pawson and Tilley (2004) encapsulate the essence of realist evaluation, positioning the approach within the family of theory driven evaluation (Pawson & Tilley 2004). The theory based approach encompasses two main types of evaluation, causal process designs (theory of change) and causal mechanism designs (realist evaluation) (DfID, 2012). The theory of change is a model that highlights how change is believed to occur by finding the links in the causal chain, for example the programme logic model which maps resources, activities, outputs and outcomes, identify intended results (Knowlton & Phillips, 2009). In the realist evaluation the context is the key to pinpointing the circumstances in which, and why, a particular program works (Pawson & Tilley, 1997).

Recognising that people are not just passive receptors of an intervention that improves their wellbeing and social standing, but the context in which they find themselves is pivotal in the study (Blamey & Mackenzie, 2007).

The design of realist evaluation relies on traditional research designs underpinning other areas of scientific designs, based on Wallace's (1971) wheel of science: theories, hypothesis, observations and empirical generalisation (Pawson & Tilley, 1997). The starting point is the formulation of middle range theories to identify and justify the regularities of a programme (Pawson & Tilley, 1997). Middle-range theories are focused on delimited aspects of social phenomena involving abstractions generated from observed data that enable empirical testing (Merton, 1949). Or in Pawson's view, they are '*propositions about how mechanisms are fired in contexts to produce outcomes*' (Pawson & Tilley, 1997: p85). The propositions are generated from existing research or knowledge of stakeholders involved in the project to focus the data collection analysis (Pawson & Tilley, 1997). The collected data contributes to refining the theories generated which does not lead to a final process, but instead a new phase of the evaluation process (Goicolea et al., 2013).

The hypotheses are generated from breaking down the programme and analysing what triggers change, who are the individuals benefiting from changes and which social and cultural resources are required to maintain the changes. More precisely, hypotheses originate from theories outlining when and where regularities should be found, which in turn are tested through various observations in order to inform generalisations. The generalisations may not necessarily support the theories, which suggest that the theory requires revision or there is a critical weakness in existing research (Pawson & Tilley, 1997; Pawson, 2005).

Distinctive to realist methodologies is the understanding of the CMO of theories (Pawson & Tilley, 1997; Pawson, 2005). A key element to realist evaluation is mechanisms which are the logic of interventions, the behaviour and relationships of interventions responsible for change (Pawson & Tilley, 1997; Pawson & Tilley, 2004; Pawson, 2006). The power of mechanisms is that connecting of the gap between theory and implications for practical recommendations (Goicolea, 2012).

The majority of realist evaluation studies in health adopt both qualitative and quantitative methods and case study design (Marchal et al., 2010). The choice of methods employed is pluralist including qualitative and quantitative methods, strategies, timescales,

viewpoints, cross-sectional or longitudinal with a large or small sample, and underpinning causal analysis (Miles & Huberman, 1994; Pawson & Tilley, 1997). The most important characteristic is that methods are tailored and appropriate to examine the research hypotheses (Pawson & Tilley, 1997).

Realist evaluations have numerous advantages in research, often being used in complex settings, generating study cases that analyse how interventions work and under what conditions. They provide evidence on why changes occur and under what circumstances (Carlsson, 2003; Keller et al., 2010); enabling policy makers to determine if the interventions can be applied elsewhere (Pawson & Tilley 1997; Marchal et al., 2010). Realist evaluation offers greater attention to understanding implementation (Sridharan & Nakaima, 2010) identifying outcome patterns to improve the intervention and the theory (Pawson & Tilley, 1997). However, drawbacks include difficulties in identifying theories, difficulties measuring each step of the intervention, testing the assumptions which may not be clearly defined, and not being able generalise findings (Baker, 2000).

### **The research methods used in Realist evaluation**

Realist evaluation does not impose a strict method of data collection or design, the choice is steered by the types of data required to test the theories, valuing a mixed methods approach (Pawson & Tilley, 2004). The methods researchers choose to employ are intended to collect data related to the social world; the two main conceptualised paradigms are qualitative and quantitative (Kuhn, 1970), although mixed method research is becoming more popular, combining the two techniques (Tashakkori & Tedllie, 2003; Creswell, 2006).

Qualitative research encompasses more than 20 genres varying from established methods such as ethnography, grounded theory, phenomenology, case study and content analysis to more reformists such as poetic enquiry, narrative enquiry, ethnodrama, autoethnography and duoethnography (Saldana, 2009). The focus of this method is on the quality rather than quantity of data (Bazeley, 2013), generating data from open-ended information, observing of respondents, or collecting other types of resources or artefacts (Creswell, 2006). In contrast, quantitative research is concerned with variables causal relationships between variables, not necessarily processes, producing closed-ended data to test a hypothesis or respond to a research question (Denzin & Lincoln, 2000; Creswell, 2006).

The controversies of qualitative and quantitative research are related to their paradigms. Quantitative methods have been extensively used in the 20<sup>th</sup> century adopting a positivist view whereas qualitative studies emerged in the last two decades in a movement to promote a more subjective and culture based approach in studying and understanding individuals (Tashakkori & Tedllie, 2003). Each approach is associated with particular types of data collection methods. The intention of this study is to evaluate the impact of social media engagement on satisfaction of information provision and self-efficacy therefore the advantages and disadvantages research methods related to these aspects are discussed.

### ***Qualitative data collection methods***

The section explores the use of interviews, diaries, focus groups and explores the ethical issues related to the use of such methods.

#### *Interviews*

Interviews are useful to gather information over a period of time, enabling the researcher to focus the discussion on specific aspects, and understand individuals or group perceptions in a specific context (Denzin & Lincoln, 2000; Brikci & Green, 2007; Creswell, 2014). The use of interviews are often geared towards understanding the how and what's of people's lives (Denzin & Lincoln, 2000), their opinions, beliefs, and attitudes in an attempt to discover decisions (Arksey & Knight, 1999). They provide an appropriate method to study people's context and their beliefs of how change occurs (Milles et al., 2014), crucial within a realist evaluation.

However, interviews are not without limitation, as information is often collected not in the natural setting of the participant, reported only through their individual perspective, which is likely to be biased or influenced because of the researcher presence (Creswell, 2014). Interview techniques vary from telephone to face to face interviews, taking forms such as unstructured, structured and semi-structured (Denzin & Lincoln, 2000). The validity of this method relies with the interviewer's ability to elicit information that reflects respondents opinion without influencing the discussion with preconceived ideas and own view though leading questions (Newton, 2010). Research acknowledges that peoples' responses are tailored to how they perceive the investigator (Newton, 2010; Creswell, 2014).

From the studies reviewed throughout the realist synthesis (steps 1-4) interviews have been commonly used as a qualitative method across healthcare settings to investigate

information needs of patients (Leydon et al., 2000; Caress et al., 2002; McCaughan & McKenna, 2006; Beaver et al., 2006; Ormandy, 2008; Astin, 2008; Halkett et al., 2010; Borgsteede, 2011). Unlike studying information needs, the interviews appear less common (or part of a mixed methods) when studying social media (Alvarez-Jimenez et al., 2013; Bender et al., 2013; Stepney, 2014). In the field of social media studied in long term conditions, there is a clear lack of the use of interviews, often the qualitative arm uses thematic content analysis retrieved from posts (Table 10).

Interviews often involve semi-structured or a more unstructured (in depth) approach, although the use of in-depth interviews are less common, used predominantly in topic areas which require detailed examination (Borgsteede, 2011). Halkett et al. (2010) opted for a more open approach to enable patients the complete freedom to direct the topics, express concerns, discuss issues that mattered to them and respond to probing questions. In both disciplines, health and social media, a semi-structured approach is preferred to structured or unstructured. Questions are used by researchers to influence the interviews with patients to enable the collection of specific information related to different outcomes of the study, with the freedom to detract as necessary to include topics considered pertinent to the participant (Beaver et al., 2006; Astin, 2008; Ormandy, 2008).

Important practical issues must be considered if selecting interviews as a data collection tool. Often people prefer interviews to take place in their homes to encourage free a naturalistic discussion, and whilst in the home the role of carers must be considered (Astin, 2008; Halkett et al., 2010). Combined interviews with carers, has been shown to inform both the interview and provide richer information to the research (Halkett et al., 2010). Consistency across data collection in different interviews needs to be considered, not just the discussion of similar topics as appropriate but in terms of length of interaction and speed of interviews (Loosveldt & Beullens, 2013). Ormandy (2008) recognised time an important factor in capturing patients experience at a specific point of time given that the renal disease is of a progressive nature.

Semi-structured interviews have been used to collect reliable and comparable qualitative data, often following observation and informal interviewing or discussion with participants to gather data on the topic to develop meaningful semi-structured questions (Cohen & Crabtree, 2006). It seems a pertinent method to consider in a context in which a call for flexible qualitative methodologies is needed to understand the concept of engagement beyond quantitative linear causal models (Gambetti & Graffigna, 2010). In addition a need for more rigorous studies on the impact of social media is necessary to strengthen the



evidence in this domain, potentially using descriptive statistical analysis or statistical correlations coupled with thematic content analysis (Merolli et al., 2013).

### *Diaries*

Diaries can be used as a data collection method for research (Bryman, 2004), where the diary is a '*research tool that requires respondents to make regular records of their daily lives and experiences*' (Wiseman et al. 2005:p394), which are close to the date that the events occurred to avoid the issue of recalling (Alaszewski, 2006).

With the current technological advances, apart from paper diaries, new ways of capturing self-reported data have arisen, including telephone diaries, audio recorded diaries, online diaries (e-diaries), and blogs/mobile diaries. Blogs among other type of content identified as data (links, videos, photos), include '*narrative text in diary form*' (Keim-Malpass et al., 2014: p1689), whilst mobile e-diaries involve completion of diaries using smart phones (Hensel et al., 2012). The key issue with the use of diaries is patient noncompliance with the tool, invalidating the benefits of capturing high quality data. Paper diaries have been found to be more prone to failure compared to e-diaries, identified as a more effective mechanism to collect diary information (Stone et al., 2003; Jacob, 2012). However, Green et al. (2006) found no difference among the two methods, but warned that researchers should not rely on this method as the only source of data collection.

Space and time are important factors captured in diary data, enabling the study of human activities over a designated span of time. The observation of activity over a period of time is of particular interest to this study to monitor the frequency of visits to GMKIN and impact without relying only on retrospective data (Elliot, 1997). Indeed in the past, self-administered diaries have been employed in the field of communication technologies, such as the Internet, to examine both social and/or spatial issues, and capture data use of SNS (Crosbie, 2006; Oh et al., 2014). However, the use of diary in capturing evidence of impact of social media in long term conditions is limited, only one study used essay writing to record and capture comments, opinions and users' experiences of the web (Nordfeldt et al., 2012).

### *Focus groups*

Focus groups rely on group interaction, unlike interviews, in an attempt to collect people's views, knowledge and experience (Kitzinger, 1995), listening and learning from them (Denzin & Lincoln, 2000). The method is appropriate for research that uses open ended

questions to engage patients in discussions that outline issues important to them and use different communication forms more appropriate to reality revealing dimensions of understanding that often remain untapped by other methods (Kitzinger, 1995). In addition, it minimises the influence of researcher on participants (Denzin & Lincoln, 2000).

This method is popular in outcome evaluation studies (Leung & Savithiri, 2009). Applebaum et al. (2013) within a social media intervention on long term conditions used four semi-structured focus groups (each lasting 90 minutes) as part of a mixed methodology approach in an attempt to generate ideas of tools that are useful in health transition periods. In a health care context, focus groups have been found to be an efficient method for examining health education messages and understanding health behaviours (Khan & Manderson, 1992; Ritchie et al., 1994; Duke et al., 1994; Light & Ormandy, 2013).

Disadvantages of this method include issues with group dynamics; some members may be more vociferous silencing quieter individuals and hence the data collected becomes biased to one or two perspectives. The moderator needs the key skills to ensure fair representation of each member and time management skills; enhanced skills are needed to manage and analyse a high volume of data (Leung, 2009). A unique issue associated with focus groups is that all members of the group are able to hear what each participant tells the researcher, which can stimulate deeper discussion (Morgan, 1998). However the this lack of anonymity could create a significant issue for the purpose of this study, where members of the research who are also active bloggers or posters are encouraged to share their perceived beliefs about other's activity in their presence, inhibiting data collection.

### ***Quantitative measures of self-efficacy***

#### *Self-efficacy scales*

The focus of this study, apart from information need and engagement, is on patient self-efficacy after interacting with social media tools and a variety of different scales exist and have been used to measure such a concept (Sherer et al., 1982; Schwarzer & Jerusalem, 1995; Chen et al., 2001). A scale is considered reliable when it produces constant and similar results on various research studies; it is stable if the resulted scores are the same on repeated trials with the same respondents; it is valid if the scale measures same factor (Chen et al., 2001). The General Self Efficacy (GSE) was devised to measure the perception of individuals of their aptitude to perform in different situations (Judge et al.,

1998). However, measuring self-efficacy was raised as a concern amongst researchers, with issues associated with the reliability of the findings the GSE produced (Chen et al., 2001; Scherbaum et al., 2006). The critique focused on construct validity arguing that the scale was measuring self-esteem and did not predict behaviour change (Scherbaum et al., 2006). To address this issue researchers began to develop different scales to measure self-efficacy, amongst them the General Self-Efficacy Scale (Sherer et al., 1982), the General Perceived Self-Efficacy Scale (Schwarzer & Jerusalem, 1995), and the New General Self-Efficacy Scale (Chen et al., 2001).

The General Self-Efficacy Scale developed by Sherer et al. (1982) was amongst the first scales to be developed; it contained a 17-item scale and has been cited by over 200 published studies (Chen et al., 2001; Imam, 2007). The scale reliability and validity is considered moderate to high (Chen et al., 2001). There is contradictory evidence on the factor structure, initially Sherer et al. (1982) reported single factor solution, however further researchers acknowledged that the scale collects multidisciplinary data and law content, but the content is difficult to analyse (Chen et al., 2001; Imam, 2007).

The General Perceived Self-Efficacy Scale devised by Schwarzer and Jerusalem (1995) was initially written in German, then later translated into 28 different languages and used mainly outside the United States (Scherbaum et al., 2006). The scale developed contains 10 items rated on a 4-point scale and reflects optimistic self-belief (Schwarzer & Jerusalem, 1995). Amongst those using the scale there is consensus that an individual is able to perform difficult tasks or cope with difficult aspects of life in various living aspects, including perceived self-efficacy, goal-setting, effort needed, perseverance to overcome barriers and recovery from obstacles encountered (Schwarzer & Jerusalem, 1995; Luszczynska et al., 2005; Shaw, 2008). The internal validation (minimisation of internal errors) of the scale varying from .75 to .91 and from .47 to .75 in longitudinal research outlines its reliability in measuring only one factor (self-efficacy) (Scherbaum et al., 2006). After examining the scale in 28 countries it was reported that it has high reliability, stability, and construct validity (Schwarzer & Born, 1997; Scherbaum et al., 2006; Luszczynska et al., 2005; Juarez & Contreras, 2008). The scale was used to measure the perceived self-efficacy of adolescents with chronic conditions and their parents, with two studies reporting valid scores (Luszczynska et al., 2005; Cramm et al., 2013).

The more recent General Self-Efficacy Scale (Chen et al., 2001) reports on eight items and was initially developed based on a scale by Chen & Gully (1997). The scoring system used the Likert-scale, from strongly disagree (1) to strongly agree (5). The scale is

reported as unidimensional (Gully & Eden, 2001), having positive psychometric results (Scherbaum, Cohen-Charash & Kern, 2006). The initial results indicate stability factors from .62 to .65 (Chen et al., 2001; Chen et al., 2004).

Out of all the General Self-Efficacy scales the Schwarzer & Jerusalem (1995) scale has over time demonstrated the highest reliability, measuring one factor and has been tested around the world (Schwarzer & Born, 1997; Scherbaum et al., 2006; Luszczynska et al., 2005; Juarez & Contreras, 2008). The scale measures the perceptions of individuals in performing task across a wide domain, and is reliable in measuring self-beliefs of patients coping with a variety of life issues, used extensively, and appears to be the best choice for this study. However, to measure a specific health-related self-efficacy (such as chronic disease) specific tools have been designed to identify particular behaviours.

#### *Self-efficacy in managing chronic disease*

The field of chronic disease is advancing in terms of medical care but there is limited support to help patients cope with the condition and comply with treatment over a period of time (Lorig et al., 2001; Chan & Dicianno, 2011). The measurement of self-efficacy has been acknowledged as an important factor in chronic disease management to help planning and evaluation of educational programmes, identify differences amongst patients and examine health outcomes and patient quality of life (Frei et al., 2009). Lorig et al. (2001) Self-Efficacy for Managing Chronic Disease 6-Item Scale (CSE) covers health domains common amongst chronic disease, symptom control, role function, emotional functioning and communicating with health care professionals. The scale has been shown to be effective in measuring patient self-efficacy; the instrument (internal consistency Cronbach  $\alpha$ =.91) provides six statements and asks patients to rate on a scale of 1-10 (1=not confident and 10=totally confident) their level of confidence in doing certain activities, the higher the number indicates higher self-efficacy. Its reliability was strengthened by verifying results when tested with 605 chronic disease participants (Lorig et al., 2001; Fogarty, 2007).

A review of self-efficacy scales (Sherer et al., 1982; Schwarzer & Jerusalem, 1995; Chen et al., 2001) highlighted that a high number focused on disease and task-specific aspects of self-efficacy; and exposed serious methodological limitations within the development and validation process of the instruments (Frei et al., 2009). These included a lack of clarity in the definition of self-efficacy (Frei et al., 2009) and a limited focus on communication, making it difficult to assess the patient's capacity to reason and act upon health information received (Clayman et al., 2010).

The Ask, Understand, Remember Assessment (AURA) was developed to respond to previous issues of communication posed by self-efficacy instruments (Frei et al., 2009). The assessment was developed to measure how effective is the process of communication amongst patients and healthcare professionals. The measurement tool is simple focusing on patient's perceived self-efficacy to gain, understand and remember health information received from the healthcare team; and it can be applicable to patients with or without a self-efficacy issue. The scale however, has only been tested with hypertension patients, therefore it may not be reliable in other patient cohorts, so further psychometric test are required to outline the tool performance and clinical outcome correlations (Clayman et al., 2010).

### ***Mixed methods***

Mixed method research has been used to solve practical issues (Tashakkori & Teddlie, 2003) and is suitable for realist evaluation (Pawson & Tilly, 1997; Pawson & Tilly, 2004). In the midst of paradigm wars, the mixed methodology enables researchers to match study aims with the most appropriate method, triangulate data for stronger results, compare qualitative and quantitative methods, and advance the use of qualitative data to develop a tested theory and supplemental data sets (Migiro & Magangi, 2011). Triangulation is the process of checking and merging the results from both methods, either in '*parallel*' (cross-checking) or '*sequential*' (integration) of data (DfID, 2012: p32).

The key factors that influenced the spread and uptake of mixed methods research were mainly to move '*beyond simple numbers in a quantitative sense or words in a qualitative sense*' and an acknowledgment that '*qualitative data can play an important role in quantitative research*' and vice versa (Creswell, 2006: p13). However this type of method is not without limitations, including the researcher's ability and experience to successfully mix both approaches, the interpretation of contradictory results and the time it takes cannot be underestimated (Driscoll, 2007; Migiro & Magangi, 2011).

Amongst the studies identified in relation to information needs or the use of social media in healthcare, adoption of a mixed methodology sought to provide multiple forms of data from qualitative and quantitative research (Creswell, 2014). For example survey combined with focus groups assessing the role of social media in health transition process (Applebaum et al., 2013); the log analysis complemented by MDS (multidimensional scaling) analysis (Zhang & Zhao, 2013); questionnaire and interviews (Ormandy & Hulme, 2013; Bender et al., 2013), semi-structured interviews and ethnography (Stepney, 2014).

Each combined or mixed approach gathering data for comparable and unique aspects of the research.

### **Choice of methods**

The review of methods identified that multiple approaches exist to measure the engagement of patients using social media in the process of information need and changes in self-efficacy. With this in mind it was clear that to answer the research question posed a mixed methods approach combining quantitative and qualitative methods was required and most appropriate. This would combine the strengths of different data collection methods (Migiro & Magangi, 2011) to explore the use of social media tools by patients in a context and understand the causality links between social media, engagement, information need and self-efficacy. Self-efficacy measured using a specific and recognised scale, similarly engagement and information need, could adopt previously tested qualitative techniques, interviews and diaries (or blogs).

The scales used were General Perceived Self-Efficacy Scale (Schwarzer & Jerusalem, 1995) and Self-Efficacy for Managing Chronic Disease 6-Item Scale (Lorig et al., 2001). The General Perceived Self-Efficacy Scale was selected to provide in-depth evidence on how patients with a chronic disease self-manage their illness to help evaluate the current format of the project and identify health outcomes specific to chronic disease. Combined with the Self-Efficacy for Managing Chronic Disease 6-Item Scale (Lorig et al., 2001) it would provide reliable evidence on how patients with a chronic disease control symptoms, emotional and communications functions. The scale despite having methodological limitations was a recognised and validated tool compared to others (Frei et al., 2009).

Qualitative methods focus on capturing '*naturally occurring, ordinary in natural settings*' revealing rich descriptions of '*real life*' (Miles et al., 2013: p11). An interview would enable the researcher to study patients in their context and collect thoughts, behaviours and feelings reconstructed from real-life experience of patient engagement (Ormandy, 2008; O'Brien & Toms, 2008). This approach would help to demystify the complexity of patients' perceptions and inter-relationships (Astin, 2008), measuring causation in particular settings (Miles et al., 2013). On-line diaries or blogs, despite known drawbacks, could be used in this study could be used to capture activity and patients' experience of using GMKIN resources across space and time (Chen et al., 2011). Indeed the advantage of using both a diary and interview is to explore the use of social media to engage patients in the process of information provision; and gain a deeper understanding of patients'

engagement with the technology and the mechanisms and influential contextual factors. Whilst the information obtained from interviews may not necessarily mirror real life events due to patients' bias or partial recall of a particular situation (Newton, 2010; Creswell, 2014), the diary could capture events/thoughts about the purpose of engagement and what triggered the process when it happens more effectively than a questionnaire or surveys (Hepworth & Harrison, 2004). As a precaution to mitigate against the inherent problems with diary non-completion the observation, log and reporting of online user activity could also be used to aid recollection or stimulate interview discussion.

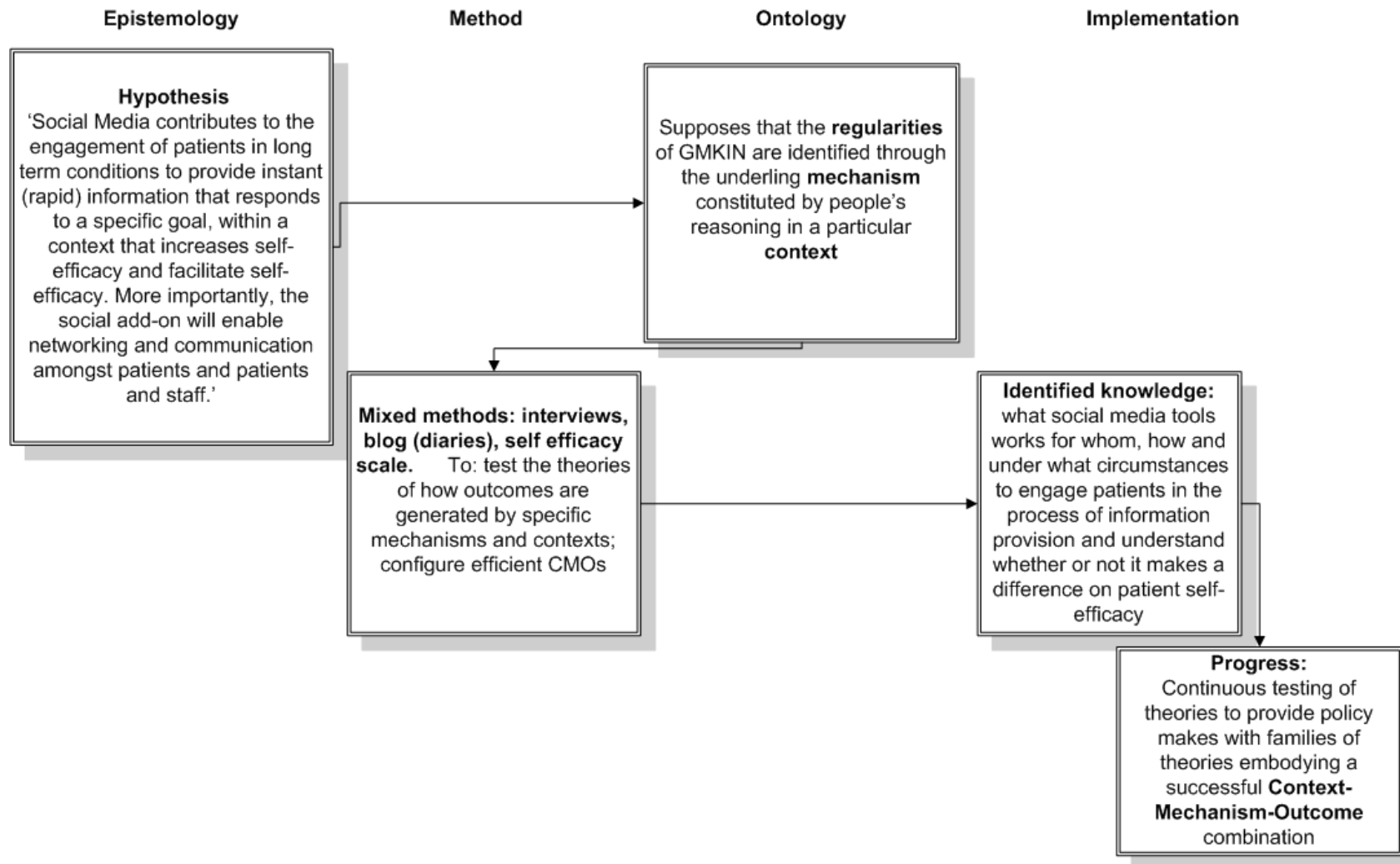
### **Realist Evaluation**

The Realist Synthesis draws together different components: exploration, description, explanation and evaluation. Exploration, description and explanation design have been adopted to understand causal links amongst factors with the aim to collect research data on patients' activity and to identify mechanism of maximising their engagement. Combining these different components and designs clarified existing concepts, identified assumptions, and offered explanations responding to questions of 'who', 'what', 'when', 'where', 'how', and 'why'.

This section takes forward the realist evaluation of the synthesis strategy, to test explain and explore the 'how' and 'why' of the propositions developed from the scoping chapter and realist review.

The realist foundations of this study are based on the assumptions that patients use different social media tools (such as SNS, OC, bespoke blogs) for different communication purposes, and the tools adopted depends on patient context and need. The research focus lies on social media engagement to satisfy an information need and increase self-efficacy. The directional flow of realist methodology outlines the importance of the methodology as a principal source of generating evidence (Figure 7). The strength of realist evaluation relies on the perspicacity of explaining how the mechanisms works and the outcomes were caused (Pawson & Tilley, 2006). Studies use different approaches to test the CMO configurations, relying on both qualitative and quantitative designs (Kazi, 2003).

Figure 7: An overview of the realist evaluation strategy within the realist synthesis methodology





To achieve the objectives of this study a mixed method approach was adopted using exploratory, descriptive and analytical design which progressed in two distinct phases:

- Phase one: the development of the Social Media Hub - GMKIN, staff and patient training (described in detail in chapter 4);
- Phase two: the six steps of realist synthesis, including scoping of existing theory, realist review to examine current research evidence, generating theories to test (chapter 2-3), realist evaluation and identifying new theory and new knowledge. The realist evaluation used mixed methods (self-efficacy scale, interviews and blogs) to explore the impact of social media on patient engagement, information provision, networking and communication (the focus of this chapter).

The epistemological view of the study aims to steer away from positivisms and relativism instead to underpin the '*mechanics of explanation*' (Pawson & Tilley, 1997: p55) of how social media contributes to engagement of patients with long term condition and the generated outcomes. Ontologically, critical realism is '*the least restrictive perspective*' because is able to '*accommodate the insights of other metatheoretical perspectives*' (Bhaskar & Danermark, 2006: p294) (Figure 7). In this context, the study aim was to identify the regularities of what social media mechanisms increase information provision, networking and communication for patients, how, and in what context, testing theories using mixed method approach.

## **Phase Two: Realist Evaluation**

### ***Study Site - Social Media Hub***

The development of a platform (social media hub) was required to provide information to local patients, but publicly available for patients with a chronic kidney disease, to form the study site and environment for the realist evaluation. The site incorporated elements of patient focussed websites, including information provision and advice to patients, availability of information with or without having to be registered; and social media tools, such as blog, forum, page comments, interest groups and friendship.

Development of the hub was informed by a series of stakeholders including: the Patient Reference Group (involvement in developing an application that suits their needs, with relevant content) and the Multi-Professional Information Working Group (specialist content producers) as well as the experience of the researcher (a web developer). For the duration of the project, feedback collected from the patients involved in the study was

used by the researcher to ensure on-going technical and educational content development within the hub.

#### (1) Researcher (digital lead and evaluation)

The GMKIN Hub development and community management was undertaken by the researcher. The role of the digital lead was to work with stakeholders to develop the GMKIN Hub, training and moderation of the community in conjunction with Multi-Professional Information Working Group

#### (2) Patient Reference Group

A local group of renal patients and carers were brought together to influence the development of resources, design (look and feel) and guided by researcher to ensure that final product meets information needs of patient. They were identified via local kidney association Hope Kidney Patients Association (HKPA). A group of 10 local patients participated in an afternoon session to comment on the initial website prototype. Four patients, who experienced the illness for more than five years formed the expert patient group, who further influenced the development of GMKIN.

Social Media Hub site moderation was conducted by two members of the patient reference group, who underwent training by the main researcher, and included: how to use GMKIN, GMKIN use policy, how to protect identity and privacy. They volunteered their time (3.5 hours a week) and were supported by the wider Patient Reference Group.

#### (3) Multi-Professional Information Working Group

Health professionals were brought together as collaborators with the digital lead within a multi-professional information group, which initially met face-to-face on a study day arranged by the research group. Additional communication was maintained through emails, and offline meetings that continuously informed and contributed to the development of the hub.

#### *Social Media and Digital Training*

The site moderators, patient reference group, health care professionals and the patients were provided with ongoing support and training by the researcher (digital lead). A set of user guides with explanatory screenshots were accessible on the website (<http://gmkin.org.uk>). These were complemented by a contact form available on the

website to ask specific questions. Quick queries were also addressed through Facebook and Twitter direct messages.

### **Sample**

The aim of the study was to engage 20 patients to examine and observe the impact of social media on patient information provision, networking and communication. To include 10 patients who are regular users of a computer and 10 patients who did not currently have access to digital technology. This group of patients were provided with I pads to facilitate their participation in the project. All recruited patients were asked initially to engage with other patients and staff to use GMKIN resources to familiarise themselves with the site and the resources, but sustained engagement was not a compulsory requirement, to allow natural personal preferences for using social media to develop and be exposed.

#### *Patient inclusion criteria*

Patients were identified from one managed clinical renal network in the North of England, which encompassed CKD patients, across different treatment modalities, all over the age of 18 years (Table 17). For the purpose of this evaluation patients who could read and write English, were recruited.

*Table 17: Inclusion criteria*

- |  |
|--|
| <ul style="list-style-type: none"><li>• Aged over 18 years</li><li>• CKD patients (pre dialysis, haemodialysis, peritoneal dialysis, transplant)</li><li>• Patients recommended by a healthcare professional</li><li>• Patients who could provide written informed consent</li><li>• Patients who could read and write English</li></ul> |
|--|

Patients were excluded if they were too ill to engage with the technology. A theoretical sample was selected to explore differences in age, gender, stage of illness, modality of treatment, and level of technical knowledge, across the theories being tested. Theoretical sampling was used to provide a flexible method that enabled the researcher to test concepts, refine and adapt interview questions and seek out participants with different characteristics as the study progressed (Glaser & Strauss, 1967; Coyne, 1996).

Participants were to be recruited via the Kidney Patients Association member database of those people who had expressed an interest in being involved in the research. An information sheet and invitation letter was to be sent by the Kidney Patient Association

Chair, and those patients interested in being involved in the study would respond directly to the research team. A master database of patient names/contact details would be created and stored on a password protected computer accessed only by the research team.

### ***Evaluation Methods***

Three different research methods were selected to test the theories of the realist synthesis through the evaluation these included e-diaries, on-line questionnaires, and patient interviews.

- *Logs or patient Blog*

Research participants were asked initially to engage with the GMKIN platforms, namely the GMKIN website (blogging/commenting/forum and informational pages), the discussion group on Facebook (GM Kidney Information Network), and/or Twitter. The Facebook and Twitter were interlinked to GMKIN website. Their interaction with one or all of the tools stated above was to be captured on monthly blog or e-diary that described their experiences/activity. The blog was private and used in a similar way to diaries, but to ensure clarity research blogs were story blogs generated by patients, for the purpose of this thesis, blogs will be named as logs.

Initially the log was intended to be kept within GMKIN as a private blog. However during development more administrators were involved in the study to ensure transferability and continuity of the hub after completion of the research project. The increased number of administrators made collecting private data an issue, to overcome this, three solutions were offered to patients including: email on a minimum weekly basis, keep a log on Google Drive, Sky Drive, or suggested an alternative personal approach.

The e-diary or log was used as a basis for discussion at midpoint patient interviews capturing data on:

- Patients overall experience with GMKIN
- Details of technical issues encountered
- Social Media Tools used: Blog, Forum, Facebook, Twitter, commenting forms (what)
- Reason for using the tool and perceived benefits (why)
- Learning occurred (what)

- Time spent on the site
  - If no engagement occurred an explanation was requested. It was equally as important to observe patients not engaging with GMKIN with those who were, to better understand engagement theory.
- *On-line Questionnaires*

Self-efficacy, feelings of self-confidence and control, is a good predictor of motivation and behaviour and an individual's self-belief in their own capabilities to be able to influence events that affect their lives (Bandura, 1995). Two valid and reliable instruments were used as repeated longitudinal measures for patient self-efficacy and confidence measured at baseline and six months later: the General Perceived Self-Efficacy Scale (Schwarzer & Jerusalem, 1995) and Self-Efficacy for Managing Chronic Disease 6-Item Scale (Lorig et al., 2001) (Appendix 3 and 4). Both instruments took no longer than 5-10 minutes to complete. The baseline scales were administered online, repeated in paper at six months. The results generated were to be used during the interviews to elicit discussion on the difference GMKIN has made.

- *Interviews*

Each participant was invited to take part in two face to face interviews: baseline then repeated at six months. Each interview lasted no more than 2 hours 30 minutes, was digitally recorded and transcribed verbatim. Written consent was obtained prior to each interview (Appendix 5). Interviews were semi-structured based on a list of topics identified during the realist review of current evidence and scoping of theories. The engagement elements of the interview were drawn from O'Brien & Toms (2008) theory on engagement, whilst the satisfaction of information needs was adopted from Ormandy (2008) (Appendix 6).

The main aim of the baseline interview was to capture information on thoughts, behaviours and feelings about social media tools used or not, the need for information and social engagement. The second interview schedule was developed building on the recorded data on patients' online profile, activity and their log; and discussion surrounding factors that contributed to their level of engagement with GMKIN. Interviewing a patient after six months potential activity sought to understand what social media mechanism patients used, why and allowed time to observe and discuss outcomes.

- *Observation*

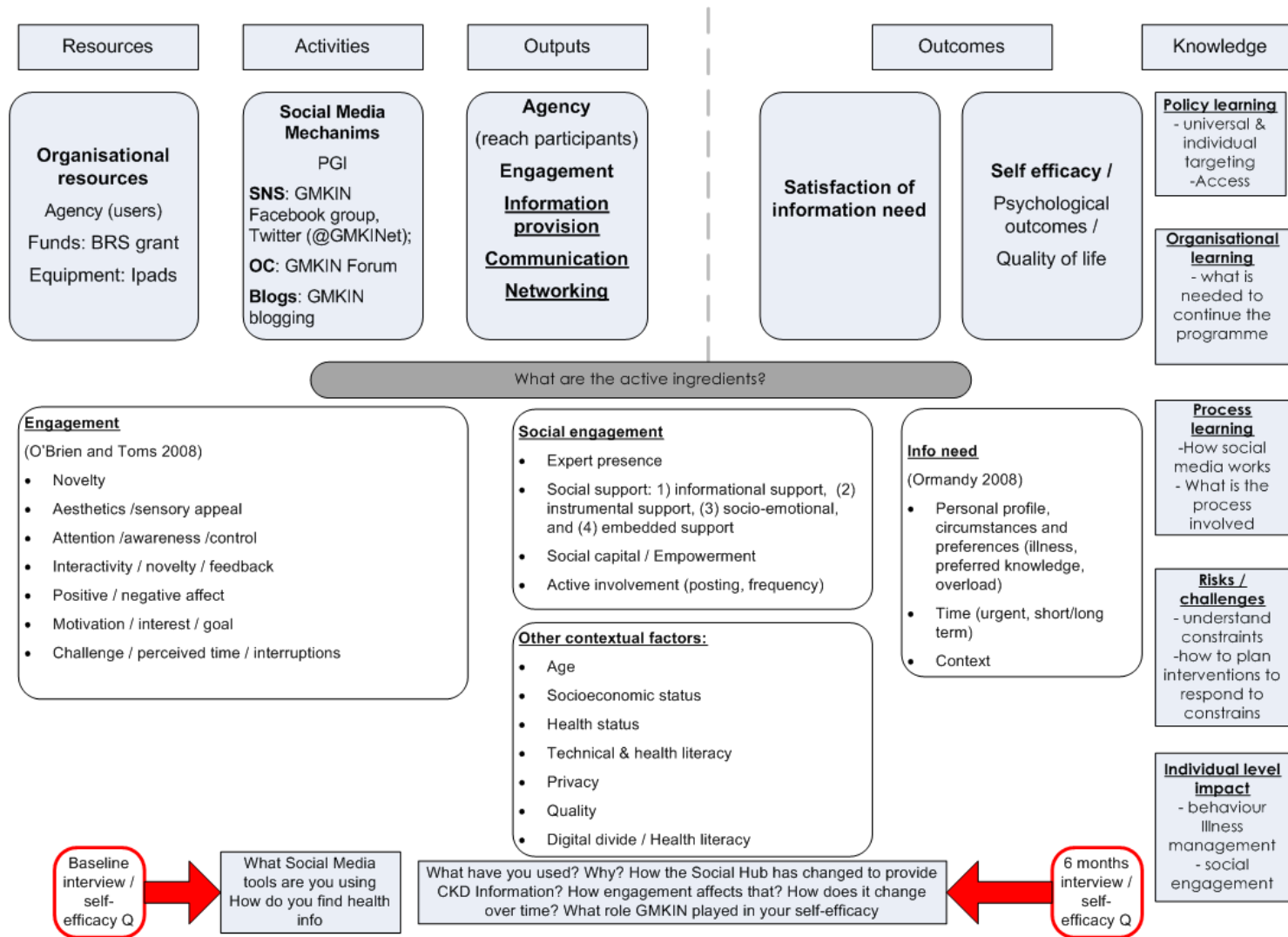
Throughout the study period the research participant's (and all users of GMKIN) were followed across all study mechanisms (Facebook, GMKIN platform and Twitter) to observe their online behaviour and track their search for information. Initially, the main purpose of the observation was to monitor patients' safety on the hub. Then it progressively developed into a more complex strategy capturing data on:

- Patients' activity on GMKIN – to support the non-completion of individual activity logs research participant activity was tracked by the researcher as the study progressed to capture both exploratory and descriptive data on user activity. In addition, this type of data provided a context for devising the second interview schedule and stimulated discussion to offer a deeper understanding and explanation of emergent engagement roles.
- Maximize engagement – continually observe the patient generated information and engagement patterns to introduce mechanisms (strategies e.g. posting a comment on blogs) to establish a sustainable online community

### ***Mapping the developing realist synthesis - The logic model***

Throughout the realist synthesis and in particular to evaluate the impact of GMKIN and map the CMO findings in a visual way the Logic Model was used. The logic model provided a comprehensive and clear visual picture of the intervention operations (Knowlton & Phillips, 2009) which created a working framework for implementing and managing a social media intervention using the right tools for different patients and outcomes (Figure 8). The key conceptual elements of the program logic model for the GMKIN intervention included Inputs (resources, activities), outputs and outcomes (Knowlton & Phillips, 2009). Resources were essential for GMKIN to occur and included initial funds to set up GMKIN, GMKIN partners (health professionals and expert patients), training (staff and patients training). Activities were actions resulting from setting up GMKIN, which included patient generated content in the form of blogs, forum, comments, Facebook community or Twitter. GMKIN outputs were participant involvement, technological skills, challenges associated with the intervention and information provision. The main outcomes of the study were engagement with patients, communication, networking, and ultimately an increased self-efficacy, each strand with specific CMO categories to respond to: what are the active components of the study and relationships, who does it work for, and why (Pawson & Tilley, 1997).

Figure 8: GMKIN program logic model, method and study outcome



## ***Ethical Considerations***

An application was processed at both the National Research Ethics Committee and University of Salford Ethics Committee and approval obtained, key ethical considerations included privacy and informed consent. The whole process of peer review enabled refinement of the recruitment process and addressing of possible concerns.

### *Issues associated with methods*

The ethical issues associated with qualitative methods are associated mainly with the role of the researcher. Establishing a rapport based on trust and respect with the respondent are valuable but ethically sensitive (Newton, 2010). Indeed a rapport with respondents contributes to more informed data, the risk is that of superimposing their view point on the topic researched narrating own conceptions (Denzin & Lincoln, 2000). Amongst other ethical dilemmas to be considered during qualitative research are those of harm to patients, privacy, confidentiality, anonymity, misuse of data, and quality of conclusions (Miles et al., 2013). Privacy and confidentiality is a high priority in the context of this study to protect unwanted patients identification (Denzin & Lincoln, 2000). Given that contextual patients' data is concerned with online activity (such as blogging, posting, commenting, available to other members of the group) there is a risk of patients being identified. To address these issues patients will receive a code (such as P1) to avoid any unnecessary connections with names from the growing Facebook group and activity. When patients refer to other patients within the group their name will be changed to protect confidentiality.

### *Privacy*

The Association of Internet Researchers (AoIR) have compiled ethical guidelines to highlight the tensions in negotiating online research, suggesting the most appropriate way of negotiate online ethical dilemmas is to apply practical judgment to the particular context. Ethical research in online environments remains flexible and open to the diversity of context and evolving technologies (Markham & Buchanan, 2012). The importance of contextual integrity indicating that *'what people care most about is not simply restricting the flow of information but ensuring that it flows appropriately'* (Nissenbaum, 2010: p2)

The rise of social media enables individuals to voluntarily place information online, changing the meaning of privacy, a frequent issue discussed in online research as the *'blurring of boundaries'* of privacy (Snee, 2013: p56). People nowadays establish how much information to disclose online including profile, geographical, photographs and other things (Beer &



Burrows, 2007). Privacy was considered from a technological and psychological perspective. Technically, data protected by password or shared within a private network is considered private. Psychological privacy is that of users' perceptions that accessible data is not necessarily public. Existing research indicates a lack of understanding of who can access existing online information and users may act as if the platforms used are private (Snee, 2013).

Privacy can be viewed conceptually as natural and normative (Wilkinson & Thelwall, 2011). Natural privacy refers to closed mediums where intrusion is accidental whereas normative privacy is expectancy that others are protective of the user involved in medium; the expectations being more like a retailer protecting banking details (Wilkinson & Thelwall, 2011). Based on that view, it is considered acceptable to use personal data from public mediums for research, as long as it is correctly reported, and that natural privacy has to be respected (Wilkinson & Thelwall, 2011). The GMKIN project involves a Facebook group, initially open to the public, later on closed to protect the confidentiality of sensitive topics shared. Data from other members of the wider community were used only to provide an overview of usage and data from the in-depth sample (consented for the research) correlated with other research data.

The recommendations from existing research indicate that careful consideration should be given to sensitive health topics, and that ethical responsibilities relies on both the researchers as well as the participants, who manage risks themselves (Markham & Buchanan, 2012; Stepney, 2014). Based on this view it was decided that the community would be moderated. In order to comply with ethical guidelines, the researcher drew on existing evidence and personal experience from being a moderator of online communities. Predominantly, hub moderation on a day to day basis was performed by the researcher, one patient and a healthcare professional; with wider members of the patient reference group a multi-professional moderation group being consulted on specific issues. Responsibility was given to already recognised bloggers, who can moderate the comments addressed to their blogpost.

User rights were implemented on different grounds of access. Access to information was regarded as 'open', with those who wanted to contribute or post having to register onto the platform. Research members were prompted on anonymity, use of nicknames and reminded not to divulge any personal information. During the registration of general members on the site, information about the research project, anonymity and confidentiality was provided and consent sought to use posts, feedback and public data for research purposes obtained.

Consideration was given to the signup process as previous involvement in online projects reinforced the need for a signup process requesting minimal information from patients.

The operating mechanisms of user access and privacy within GMKIN informed national research guidelines on use of social media in research, developed by INVOLVE (National Institute for Health Research, 2014).

### *Informed consent*

Informed consent was drawn from the principle that individuals involved in research have the right to participate or not (Snee, 2013). Each patient was recruited via email, newsletter via the GMKIN, and mobile phone after being referred to by a HKPA member. The patients' information sheet and invitation letter were sent to patients using email; those with no access (or mobile access) were recruited via face to face interaction during educational events held at Salford Royal Foundation Trust (Appendix 7 and 8). Prior to each interview and enrolment of the study each patient signed a consent form.

### *Minimising bias but acknowledging research involvement*

The researcher's role as a developer, trainer, and influencer of engagement had the potential to influence the results of the study. One of the continuous dilemmas throughout the research was to minimise researcher bias whilst developing the study site and being responsible for stimulating meaningful interactions among users of the site. The iterative approach involved a number of strategies, which particularly included continuous reflection on actions and discussion with supervisors, drawing on their expertise in research. The key strategies included:

- Observing participants using the GMKIN platform during training to understand how easy it was to use the technology, and introducing a forum on technological issues where people could anonymously or openly comment on any issues or experiences. The information captured in this arena resulted in a new version of GMKIN being deployed which incorporated and encouraged feedback from patients, removing the need for my direct involvement as the researcher to continually canvas user experience.
- I refrained from posting my views of social media throughout the duration of the realist evaluation to prevent influencing the views of the users, which was a challenge.

- The triangulation of data from different methods (interview, study logs, self-efficacy scales and observation of activity) enabled participants multiple opportunities to report issues or problems outside of the direct interview, if for any reason this environment prevented them from offering an accurate perspective. I observed where possible patients activity across platforms to gather information on their engagement and correlated with data from blogs, then used this information to set the agenda for the second interview, not biased by the researcher themes but tailored to each individuals to gain a deeper understanding of their activity and their perspectives during interviews.
- I was explicit from the outset with each patient that my research intention was to develop an understanding of the usefulness of these technologies and how patients could benefit from and acknowledged that activity and non-activity would be equally as important in terms of study, to minimise positive use of technology but encourage individual preferences to emerge within the user group.
- To minimise bias during data analysis a framework was developed and matrices derived from the themes from the literature and consistent data extraction was confirmed by independent researchers to ensure no bias was present, described in detail in the next section

## **Data Analysis**

The study employed a mixed methodology hence the need for different analysis strategies to formulate the CMO relationship amongst the concepts of social media, patient engagement, information provision, networking, communication, and the influence on self-efficacy.

### ***Quantitative data analysis***

Quantitative analysis typically includes both descriptive and inferential statistics. Descriptive statistics have been applied to the Self Efficacy scales presented using means, standard deviations, medians, percentages, and range. The General Self Efficacy Scale score is calculated as a mean of all scores (Schwarzer & Jerusalem, 1995). The score is calculated if no more than three results are omitted (Schwarzer & Jerusalem, 1995). The Self-Efficacy for Managing Chronic Disease 6-Item Scale is analysed by calculating the mean score over at of at least four of the six items; higher number indicates higher self-efficacy (Lorig et al., 2001; Hu et al., 2013).

However, the small exploratory sample of this study did not lend itself to inferential statistics therefore comparison was used to present data findings and individual self-

efficacy/confidence scores over time. Therefore the quantitative data was used as a barometer to engage patients in discussing the outcomes of the study, explored further with each patient within the in-depth interviews to understand influences of change on self-efficacy domains. Baseline data was compared with 6 months data on which patients were asked to reflect on for further validation, but also to understand the GMKIN influence on self-efficacy and raise discussion. The scores at baseline and follow up for each patient were compared to indicate any difference over time. Despite that the intention was not to statistically analyse the results it was decided to do a t-test to reveal if the two sets of data for each patient (baseline and follow up) were significantly different from each other to strengthen the evidence resulted from score as well as qualitative findings.

### ***Qualitative analysis***

In realist evaluation no analytical method is most suitable; therefore data analysis is performed in relation to the proposed theories (Pawson & Tilley, 2004). Qualitative data was analysed using a specific form of data analysis (Miles et al., 2013). Analysis was a technical process of constructing meaning from research data (Bazeley, 2013).

A matrix was initially developed from themes identified from the review of the literature, then refined during the interviews to include emerging themes. Interview and blog data were analysed using an analytical framework, to expose, describe and map conceptual findings (Miles & Huberman, 1994). Data was compared and contrasted across individual cases to explore contextual factors, mechanisms and patient outcomes. This approach facilitated analysis of data based on research theories (deductive) and data exploration and interpretation (inductive).

The matrix (framework) approach was considered a suitable analysis method for the purpose of this study which collects cross sectional descriptive data. It highlighted different aspects of the phenomena examined (Ritchie & Lewis, 2003), to draw meaningful themes from collected data whilst maintaining accuracy in on behalf of patient views (Braun & Clarke, 2006), and guided the novice researcher throughout the interconnected stages from initial management to development of descriptive accounts (Smith, 2011). As the analysis progressed the overarching themes were continuously refined, and further subthemes added (Ritchie & Lewis, 2003). Framework analysis is used more often in the thematic analysis of semi-structured interviews as well as adapted for other types of data generated from diaries, observations, documents.

To develop the matrix the following steps were taken: identification of overarching themes, (tested with patients at baseline, 6 months), baseline data, and six months data. The identification of key themes occurred by reviewing existing resources (Chapter 1, Table 2, Steps 1– 4). The overarching themes were extracted based on the study main concepts: social media, factors that inference engagement, social media tools used, information generation to satisfy an information need, outcomes (Table 18). During the first stage data was structured to relate to context, mechanism, and outcome. This reflexive approach influenced the interview, revealing discourse and shaping features (Speer, 2007) relating to social media engagement, information provision and self-efficacy.

*Table 18: Initial matrix analysis*

|                    | Overarching Themes  |
|--------------------|---|
| Contextual factors | Patient health profile (whom)   |
|                    | Patient online profile (whom)   |
|                    | Goals   |
| Mechanisms         | Patient activity  |
|                    | Engagement factors  |
|                    | Role of Ipad (for patients who received an Ipad)  |
|                    | Most used (favourite) Social media tool: Facebook, Twitter, blogs, commenting, forum (why?) |
|                    | Information generated   |
| Outcomes           | Satisfaction of information need  |
|                    | Self-efficacy   |
|                    | Patient perception of the difference GMKIN has made   |
|                    | Psychological benefits  |

### ***Combining analysis from different methods***

Baseline data generated was analyzed using a case and thematic analysis to expose, describe and map conceptual findings (Miles & Huberman, 1994). The focus on this analytical stage was to understand patients in the context of which they decided to use GMKIN and social mechanism (Pawson & Tilley, 1997). The contextual factors clarified were: goals, perceptions of social media concepts and use. The mechanisms were about *‘people’s choices and capacities’* (Pawson & Tilley, 1997: p66) in relation to information seeking and satisfaction of information need.

The six months data expanded on the baseline to understand the outcomes of using GMKIN, seeking to clarify the main questions of impact evaluation, focusing on the realist principles (of this study) (Table 19). Qualitative and quantitative analysis was combined mapping questions and overarching theories.

*Table 19: Mapping of questions and overarching theories (adapted from DfID, 2012: p37)*

| Questions identified  | Study   | Overarching theories  |
|---|---|---|
| To what extent can a specific (net) impact be attributed to the intervention?       | <i>What worked for whom and why</i>   | <i>Engagement with social media tools enhance networking and communication of health information to satisfy an information need</i> |
| Did the intervention make a difference? How has the intervention made a difference? | Seeking to find regularities (O) as a result of mechanisms (M) in a particular context (C). | <i>Engagement with social media tools and satisfaction of information need increases self-efficacy</i>                              |
| <i>Deeper understanding of the mechanism factors</i>                                | <i>Engagement</i>   |   |
| Will the intervention work elsewhere?   | <i>Recommendations</i>  |   |

The follow up data, provided a record of what patients have done (activities), their engagement (or not) with GMKIN and what influenced that, and resulted outcomes (Table 20). The initial matrix (Table 18) was updated to include sub-themes resulting from the qualitative enquiry. The data was disaggregated by using the overarching themes and sub-themes organized by case (patients), which then enabled to map CMOs patterns of data. This type analysis process sought to understand the context-mechanism-outcome (CMO) statements.

Data was analyzed in steps using taxonomies to capture hierarchical sets of data (Denzin & Lincoln, 2000) that occurred after patient interaction with GMKIN. Data from six participants (three with access and three with no access) that appeared to experience the most complex circumstances were used to develop an initial analysis matrix that was discussed with supervisors in order to test feasibility.

*Table 20: Mapping of analysis approach for tool, data and purpose*

| Data collection tool | Data included  | Purpose   |
|----------------------|--|---|
| Interview 0 months   | Patients characteristics, goals digital and IT use     | Used to understand the context of each patients entering the study      |
| Logs/blogs           | Weekly activity and impact                             | Understand levels of engagement and what works, why among the mechanism |
| Observation          | Complement weekly logs by collecting data on perceived | Create individual profile of monthly                                    |

|                                  |  |   |
|----------------------------------|--|---|
|                                  | interactions (blogs, comments, posts and Twitter activity). It followed: comments posts/views on Facebook, blogs and comments posted and profile updates on GMKIN, twitter activity (posting, favorite, and re-tweeting) | activity<br><br>Identify usage by mechanism   |
| Interview 6 months               | Very patients perceived perceptions on activity, behaviour and difference made by being engaged  | Gain knowledge on key themes explored: engagement; role of tools (mechanisms) used; satisfaction of information need and outcomes (self-efficacy) |
| Self-efficacy scale (0/6 months) | Self-efficacy scale  | Identify the difference made by being involved on GMKIN   |

## Chapter Summary

The mixed method evaluation approach for this study examines the realist phenomena of how social media engages patients in the process of producing and sharing health related information and the ultimate impact on self-efficacy (Figure 8). To explore the experiences of patients; how, whether and why social media tools works, and which one is more efficient to engage patients in the process of information provision, the most suitable method was semi-structured interviews repeated over time, supported by weekly e-diaries to record and log activity. Self-efficacy, to identify the impact of social media on health outcomes, was measured using the General Perceived Self-Efficacy Scale (Schwarzer & Jerusalem, 1995) and Self-Efficacy for Managing Chronic Disease 6-Item Scale (Lorig et al., 2001) both recognised and validated methodological tools. The data analysis method combined qualitative and quantitative data using a framework matrix to map outcomes and data findings to theories being tested. The findings of the study are presented in the next three chapters (6-8). These findings chapters bring together key themes: Engagement (chapter 6), Social Media Mechanisms (what works for whom and why) (chapter 7), and Positive and negative outcomes in real life (chapter 8).

## CHAPTER 6: TESTING ENGAGEMENT MECHANISMS

### Introduction

Fundamental to the thesis is identifying the phenomena of how social media engages patients with a long term condition in the process of generating and sharing health information, and the impact on their self-efficacy.

In this chapter the attention is turned to exploring the roles of patients and other agency users, the processes involved and the various factors that influence patient engagement with the intervention, through the presentation of the study findings. The key themes explored include:

- Characteristics of the sample
- Levels of engagement with GMKIN
- Process of engagement
- Emerging health engagement model

Engagement was identified as an overarching mechanism triggering change. The assumption is that a certain level of patient engagement was needed to activate successful outcomes; levels are explored in this chapter.

### Characteristics of the sample

It was initially intended to recruit patients from various ethnic backgrounds. Identification of the sample took an unexpected four months which influenced the decision (given the intention to follow patients over time) to include patients on a first come basis on who came forward. Participants were put forward or the study recommended by KPA patient representatives or other patients, and medical professionals from a local hospital.

### *Recruited patients*

- Baseline – An eligible sample of 18 patients agreed to be part in the in-depth observational study with GMKIN to examine the impact social media has on information provision, networking opportunities and sharing experiences on patient information need, self-efficacy and illness management. Among the 18 sample recruited, 8 were given an Ipad and 12 months paid internet connection to be able to access GMKIN.



- At an approximate 6 months interval – 14 patients continued with the study and agreed to complete the Self-efficacy scales and take part in a second interview.

Among the four patients (3 male, 1 female) who withdrew from the study, two never engaged (one of which received an Ipad), and two contributed to GMKIN but were unable to take part in the second interview or undertake the follow up self-efficacy measurement (Table 21). Receiving access via a device (Ipad), age or gender did not appear to influence a patient's decision towards using GMKIN.

*Table 21: Non follow-up patient characteristics*

|             |                                     | Ipad | Contributed to GMKIN | Did not contribute to GMKIN |
|-------------|-------------------------------------|------|----------------------|-----------------------------|
| Patient (A) | Male, dialysis / depression therapy | X    |                      | X                           |
| Patient (B) | Male, dialysis                      |      |                      | X                           |
| Patient (C) | Male, 68, dialysis                  |      | X                    |                             |
| Patient (D) | Female, 21, dialysis                |      | X                    |                             |

Patient (A) who received an Ipad met the researcher once more at an interval of approximately two months after the baseline interview to receive further training on the device. Patient (C) could not take part in the second part of the study because of illness.

***Patient context: characteristics of recruited sample***

Fourteen patients were interviewed twice at an interval of approximately six months. Patients were of different age groups, gender and stage of illness. During the interviews, patients made reference to unemployment hence that characteristic was included in the analysis of context. The sample spanned different ages, with a comparable number of male and female participants and included people at different stages of CKD, receiving different treatments, indeed a carer asked to take part and was also recruited (Table 22).

An important characteristic of realist evaluation is that of context. The context explored in this study is predominantly focused on patients, their age, illness, employment and how they progressed from baseline to follow up. At baseline, their use of social media and IT in general was collated to gain a deeper understanding of their progress and changes in their perception of the social media tools. The majority of patients used Facebook at baseline and remained active on using this tool at follow up. Two patients (P5, P13), who were originally users of Twitter have progressed towards being more active on Facebook.

Table 22: Characteristics of the sample

|                    | (N) |                                   | (N) |
|--------------------|-----|-----------------------------------|-----|
| <b>Gender</b> Male | 8   | <b>Ethnic group</b> White British | 13  |
| Female             | 6   | Pakistani                         | 1   |
| <b>Age</b> 18-30   | 4   | <b>Treatment Modality</b>         |     |
| 31-40              | 2   | Transplanted patient              | 3   |
| 41-50              | 2   | On dialysis                       | 5   |
| 51-60              | 3   | Pre-dialysis                      | 5   |
| 61+                | 3   | Carer                             | 1   |
| Employed           | 4   | Unemployed                        | 10  |

P7 and P11 progressed to opening an account on Twitter, but were not actively involved, with P11 using it occasionally. Patients' characteristics from baseline to six month follow up are summarised (Table 23). The changes from baseline to six months with respect to engagement with GMKIN will be discussed within the chapter themes.

### **Analysis of data**

This report includes data gathered from 14 patients, who agreed to take part in the second interview and completed the self-efficacy scales, with pseudonyms (P1 to P14) used ensure anonymity of data. The analysis framework employed to analyse the qualitative data was gradually updated as the study progressed to include the identified topics (Appendix 9). The data presented is a result of the first and second level analysis (Appendix 13 and 14) of the data matrix generated using data from baseline/6months interviews, and combining data from participant study logs and researcher observation field notes (Appendix 10, 11, 12). The data from observation complemented the study logs by adding information on: patients' posts, views and content posted which was used in the second interview to understand levels of engagement. The analytical approach sought common patterns related to engagement (O'Brien & Toms, 2008) and social factors, considered determinants of engagement (Figure 4, Chapter 3).

Three core themes which emerged were explored and tested from the data findings:

- Patient Goals
- Levels of engagement
- Process of engagement

Table 23: Patients characteristics at baseline and follow up

| Patient                     | Baseline Context  | Six month Context   |
|-----------------------------|---|---|
| <b>P1</b><br>Male<br>(58)   | Transplanted patient, not depressed but seeing a counsellor. Has worked in IT. Not in employment. Use of Twitter and Facebook. Prefers Twitter. Joined to avoid loneliness and offer support to others.   | Has become the <i>influencer</i> of the community. Sharing administrative tasks and manages the Twitter account. Use of all GMKIN mechanisms, still prefers Twitter.  |
| <b>P2</b><br>Male<br>(58)   | On dialysis for 3.5 years and diabetic. Not in employment. Low IT skills. Use of Facebook on the phone. Wanting to improve at using technology. Received an Ipad to gain access.  | Predominately <i>browsing</i> role. Using GMKIN Facebook group and occasionally the GMKIN platform. Has used the information retrieved from GMKIN to manage his illness, use of GMKIN Facebook and website.   |
| <b>P3</b><br>Male<br>(74)   | Pre-dialysis, CKD diagnosed 1998 with other co-morbidities. Computer courses. Not in employment. Account on Twitter and Facebook. Joined to communicate with other kidney patients.   | Sharing and <i>conversationalist</i> role. Using GMKIN Facebook group and GMKIN platform. Has used information retrieved from all GMKIN mechanism apart from the forum, use of all GMKIN mechanisms   |
| <b>P4</b><br>Male<br>(20)   | Carer. Very good IT skills, use the internet, Ipad, mobile, Iphone. Account on Twitter but not in use. Predominantly use of Facebook. Joined as a result of using information from GMKIN.   | Predominantly <i>browsing</i> role. Predominantly using Facebook and navigating to GMKIN website though Facebook. Has used information from GMKIN. New ways of thinking as a result of information shared and positive news.  |
| <b>P5</b><br>Male<br>(45)   | On dialysis and diabetic, struggling with depression. Employed, struggling to use IT but finds his way around. Account on Twitter, never used Facebook. Received an Ipad to access GMKIN. Joined GMKIN because it was convenient and to get a voice.  | Predominantly <i>browsing</i> on GMKIN Facebook and website, active use of Facebook for personal purpose. Active use of technology. Has used information from GMKIN. GMKIN has helped to stay connected with people, Ipad is his lifeline.                            |
| <b>P6</b><br>Male<br>(21)   | Transplanted. In employment. Started a computer course to retrain. Account on Facebook. Prefers real friends and face to face interaction. Joined GMKIN to chat with people and motivate them.  | Occasional use of GMKIN resources, predominantly <i>browsing</i> and posted couple of blogs. GMKIN is not working for him personally, especially as he found some of the negative stories overwhelming.   |
| <b>P7</b><br>Female<br>(68) | Pre-dialysis. Not in employment. Low IT skills. Use of Facebook, more as result of joining the GMKIN Facebook group. Joined GMKIN to find information and mix with people.  | Predominantly <i>browsing</i> on GMKIN Facebook and website. Has open an account on Twitter but not actively involved. Occasionally felt the information was overwhelming but has made life changes to preserve the kidney function left. Joined local KPA committee. |
| <b>P8</b><br>Male<br>(75)   | Transplanted. Not in formal employment but runs own business and occasionally is acting. Self-taught IT skills. Use of Facebook. Account on Twitter but not used. Has joined GMKIN to promote organ donation and share knowledge, (medically trained) | Actively <i>browsing</i> on GMKIN Facebook and website. Use of Twitter for business. Has not reported any difference made by GMKIN in terms of information as had the illness for over 20 years.  |

|                              |   |   |
|------------------------------|---|---|
| <b>P9</b><br>Female<br>(31)  | Pre-dialysis, diagnosed with CKD (pre-operation of aneurism). In employment. Use of Facebook. Received an Ipad to access GMKIN. Has joined GMKIN to blog to help others. Anonymous because of work. | Occasional use of GMKIN platform as a <i>conversationalist</i> . Has gone through removal of two aneurisms. Not using GMKIN Facebook or Twitter. Has gained information from GMKIN.   |
| <b>P10</b><br>Female<br>(27) | Pre-dialysis diagnosed with CKD. In employment. Use of Facebook (never thought of using Facebook for a medical purpose), Twitter.   | Using mainly GMKIN platform to blog contributing to the <i>conversations</i> . Keeps in touch with Facebook via notifications. Not much use of Facebook. Has used information from GMKIN to understand the illness and discuss with healthcare professionals  |
| <b>P11</b><br>Male<br>(41)   | On dialysis. Not in employment. Use of Facebook. Received an Ipad to access GMKIN.  | <i>Conversationalist</i> , mainly posting feedback. Use of all GMKIN resources. Mainly uses information related to people's stories and medical advances  |
| <b>P12</b><br>Female<br>(27) | Pre- dialysis, diagnosed with CKD and Diabetic. Not in employment. Use of Facebook and Twitter. Received an Ipad to access GMKIN.   | Predominantly <i>browsing</i> role on GMKIN Facebook and website. During the first 3-4 months of using GMKIN suffered from depression and engagement challenging. The information was overwhelming but has since made life changes to preserve the kidney function left. As a result she decided to get involved with a local community for local young adults. |
| <b>P13</b><br>Female<br>(55) | On dialysis, and suffers with anorexia. Not in employment. Use of Twitter. Received an Ipad to access GMKIN. Joined to know what is happening in the kidney world.                                  | Predominantly <i>browsing</i> on GMKIN Facebook, Twitter and website. More keen on using Facebook as an outlet for drawings. GMKIN and gaining access (Ipad) has helped to feels part of a community, increased drawing. No comparison with life before GMKIN.  |
| <b>P14</b><br>Female<br>(37) | On dialysis. Not in employment. Use of Facebook. Never used Twitter. Using other forums.  | Mainly <i>browsing</i> . Minimal involvement with GMKIN Facebook and website. Keep in touch mostly via notifications.   |

## Patients' goals

The majority of patients who interacted with GMKIN identified the reasons underpinning their willingness (or goals) in engaging with GMKIN resources.

Patients have expressed as their goal, the readiness to offer something to others in a similar situation:

*'I really thought I have something to offer, I want this project to be a success I think it has an enormous potential and enormous value' (P1)*

*'I'd like to go on there and give a bit more motivation' (P6)*

*'I have a little knowledge that may help somebody' (P8)*

*'If I write a blog and it helps one person it is worth it' (P9)*

*'The biggest goal is to show another person that is possible... that even if you are suffering from this illness you can still get out there and still do things' (P10)*

Other patients indicated that they wanted to see what was happening in the renal field:

*'Obviously to see what is happening, to be honest it has become part of me in the sense because as you see I can't run out and dig the garden but I can run onto GMKIN and spend a happy time' (P3)*

*'I just wanted to know what was going on in the kidney world or with kidney disease because I didn't really bother about it... It was secondary' (P13)*

*'...it is regarding the kidney group it might be good for me in the future' (P4)*

Patients have also suggested that one reason for using GMKIN was being in a community to get new ideas from experienced patients of how to cope with CKD:

*'From my point of view I want to learn about kidney disease... myself as much as anybody else so if anybody can give me information that can help me in my eyes it is a lot better for me as well as other people because I am not so up on it... that's why half of the time I look at John's site because I know with him being long term ill, I can take advice from what he was been saying to people' (P7)*

*'I get into it I will be able to get to talk to people and there are lots of people in the same position like me' (P2)*

One patient felt that being part of GMKIN has enabled him to have a voice:

*'...and I can raise my voice. Without being shy I can put something in the blog because I hesitate to talk face to face sometimes if I have a problem so this way I can speak my mind and just wait for the response' (P5)*

Others joined without having any direct goals:

*'I have no such expectations but I am thinking that it can be one day that ... that we can have a better way to treat the kidney disease' (P4)*

*'Yeah, getting involved but I don't think... I don't expect anything' (P11)*

*'Not really. I was just wanted to have a look because you never know that you will find something useful or not' (P12)*

*'No, as I say I just find it a handy tool for everybody who is involved with renal transplantation and organ donation' (P8)*

A patient associated Facebook with the TV, stating that the medium is continuously updated.

*'Because I am expecting something on...it is like why do you switch the TV on...you don't know what programs will be on. Normal people will just put it on. They'll say let's see what is on. That is how I see Facebook: let's see who has put what today, that is why. I think that is the main reason, let's see if someone has put something on and what can I say, has put something offensive can I say something about it and put it right' (P5)*

The baseline and months data indicated that for some of the patients their goals have been accomplished throughout the process of engaging with GMKIN, after which a new purpose arose. For example, P1 at baseline indicated that GMKIN:

*'Intrigues me because I think I may have something to offer' (P1)*

It seems that at six months point, P1 may have achieved his goal wanting more users to benefits from getting involved:

*'I really thought I have something to offer, I want this project to be a success I think it has an enormous potential and enormous value' (P1)*

One of the patients who received an Ipad stated his main goal was the willingness to improve at using technology *'I expected to be a silver surfer' (P2)*. He indicated that during

the six months he had achieved important milestones, which included applying for a job using email.

*'I had to write things down, like an email interview really so I managed through that and sending things it was alright. I did not get the job [...] It was good experience, I have never done that before'* (P2)

At six months his aim was to continue to improve.

*'I want to improve, To be honest now a lot of jobs that that you go for are all oriented orientated like this, you are emailing things [...] I like to improve don't even thinking you go straight into it [...] just like writing you're not thinking just doing it.'* (P2)

Patient goals in using GMKIN varied from supporting other patients with a similar condition to gaining knowledge, improving IT skills, and having a voice in debates concerning aspects of CKD and patient care. Indeed patients' goals influenced a person's level of engagement with the social media tools and GMKIN.

### **Levels of engagement**

Patients were asked to describe their activity and levels of engagement with GMKIN. By grouping their answers, three main categories of activity were identified: Influencer, Conversationalist, and Browser (Table 24).

- The influencer results of an expressed willingness of making GMKIN work, by contributing to the community and advocating.
- The conversationalist was a less intense level of engagement that involves communication and contribution to the community to keep the conversations alive and interesting.
- The browser was a level of engagement shared by patients, whose contribution to the conversation is minimal, they mainly brows, read and collect information.

Table 24: The levels of engagement

| Type of Engagement  |   |
|---|---|
| <b>Influencer:</b><br>contributing,<br>promoting,<br>advocating<br>(Appendix 10)                            | <i>'I am focusing more on making GMKIN work. The original concept was sharing patient experience I feel as though I am pushing information into people to try and stimulate them' (P1)</i><br><i>'No, I will be promoting GMKIN at Fairfield hospital.'</i> (P3)  |
| <b>Conversationalist:</b><br>create content,<br>provide feedback as<br>a result of reading<br>(Appendix 11) | <i>'I engage in conversations, I post, I post a lot, I am posting more in terms of my social activities' (P1)</i><br><i>'I put comments and chatter and keeping in touch with people to join the laughs, they inevitable the lighter side you know and taking the serious stuff' (P3)</i><br><i>'I comment as well, I sometime post as well, I read most of the blogs' (P4)</i><br><i>'I can kind of do both. I do reading a lot because I don't post as much as I used to' (P11)</i>   |
| <b>Browsing:</b><br>reading and<br>collecting<br><br>(Appendix 12)  | <i>'Reading bits is brilliant. If I do know about something and I am 100% sure that I am right I will say something down, but I have to be 100% sure' (P2)</i><br><i>'I read the blogs and all the events they have in different places' (P5)</i><br><i>'To read, I am a reader just to absorb information, I don't like to share my information, that is mine' (P6)</i><br><i>'Looking at what people have written on the blog' (P7)</i><br><i>'I browse a lot, I'll answer certain people if I can but if I don't know I just look at what other people have said...I do collect a lot of information' (P7)</i><br><i>'I browse through I don't tend to post much, never posted much on there...' (P10)</i><br><i>'I just tend to browse, go on the site and have a look through and I just kind of, I don't really go looking for anything specific' (P12)</i><br><i>'I quite like reading and picking up information though, so I do reading but someone tells me information and I never forget it if it is something decent unless I want to forget it' (P13)</i> |

## The Influencer

Throughout the process of engaging patients within the GMKIN community, two main influencing roles emerged: firstly, that of the GMKIN community manager (researcher) and the secondly, that of community leader (patient). Both roles were significant in generating patient to patient communication, social support, information provision and a safety environment through meaningful discussion, networking and passion for making GMKIN work.

### **The researcher influence**

The community manager role was significant in creating an environment that stimulated conversation and empowered other members, which was achieved by observing, analysing



and posting content. The process was crucial in understanding the community stakeholders' needs and preferences. It involved watching interactions amongst users, posting various types of content (news, medical information, and/or day to day stuff) and following the discussions to understand what type of content engages patients in the discussion.

One way to initiate discussion on GMKIN Facebook was by posting welcoming messages promoting the GMKIN functionalities:

*... there is also a blogging facility for patients, who can post anonymously or using own details. The blogs will help patients share information and support others. Blogs help with sharing information difficult to share otherwise, or to share with people who can understand, reflect over things, or simply let go of burden. I will arrange any training if requested... (Field note, 15/05/2014)*

In response, other members of the group have started to follow the same process. This has become the practice. One patient indicated:

*'I always [post] even if it is good luck and I hope you well. I have to do that, they might have just started in the group or you don't even know them' (P5)*

In addition, fundamental to this role was developing meaningful relationships among users through light and friendly discussions, sociability and supporting prospective leaders. Amongst the light and friendly discussions, a classic example is a photo of my garden which I posted on the Facebook group. This had such an impact that patients recalled it during the interviews:

*'And your flowers [picture of my garden], I mean it is part of it you don't have to be thinking of dread and doom serious as it is I mean I say thank god I am not on dialysis' (P3)*

*'I'll apply for a job in your garden...(laughs)' (P2)*

P12 identified the importance of social relationships that shaped the quality of the interaction among the community members:

*'...when you post pictures of your home town and your tomatoes ... and I think the more you know people the more you are interested in what they say and it's... if you start to know someone it's more interesting to know what they are saying than it is if they are just a complete stranger' (P12)*

Through observation of the hub, I was able to identify when further interaction from manager/leader was required on the GMKIN blogging platform to stimulate activity. During periods of silence from bloggers, I stimulated the leader to post comments on the blogger's latest posts, which in return triggered further interaction in the form of comments or another blog.

My role as researcher and community influencer has been acknowledged by participants in the research and other members of the community. Patients appreciated the dedication, perseverance, friendliness and trustworthiness:

*'...to reach someone so dedicated, you have put so much hard work in' (P3)*

*"You reminded me so many times it will develop it will happen, we find a subject that people are interested in classic example is the photograph of your garden and the conversations we had coming out of that nothing at all to do with CKD' (P1)*

*'A little whirl wind who came into my life #madeitbetter'" (Field notes, Twitter chat)*

By testing the various types of content and observation (monitoring) of the community has enabled me to understand the needs of members, what their interests are as well as gain an understanding of how to stimulate discussion. Personal posts helped patients to see the human side, which positively influenced the conversations and sociability. The community members appreciated my dedication, perseverance, friendliness and trustworthiness.

### ***Best practice***

The role was not without challenges. A major concern associated with this role was that of maintaining a safe environment that protects patients' privacy and confidentiality whilst stimulating the conversation. There were a number of key issues, which emerged throughout the process. Once these had been considered recommendations/best practice emerged and was incorporated.

#### *Confidential group on Facebook*

Initially the group on Facebook started as an open group (all Facebook members could see members of the group and their posts; approval was needed to join). The decision was not taken in isolation, it was a result of discussions with the Patient reference Group. This was to promote GMKIN, to allow members to get a sense of the discussions before joining as well as raise awareness of the implications of the illness within the wider population.

*The main issue with open groups are that friends of members are able to view their posts; hence enhanced monitoring was required. To manage that I had mobile notifications (messages) switched on and verified the posts as soon as a post was made. The measure has proved crucial when a member of the group has started to discuss important family affairs, risking that the family will see that on the open platform. As a result I took an instant decision to close the group so that no members from outside the group could view the posts minimising the risks. This decision was then shared with the community, asking members opinions as to whether or not the group should remain open (Field note, 10/01/2014).*

*Two views emerged from the discussion, one which was in favour of keeping the group open to raise awareness of the illness, and the second which preferred a confidential group. My role was to mediate the discussion and explain the implications, which resulted in a consensus decision to keep the group closed (Field note, 10/01/2014).*

As a result of closing the group, a moderator of another renal group on Facebook asked about the implications and I shared the main outcomes.

*The first outcome was one of concern about protecting the member's privacy. Despite that the group was closed within a matter of minutes, the poster indicated that a work colleague has inquired about the issue shared on the group. It was fortunate that no family member was active on Facebook to see the post. Therefore, it is good practise to close the groups created on Facebook in order to protect confidentiality and privacy.*

*The second outcome is that of continuously reminding members of the group status to ensure that new members are aware of the implications. It was also noted that after closing the group more members have started to post and join the discussion. The discussion I had with the moderator of the group has influenced moderators of another Facebook group, who decided to follow the same closed group policy (Field notes, 10/01/2014)*

In summary, closed groups are recommended to maintain members privacy and confidentially. If the group remains open, closed monitoring is required and reminders of the group policy must be posted frequently to reinforce potential issues associated with an open group.

#### *Allowing healthcare professionals to join the Facebook group and write blogs*

My role was also to promote GMKIN to local healthcare professionals. I have joined various advisory groups formed by healthcare professionals in a local hospital to advice on use of social media to provide information to patients. Patients as part of research expressed on various occasions how beneficial would be for GMKIN to have professionals from local

hospitals joining the group. As a result of continuous promotion and discussions healthcare professionals decided to join the group. After seeking the wider GMKIN Facebook members' opinion to avoid restricting discussions and information shared, the decision was unanimously in favour of healthcare professionals to join the group. In addition, renal consultants started to post blog on the GMKIN platform. The key knowledge gained was that transparency and involvement of the community members in decisions led to more trust in the community and on-going engagement.

### *Sustainability*

One main concern associated with online communities is that of developing a sustainable community. A conversation with an expert in social media on Twitter was indicative of that:

*Excellent work there – very impressive site – good luck with sustainability (Field note, Twitter conversation, 18/03/2014)*

Therefore, I invested a considerable amount of time in discovering potential leaders. There were two aspects associated with this: discovering the leaders and supporting their development. Community leaders were identified by working closer with patient experts from the Patient Reference Group to stimulate potential leaders. It included a permanent contact with patients via Facebook private messaging function, discussion of content and making suggestions of how to simulate the conversation on Facebook. As a result of observing and collaborating with patient's part of the Patient Reference Group, it became clear that:

*...to be a patient leader the right skills are necessary, including sociability, comfort with the medium and openness. Sociability was seen as someone's ability to engage, converse, listen and create friendship with other members, feeling comfort with the platform in terms of both, technically and socially. This will enable construction of the conversations. A level of openness is required, in order to be comfortable in disclosing information in a way that is authentic (Field note, 20/11/2013)*

In GMKIN's case, the leader was not identified from the Patient Reference Group, it was a patient, member of GMKIN who asked to be part of current research and;

*'...wanted to make GMKIN work' (P1)*

The second step involved supporting, guiding and empowering the leaders. P1 in his feedback indicated how my role as the community manager provided gentle support and guidance:

*‘Supportive and undemanding...providing gentle guidance, steering rather than pushing. I’ve particularly enjoyed the openness and honesty that has typified and underpinned the relationship and made our conversations easy and productive’ (P1)*

Another important element was the research managers’ availability, as indicated by P1;

*‘The only difficulty I’ve encountered has been the lack of communication caused by Cristina’s recent workload’ (P1)*

To sustain an intervention using social media it is crucial to identify leaders of the community who are sociable, comfortable with the medium and open. In addition, the community manager should adopt an open and honest approach, provide support and gentle guidance.

#### *Ethical boundaries*

The researcher dilemma was that of complying with ethical boundaries whilst having to simulate meaningful interactions and relationships among users, create a sustainable community and become part of their ‘Facebook’ friendship base.

*In various conversations with the supervisor it was agreed that I should consider my influencing manager role within the community and record key outcomes to understand the contextual elements that influences the success of GMKIN (Field note, 30/10/2013)*

None of my posts were indicative of my beliefs of social media, how I used it on various contexts and the resulted outcomes. Furthermore, I reduced the activity on Twitter so as not to influence the perceptions of patients following the researcher.

For example, on Twitter, INVOLVE (an organisation funded by National Institute for Health Research to support public involvement in research) initiated a chat on the role of social media on people involvement #SoMePI. One of the patients involved in the GMKIN research study, and a follower of mine (@cristinavas) and INVOLVE (@NIHRINVOLVE) involved me into the discussion on Twitter.

*Despite feeling that by joining the discussion will have several gains, including raising the researcher profile, the decision was to avoid contributing and just add one tweet at the end of the conversation to apologise for not having the time to join. Much consideration was given to the fact that by conversing on a twitter chat will influence patients’ perceptions of engagement and social media and the interviews (Field note, 18/07/2014)*

In addition to the influencing patients’ perceptions, ‘making friends’ on Facebook was another concern, which was shared not only by the researchers but healthcare professionals

in general. Given that Facebook is associated with a close friendship network, where everyone is able to access friends' private information; various individuals have taken a different approach. For example;

*...a researcher working on a different research project indicated they had created a second account to use it for the research, one participant found the personal account and asked for an explanation. In communities, where trust is deemed as a significant factor, an event like this could seriously harm the sustainability of the project. Therefore my decision was to use the personal account, accept potential friend request and manage personal information using the Facebook privacy functions to restrict the information patients can view. That would limit the extent of which friendship could influence patients' perceptions of social media. (Field note, 10/10/2014)*

Another example is that of a healthcare practitioner being sent a request to join the GMKIN group on Facebook and denied stating that is against the work ethics;

*...the NMC does not allow for me to have personal information shared with patients (Field notes, private conversation on Facebook, 09/07/2013).*

It was an interesting perception given that after checking their profile, as a non-friend, all personal information was available for the wider public to see. Some would argue that by joining the group the risk of patients accessing personal information is higher, yet the risk remains unless the right privacy is not configured.

With the rise of social media the ethical boundaries have changed, and perhaps a different approach, in which relationships are reviewed based on context, is needed. Especially on Facebook and Twitter more consideration should be given to factors such as openness and trust in order not to deceive the community members. In addition, training of healthcare professionals on the implications of having a personal account open to the public on social networking sites may be needed to address existing ethical tensions.

### ***The patient leader***

This role emerged as a result of a patient (P1) expressing his willingness to contribute to GMKIN beyond the research study to stimulate patient engagement in order to;

*'...get as much out of it as I do' (P1)*

The patient leader role involved;

*'...pushing information into people, constantly posting things on Facebook, getting involved with twitter, blogging' (P1)*

In addition, the patient asked to take on more administrative tasks including publishing news, managing the GMKIN Twitter account (@GMKINet).

*'I spend a considerable amount of time monitoring Twitter feeds, Google News Alerts (30-40 per day) as well as planning my own contributions to the website. I aim to share at least one relevant news story per day and try to add a brief introductory comment to stimulate debate. I adopt the same approach to posts on Facebook and Google +, hoping to give the readers something to consider when reading the article' (P1)*

The productive time required to manage the community and producing content;

*'...lasts between 2 and 6 hours per day depending on the type of interaction and content production involved' (P1)*

This type of role is not restricted to working hours (9-5pm), hence availability throughout the day, seven days a week is required.

The patient also identified what was needed, in his view, to fulfil the role. It involved continuous learning especially to be able to make the connections in order to push out existing information.

*'I miss opportunities that you see in instance [...] we have a question on Facebook about a specific subject and you automatically think of referring that back to what we have done on the website and you suggest posting things to a blog that may come to me but not nearly as quickly as it comes to you [community manager]' (P1)*

Familiarity with the technical process of posting the blogs triggers a sense of technical conformability with the environment, removing;

*'...significant barriers to achieve anything I want within the frameworks' (P1)*

In addition, the process of creating and distributing content was often made difficult because of the complexity of language in written research documents;

*'...it does not have to be couched in such a difficult language' (P1)*

Therefore, it was important that only readable and understandable information was posted. P1 suggested a test, which proved useful, patients indicating the clarity of the information posted.

*'I do have a test that I do, if I don't understand what I am reading about I tend not to post; not because I don't think that many people will not understand just that I could I will not be able to explaining to anyone' (P1)*

*'He is good when he writes things down [...] I would say layman terms so that people like me can read it' (P2)*

This role was highly significant in engaging other patients in GMKIN, for two main reasons: it contributed to the process of collecting, writing and pushing GMKIN generated content, and it engaged patients in conversation. The content published by P1 was regarded by patients as evidence based, and trusted:

*'...if you see P1 you know it is all right. I know he has researched it, looked into it, it has been properly done and I'm reading text like that' (P2)*

*'...ease of access in my ears [...] like a fantastic magazine article' (P3)*

In response to the information shared by P1, other members were adding comments, as P2 suggested:

*'if it was something more serious, one of P1's information or something like that I have added stuff on the website' (P1)*

As a result of the whole process, the patient indicated that the influencer role was enormously beneficial in terms of:

*'...growth in self-confidence, self-esteem, and feeling of self-worth' (P1)*

The role of patient leader was crucial in posting and sharing information, contributing to conversations, which stimulated engagement. However the role was demanding and required familiarity with the technical process and understanding of complex research language. There were positive outcomes associated with this role (Box 4).

### *Box 3: Role of influencer*

- Testing various type of content to understand user's needs and interests to stimulate discussion
- Personal posts influences conversations and sociability



- Community members appreciate the dedication, perseverance, friendliness and trustworthiness of research
- Support groups on Facebook are recommended to be closed. Open groups should be closely monitored and continuous reminders should be posted
- Transparency and involvement of the community members in decisions stimulates trust and engagement
- Identify leaders of the community who are sociable, comfortable with the medium and open to sustain the community
- With the rise of social media the ethical boundaries have changed, and relationships should be reviewed based on context
- The patient leader stimulates engagement
- The roles is associated with increased self-efficacy

### **Conversationalist**

The conversationalist role was shared by patients contributing to GMKIN, who indicated that they were either posting, reading or engaging in conversation with other members of GMKIN. P3 sums up the characteristics of the conversationalist;

*'I put on comments and chatter and keep in touch with people to join in the laughs... the lighter side you know and taking the serious stuff' (P3)*

The conversationalist engaged in the process of sharing pertinent information, creating and providing feedback in the form of personal knowledge and experience and other topics of interest.

### **Create content**

Patients engaged in the process of creating information by posting on Facebook group or writing blogs on GMKIN platform. Facebook was perceived as a popular choice for patients to start posting, as P9 suggested;

*'...always somebody is there, is always someone putting something up, whether will be [name] and myself' (P9)*

Patients indicated that posting on Facebook was different to posting a blog. The process of posting on Facebook was:

*'...short and sweet on Facebook just, a different way of doing it you don't need to try and explain certain things. On the blog is different towards just few little words you say on Facebook' (P7)*

Therefore, patients used the blogging facility to write detailed posts, which were used as the starting point for conversations.

*'Can do so much more with a blog than you can with a Facebook conversations, you can focus, you can put your ideas out there and they do generate comments' (P1)*

*'All my blogs have been quite long .... I think if I have done the first blog and no one commented on it I would have not bother doing another one' (P9)*

*'When you put a post on there the comments back are always very supportive and very friendly' (P10)*

One patient associated the conversationalist level of engagement with listening.

*'Listener in the sense that if someone has posted a thing on the group and someone has posted down commenting on that statement or that blog' (P4)*

### **Providing feedback**

Another level of posting was that of joining the conversation by providing feedback (comments) on existing content, either on Facebook or blogs. For example, P3 stated that;

*'I put comments and chatter, keeping in touch with people' (P3)*

Patients have indicated that one reason of influencing the chatter was willingness to praise people's efforts, greet new members and provide reassurance.

*'I always [post] even if it is good luck and I hope you are well, I have to do that, they might have just started the group or you don't even know them [...] because they made the effort to put something on you just read' (P5)*

*'...last week, I was saying hello to S and I realised who he was, our M father in law' (P7)*

*'I am right or wrong, someone can guide me through that process' (P4)*

Posting feedback was crucial in engaging patients in the process of blogging and starting conversations, which was another level of engagement that came within the conversationalist role. P9 summed up the benefits of receiving feedback;

*'I say I wouldn't have carried out blogging but it does give you a really nice feeling when people are saying nice things about you' (P9)*

Apart from stimulating further engagement, feedback, regardless of its positive or negative nature was associated with psychological benefit.

*'I love posting and getting feedback in regardless of what that feedback is, whether there's good feedback, well I haven't really had any bad' (P13)*

In addition it reinforced the idea of self-achievement as a result of helping others.

*'If I write a blog and it helps one person it is worth it, and more than one person commented on it so that was probably my only goal which I think I achieved by doing it and I did the first one and then obviously got my comments' (P9)*

Feedback directly influenced the process of engagement to creating content. As patients indicated the feedback received, apart from stimulating their contribution and returning to the GMKIN website, it had psychological benefits such as self-achievement and feeling good.

The conversationalist role played a crucial role in engagement through maintaining the conversations. The two fold outcomes of this role were interrelated as without creating content there is no opportunity for users to provide feedback, which in return feedback stimulated further patient content generation (PGI) (Box 5).

*Box 4: Role of the conversationalist*

- Plays key role in engagement
- Creates content, which stimulates further engagement

## **Browsing**

Browsing through content seemed a popular choice among patients. It involved reading and/or collecting information. Patients who were new to their illness preferred this route because of their perception that they did not have enough knowledge or experience to share. A patient on dialysis indicated that as a private person they had dwelled on sharing the information:

*'I would love to write it sometimes I think shall I write it or not? Is it personal, is this? I just have two minds' (P5)*

In addition patients who preferred face to face interactions were less likely to contribute to blogs. Despite posting three blogs, P6 indicated:

*'I don't know what to type. I don't know what to put on. I don't care. I am not fussed about it. I don't know what to put on social media like I'd say if I have to speak with someone I will ring'* (P6)

Patients read the posts to find out about other patients experiences as well as medical information.

*'I think while at first that was what I found difficult it's actually become the most reassuring bit about it, that it's, even though they are on dialysis or they've had transplants so they're on the list or whatever they start having a laugh like everyone else, it's that humanising'* (P12)

*'You can find out information about other places as well. But it is finding out what other people are doing as well'* (P11)

Although browsing was often associated with lurking, patients acknowledged that learning occurred as a result of accessing the information.

*'That way you learning more by people actually speaking out right to you and saying what is going on'* (P7)

*'I didn't realise that the pain in my legs was due to my kidneys until somebody was writing about it. Silly, little things like that crop up and makes you realise how bad you are'* (P7)

Browsers had a predominant role in engagement with patients newly diagnosed were reluctant to post or share personal data, but browsing was associated with learning (Box 6).

*Box 5: Role of Browsing*

- Predominant role in engagement
- Patients were not posting if they were new to condition and dwell over posting personal data
- The process was associated with learning

## Learning through legitimate peripheral participation

Whilst examining the study site as a COP was not the main focus of the study it was worth noting the similarities between with the concept described by Lave & Wenger (1991) as legitimate peripheral participation and the learning which occurred through social interaction on the GMKIN site. The categories, browser, conversationalist and influencer demonstrated three different levels of engagement with GMKIN, although it was observed that participants could alternate between roles, or have multiple roles. For example, P13 highlighted being predominantly a browser and occasionally a conversationalist.

*'I like reading, I suppose! I liked reading all the blogs [...] I suppose I'm a listener mainly and a supporter I think. I like to support people, I like to show them that I'm there and that I'm trying to be part of their lives in same way you know' (P13)*

Learning occurred as a result of being involved in GMKIN and the legitimate peripherality was shared among all engagement groups. Observing the activity of participants it was identified that newcomers were predominantly browsing. Then gradually they became acquainted with the practice of the community: the language and the operating norms. At this level they learn by being involved in the GMKIN community and observing others:

*'Well you don't want to reply because you don't want to look foolish, let somebody else reply first and see what they does' (P2)*

The same level of learning occurs among the conversationalists. For example P3 indicated how being of the community had contributed to enhancing their knowledge about the disease treatment options.

*'Obviously I got more and more involved in it since its form [...] to be quite honest with you I did not know the difference between HD and PD, I do now but even before dialysis that was it I did not realise that was different forms of dialysis and this is something I picked up' (P3)*

At the influencing level, the community leader began his activity to stimulate other patient engagement by doing peripheral (novice) activity. Gradually as a result of being involved in the culture of practice and observing the my (the community manager) activity, the leader started to accomplish what constitutes GMKIN practice and the level of learning required to sustain the community:

*'I miss opportunities that you see for instance [...] we have a question on Facebook about a specific subject and you automatically think of referring that back to what we*

*have done on the website and you suggest posting things to a blog that may come to me but not nearly as quickly as it comes to you [community manager]' (P1)*

An essential trigger of strengthening and sustaining GMKIN community was the collection of posting and sharing activities and the community norms of practice which interested and kept members of the community engaged.

A further step of engagement was that of understanding the process, more precisely, how patients navigated through GMKIN resources, the role of each mechanism (Facebook, GMKIN platform, Twitter, Forum) and the influential factors.

### **The process of engagement**

The roles of influencer, conversationalist and/or browser that originated from the findings demonstrated different levels of engagement. The findings are now examined to better understand the engagement process and the factors that underpinned or influenced levels engagement. The O'Brien & Toms (2008) model of engagement was the starting point to analyse the process of engagement. The model identified four steps, namely: point of engagement, period of engagement, disengagement, and re-engagement, each stage being influenced by specific attributes. The analysis and interpretation of data from the interviews, diaries and field notes revealed similarities. Patients engaged initially because they had a goal in mind and they continued engaging with GMKIN because their goals were accomplished. The subsequent steps (period of engagement, disengagement, and re-engagement) were less linear when compared to O'Brien & Toms' conceptual framework, in which the process happened sequentially. Patients indicated that whilst they temporarily disengaged from GMKIN they remained connected by receiving notifications of Facebook and/or blogs, or they discussed the stories with others. In addition, they stepped out of one platform to navigate to another platform or to read stories or connect with friends on Facebook. It was felt that disengagement happened in two states: inattention and stepping out or decoupling from GMKIN. Thus the identified processes were: Point of engagement, Period of engagement, Inattention, Decoupling and Re-engagement. The findings provided data of how the model by O'Brien & Toms (2008) was applied and offered evidence based explanations of the states of engagement and influential factors.

### ***Point of engagement***

Patients indicated various goals that initiated their engagement with GMKIN. As highlighted in the previous (patients' goals) section, in some situations, they became involved to support other patients or to be more aware of what is happening in the renal community. In other

cases, learning how to cope better with the disease, learning how to use technology and gaining a voice were among the reasons for joining GMKIN.

Patients indicated that they voluntarily engaged with GMKIN, because of a specific reason, for example posting a blog, reading posts, learning and curiosity.

*'It is entirely voluntary. I don't feel as though I am under any pressure, the past 4 days I have been away I still managed to try to keep up, trying to post, even when I am away I am trying to moderate comments on the blog, and things like that'*(P1)

*'If I am honest messing about doing something whether you go and you want to find something out. Obviously you go and look and in that you have a rough idea of it is...'*  
(P2)

*'First before I do anything I open the GMKIN Facebook group'* (P4)

*'A lot of time I am being on it believe or not like I say when I am in bed or when I am sat downstairs and I just looking through it and I always end up going to the GMKIN section for some reason but I can't tell you any other way of why I am doing it [...] Part is curiosity and part is just learning new things about the kidneys and what it entails if you like'* (P7)

The majority of patients started their engagement process via GMKIN Facebook. Occasionally, they would access GMKIN directly via the browser. Twitter was rarely accessed by GMKIN members with the exceptions of a couple of users. There was no indication of patients engaging with GMKIN forum. The role of the platforms was explored in more detail.

#### *Facebook – the hub of engagement*

Half of the respondents indicated that Facebook was the platform they always accessed first (Table 25). The platform acted as the hub, linking to other resources and other posts. The links connected patients with GMKIN platform.

*'I click on that sometimes it goes on the GMKIN website or sometimes the blog it may be an article from a website'* (P4)

Table 25: The role of Facebook in triggering engagement

|   | Emerging patterns   |
|---|---|
| <i>'I put it on Facebook first then I put it on Safari... Because you know, you go on the Facebook first, it is very easy just press Facebook and you are on. That is why I am on Facebook it is pretty easy' (P2)</i>  | Facebook first  |
| <i>'I just open the group and see whether they are posting and I read... click on the link if it is opening on the website then I read it the whole blog on the website. Then I close that link then I go up the group, I keep reading on the group and go outside and see if there is anything I would like to read...I receive the notifications as well but on the left hand side when I open the Facebook it is written that GMKIN tells me how many posts...can be many notifications it is difficult...I directly open the group and go down and see what other posts are available' (P4)</i> | Facebook first<br>Accessing other resources via the links on Facebook               |
| <i>'Facebook first then there will be a link to GMKIN. First thing I wake up and Facebook. I go to work and I check my FB. Is the norm now, you know what I mean. I mean when I sat in hospital I am on Facebook what else can I do' (P5)</i>   | Facebook first<br>Accessing other resources via the links on Facebook               |
| <i>'On the phone most of the time Facebook came up and then certain people will come up for the GMKIN like the kidney section comes up and that is when I will click onto them and I will go down and see what people are saying and questions they all asking [...] I look on Facebook anyway I look on Facebook most days so sometimes it does not come up because I am on it. If I am not on, it will come up notifications and I will look up then' (P7)</i>  | Facebook first  |
| <i>'The first thing I do when I turn my computer on is go to my emails and that is again not just business private as well...then I go on Facebook I look on the website for different things and GMKIN automatically comes on all my messages...When notifications comes up it says you have 20 messages. I click on and I scroll down messages to see and if there is nothing urgent I will go back to them, then I scroll down my wall to see if there is anything' (P8)</i>   | Facebook first (after emails)   |
| <i>'It is normally from the app on my phone because of auto-updates so it will come up and say there is an email from GMKIN Facebook page and then I just open up and read it and then sometimes I click on the link just to go to GMKIN.[...] I get notifications every day. To going onto the website probably once maybe twice a week...Facebook I read all the notifications because it is on my email, when I go to Facebook page it will normally just clear all, through my email I read all of them' (P10).</i>   | Facebook first (accessed through notifications on emails)<br><br>GMKIN occasionally |
| <i>'We do have links on Facebook to blogs, to news, you know a lot of new research...That's when I go on it like that, through the links, yeah. But not just typing the GMKIN. I do use the website but not as in just going in and look up, or through Google or whatever. Usually via link' (P11)</i>   | Facebook first<br>Accessing other resources via the links on Facebook               |

The various functions of Facebook were sometimes confusing to patients who were not familiar with the platform. One issue associated with Facebook was that of group posts appearing on the personal wall. This created two different types of confusion; the first that patients post on the personal wall believing that members of GMKIN had access to it:



*'Actually you remind me I tend to forget about it and I am going on main Facebook, I think I am a bit confused I think that If I am just putting on Facebook is going to go everywhere this is what I have been thinking and then you remind me 'can you please put it on there as well'. Then I realised that is not going everywhere. Because when you put it on the main Facebook it goes on your timeline so I thought is going on everyone's' (P5)*

The second being the opposite that patients were not joining the group for privacy issues thinking that friends were able to view their posts.

*'I was a little worried I did not want to, I am under anonymous name when I am blogging that is just because of work I am a bit conscious, I am a bit scared of social media once you write something is up there and you cannot take it back so just from a Privacy point of view I don't mind people knowing my story but I don't know if I want everybody at work knowing how vulnerable I felt' (P9)*

*'I think because of the GMKIN Facebook page I have been logging onto Facebook more often [...] don't post a lot personally on Facebook because I know is friends and family but it is more an trust aspect' (P10)*

The role of Facebook in sustaining user engagement was crucial. Patients identified that the platform acted as a hub of resources, from which they navigated to other platforms, such as GMKIN.

#### *Twitter and the GMKIN platform*

These two platforms were less frequently accessed by patients directly. Data retrieved from interviews indicated that patients who were not using the Facebook group were accessing GMKIN directly.

*'I must go on, must see what people put through but I just forget, now I set it off I get the notifications so I had few notifications this week people putting stories and then I can just click on it and see, I think that is much better actually' (P9).*

*'I was on GMKIN. I bookmarked it so I had a little like on there so I used to go to my bookmarks and then click on the icon rather than typing so it brought me to that front page and then I'd just go and look up. I'd always go to like put my name in and look around and just surf around and see what was posting and you know all that thing at the bottom where it comes up, goes around in a loop' (P13).*

*'...sometimes I go through the links that are on Facebook and other times it'd be if I*

*have sort of spare half an hour or whatever, or if I'm waiting at the doctors for an appointment I start to click on and have a look through, but it's, I would say it is mainly because I read the...I've seen something or like seen a specific thing on Facebook' (P12)*

One patient has indicated that Twitter is the favourite platform to start engaging with GMKIN.

*'I invariably start with Twitter [...] I fire the Ipad next to my bed, and I look on twitter and check my emails or Facebook comments [...] I switch my laptop on especially when I start posting links and things like that. And I dip in and out of the website to see any comments needs approving and things like that' (P1)*

GMKIN platform and Twitter are platforms less accessed by patients. The GMKIN platform was accessed mostly by patients, who were not on Facebook, whilst only one patient had indicated that Twitter was the first mechanism accessed. The role of the different platforms, why and how patients used them and the outcomes, are the focus of the next chapter.

### ***Period of engagement***

The continuity of engagement was due to various factors, which influenced a patient's decisions. Patients remained engaged as a result of the site's sociability, to follow other patients' stories and gain information. In addition, they felt they could provide help to people within the renal community. The application of five key sub-themes with respect to the period of engagement, initiated from O'Brien & Toms (2008), were examined: attention, novelty, sociability, information and interactivity.

#### *Attention*

Patients suggested being on GMKIN or using social media was often time consuming requiring a great deal of attention, indeed they experienced losing long periods of time or recognising it could take over their lives.

*'There was one day I could not remember what was going on but it was 6.45 in the morning when I switched my laptop on and I didn't get away until - it was when we did the twitter chat - and apart from going to get the sandwich at lunch time and the odd drink during the day I did not leave the laptop and I was still there at 9pm' (P1)*

*'Let's be honest the computer takes over your life' (P8)*

#### *Novelty*

GMKIN was associated with elements which were new and unusual, and fun.

*'You can have a bit of a laugh and joke and that is all about it really, humorous. I know it is serious side, and lots of serious things are in obviously you need to make it a bit light hearted' (P2)*

*'I mean it is part of it you don't have to be thinking of dread and doom serious' (P3)*

### *Sociability*

Patients acknowledged that being part of GMKIN had led them to create friendships:

*'...you do build a friendship even just because most of the people I've not met' (P11)*

*'...have made friends so, I suppose, yes, to answer to that. I have become close and it does affect me on what's going on and how they're coping and how they're getting on' (P13)*

The friendship created was often taken by patients outside the intervention after they started to engage via private messages on Facebook or Twitter.

*'I suppose I have. Yes, I think with A from [...] I think that is totally outside GMKIN and we can chat to her about her day, converse about music and things like that... Twitter, direct messages' (P1)*

*'They may message me or they may see something on Facebook and message me about it and these things' (P13)*

*'You know on Facebook you can do private messages. If I think is something personal that is what I do, I don't put it on a wall [...] I had fewer off X but I expected it of him' (P8)*

Patients moved beyond the initial friendship to build affection for other members of GMKIN.

*'I love being part on it. It is not affection is beyond affection, it is part of me now and again that is something I did not really envisage when we had the first meeting 6 months ago' (P1)*

*'...bond in the sense, you know all this people, a bit of empathy and a bit of you know obviously banter and that it is good' (P3)*

*'...is a weird think you don't know that person, you don't know them at all you just sharing something and you feel so close' (P5)*

P4 demonstrated affection towards the people within the group:

*'The best way to interact with the people, so I like this group...It is an easy way to access that information' (P4)*

One patient suggested it was a natural process to build affection when having a chronic illness

*'If you're going to go through a chronic disease you are always going to feel like that and that level of affection is to be expected really' (P6).*

P9 acknowledged that GMKIN was an example of social camaraderie, which nowadays was not often seen.

*'I just think is amazing that people had the time to kind of develop something good for the condition, is really nice that people are going on there and helping each other through, in this day and age when you read all this horrible stories and there isn't much of social camaraderie really that people are taking the time and effort to support complete strangers through the condition' (P9)*

However, not all patients developed friends or relationships on GMKIN; one preferred not to make friends because of his background and work experience another didn't want to get too personal.

*'I have no friends in there; I don't know anyone on GMKIN never spoke to anyone, I don't' (P6)*

*'..don't get too personal' (P8)*

Nevertheless being part of GMKIN helped to avoid loneliness

*'Some people might feel isolated with their condition 'why me' and then when you read other people is makes a community' (P5)*

#### *Information*

Among other factors that patient's indicated as influential to their engagement, information played an important role. The interests associated with information included new developments in the renal community and personal information shared by other members of the group.

*'It is interesting to hear what is going on and new developments that are happening all the time is my one contact with the renal functions and how is developing' (P8)*

*'It's really blogs I like to read and what's going on in people's lives' (P13)*

The presence of other patients in the group, who shared real stories, was another reason that influenced patients' returning to GMKIN. Patients found it helpful to read other people's stories and experiences, which were inspiring and helped people cope with the illness.

*'My journey has not been easy but it is been absolutely a walk compared to what other people gone through and that's made me realise perhaps my quality of life is better than what I was perceiving it beforehand' (P1)*

*'It does it makes me realise just how poorly a lot of people are with it and I feel – I do get a bit weary you know upset for a lot of things have been put on there to realise just how bad people are and then on the other side of things when people are saying that they doing well again that is a nice feeling that somebody is getting better' (P7)*

*'Somebody is ill and you hope is getting better and how is carrying on and see that they are all right and what happens to them' (P2)*

Patients indicated that their experiences could perhaps help others. P9 wrote about her condition and after receiving comments on the blog, was stimulated that it helped others, which in turn helped her.

*'Just like I say people commented back and obviously have found it helpful, I will do another update now like I have been discharged and sort of say where I have been out with my clinical psychologist and that kind of thing and I think that will help people' (P9)*

*'I think it helped me that he is going through so much and has dealt with the condition for such a long time and lived a positive normal life, he is got married, good job, plays sports, all this kind of things, few tips on healthy eating and that kind of thing so it just make...it makes me think don't feel sorry for yourself because other people are going through all sorts but then also positive that he was also getting through it and that' (P9)*

### *Interactivity*

Interviewees referred to interactivity, as a twofold concept, which influenced their engagement with GMKIN. One was that of the website (system) interactivity given by certain interactive features.

*'The bar on the side which goes through, does somebody posted or left a comment on things which is quite handy as well if you are looking at every couple of days you*

*can see what has changed without having to skim through everything again. I use that more than looking at website' (P10)*

Apart from the sidebar on the GMKIN website, notifications were mentioned that stimulated activity. However, the majority of patients associated interactivity with other people's presence on the site, and the conversations that just happened.

*'Yes it is part of life. Is like a mobile phone you won't go anywhere without. First thing you wake up you see any messages alerts is like that Facebook just automatically pick it up to know what is happening and next minute you know you had an hour and it is time to whenever you have to go' (P5)*

*'Yes it is from a personal perspective yes it is, I love getting feedback...the feedback is part of the process, it is the validation of what you are saying it also being able to express something openly and honestly it is partially that they understand what you are saying' (P1)*

*'That's why I do it. It's like if you don't interact, if you don't comment or you don't tick or favour it or whatever it is you're just like a voyeur, you're just looking and not giving anything of yourself (P13)*

One patient associated interactivity with the different opinions that patients shared.

*'...it is basically the difference of opinion but both sides of the things get considered' (P4)*

Interactivity was a source of increased trust on the resources, indicating that they are being used and up to date.

*'it's good because it shows how current everything is, that it is being used, you go on some websites and you think when was this updated...I trust in the information and the people using it' (P9)*

The period of engagement is triggered by factors such as sociability and the possibility to create friendship and affection with the group, this helped reduce loneliness. Information and access to real stories was equally important for patients to remain engaged with GMKIN, and system interactivity and the presence of other patients with a similar condition was highlighted as a key factor influencing sustained engagement.

## ***Inattention***

Inattention is a temporary phase of disengagement, especially with the group on Facebook. Although patients were disengaged, they received notifications regarding activity, which kept them connected with the intervention without being online.

*'I still manage to fit into the other things I do during the day, still trying to do my walking during the day but even then I crank up my volume on my laptop so I can hear messages coming through and notifications coming through and I stop my walk and I go and amend and carry on with my walk again' (P1)*

Furthermore, patients take some of the online conversations to discuss in offline interactions:

*'...and I had a bit of conversation with X, she said she was very nervous and mentioned the fact she is in good hands, she mentioned the school she went to...'*  
(P3)

*'I talk to some of them. Y wouldn't leave me alone, he'd message me every day'*  
(P11)

*'A lot of people contact me and I contact them. I am now in connection with one of the patients at Rochdale... she comes to our GMKIN as well. She keeps in contact with me through Facebook' (P5)*

Patients entered the Inattention state because of environmental interruptions, or to navigate to other platforms to perform other tasks. They acknowledged the source of environmental interruptions, including charging the tablet, family affairs, or chatting with friends. One patient indicated religious customs as a disengagement factor.

*'I practise. I never used to be practising now I am practising. So I am occupying myself with mosque activities as well. I go five times a day and spend time there as well. That is the only thing that gets me away to be honest. If I am not there I am there [Ipad]' (P5)*

Inattention was a state of engagement in which patients were not actively engaged with GMKIN but cognitively remained connected with the resources. The inattention was mainly influenced by environmental factors and decision to navigate to other platforms.

## **Decoupling**

Three patients (2 pre-dialysis, 1 transplant), indicated that stepping out was a voluntary action as a measure of emotional protection against overwhelming information.

*'Just one of them was saying that they were really off colour and could not get out of the house for few days because they could not move and the kidneys were causing all this problems and that is when I stop reading because I don't want to know the problems if you like. I suppose is selfish' (P7)*

*'Sometimes I feel like I have already said a million times that sometimes you don't want to go and read how someone has got a problem because sometimes you can be in the best mood in the world, I am not being horrible but you can read something like that and you can go 'Oh no''(P6)*

*'A photo of dialysis or something like that and that was the first time I've seen it...., for someone who has never seen it before it is not very nice. I'm not criticising the people who put that up' (P12)*

Health issues such as periods of poor mental health or other associated illness of the disease were factors that contributed to decoupling from GMKIN.

*'Just my own mental health condition I wasn't going on the internet at all, I wasn't responding to text messages, just a general isolation because I just didn't feel like I can cope with any social interaction apart from my mum and my best friend...it was a really tough time... I didn't feel I can really engage' (P9)*

*'I am losing my eyesight. I have got swelling on my nerves and there was a new treatment for that it is an injection which is injected in the eye, it's not painful when injected but after your vision is blurred and when you concentrate too much on the screen it hurts, it was causing my eyes problems' (P5)*

*'I hold my hands up with being ill, but I have started going back on it again so I have been on it since I came from hospital (P7)*

For another illness was a trigger of engagement:

*'Only when I am feeling a little unwell, or a bit tired or a bit fed up then it helps to go and have a look at it' (P10)*

Some patients expressed concerns about positing their story because it felt too positive.



*'If other people are struggling how they are going to see if somebody else is not struggling' (P10)*

The negative stories and/or repeated negativity influenced more patients' decisions to step out of conversations.

*'I felt like saying you need shaking up, get a grip what you're saying is all wrong' (P8)*  
*but that is 'not negative like I want to turn it off' (P8)*

*'You get some people who are constantly just saying everything is bad' (P4)*

*'...sometimes I wonder if they making a bit harder for themselves' (P7)*

In addition, negative stories carried emotional implications but did not necessarily affect people in a negative way:

*'I mean some of them made me cry, if you like but no, I wouldn't take any of that into my life or think about it or try and relate to something that's bad, that's happened and make it hurt me. No!' (P12)*

Patients stepped out of using GMKIN for various reasons, often when they made an internal decision to disconnect in order to emotionally protect them. Other people's negative stories and explicit health information had a negative emotional impact. Illness and people's negativity influenced their decision to stop the activity.

### **Re-engagement**

Patients indicated that decoupling from GMKIN did not mark the end of engagement with GMKIN. Often even though they were not engaging the notifications sent via email for Facebook reminded them of GMKIN resources and stories shared by patients.

#### *The role of notifications*

The notifications were effective engagement triggers. Patients received notifications acting as reminders and/or sending updates of activity from Facebook or posted blogs, received via email or mobile.

*'It comes up on email and then it dings or whatever, but mainly I get everything through email' (P13)*

*'After I've been on here (mobile) you sending the message every day' (P3).*

Notifications had a high significance in sending reminders patients revealed that notifications acted as repeated invitations to return to the group.

*'I set it up so that I get notifications and I think that is probably more helpful because it just reminds me more than anything because now I am really forgetful' (P9)*

*'I didn't come off the Facebook group, I will still get notifications, so it was almost like a little 'C'mon, just c'mon and have a look'. You know what I mean it was like I couldn't put it at the back of my mind' (P12).*

*'All those notifications or likes or they've tagged me on something or... So the ones from J will come up and then if I see is from GMKIN and I'm interested I'd go in and log and read it. And then I start to look around see what's been going on since I last was on there...'* (P13)

Patients also explained how Facebook reminders contributed to conversations.

*'And then I get alerts on my mobile saying welcome to so and so person and then they have a story and then [name] he is always putting something on and then [name]. Is like that Facebook just automatically pick it up to know what is happening and next minute you know you had an hour and it... You get alerts that so and so people joined the group' (P5)*

The onsite Facebook notifications were also named in patients' discourse. These notifications appeared on Facebook and highlighted the activity from members, groups or pages. As patients indicated it was difficult to navigate through these messages because of the high numbers hence the approach was to scroll down the Facebook wall.

*'When notification comes up it say you have 20 messages. I click on and I scroll down to see if there are any messages and if nothing is urgent I will go back to them but then I scroll down my wall to see if there is anything there' (P8)*

*'...instead of using notifications that can be my personal, can be many notifications it is difficult to find how many notifications I directly open the group and go down and see what other posts are available' (P4)*

The GMKIN platform also had a function that enabled users to set up notifications as patients had highlighted that it would be useful.

*'I'd like to see an option to subscribe to a blog so that I could receive email updates from blogs I comment on' (P1).*

*'It will be nice to have notifications if someone else puts blogs on' (P6)*

The data indicated the importance of notifications in connecting patients back to the GMKIN. The notifications were sending constant reminders of information shared inviting patient to reconnect.

### **Other influential factors**

Other factors that influenced engagement included: time, health literacy, confidentiality and privacy, age, the quality of information. In addition patients suggested the role of healthcare professionals.

#### *Time*

Some patients mentioned time as influencing continued involvement, meaning that they had more time, by not being in work or busy with other things, they could get more involved:

*'Yes, half of the time yes. Waiting for it to set up then going on it, then having to remember what my number is, my name, what the password is, once I am on it I am alright. Laziness I suppose in my part' (P7)*

*'...is the time factors you see I can never – you see I can turn on my phone and they say we need you tomorrow Hayfield or Liverpool you are on start at 7 and it is all last minute I can never plan anything' (P8)*

*'I think is because I've got the time to do it. I mean before I wouldn't use it as much when I was working' (P11)*

#### *Health literacy*

Health literacy emerged as a factor that influenced posting and reading, one patient indicated that if they were not sure about something they would not post because:

*'It will let me look stupid...is just pride I suppose' (P7)*

Indeed one patient highlighted that withdrawing from the research was not written in a clear manner, or;

*'...digestive form and that is another problem with research documentation' (P1)*

In contrast the information produced by patients was written in layman terms:

*'The way he does it I would say layman terms so that people like me can read it, sometimes you can read things that doctors put down and you can't understand it*

*because you don't know about, they put some big words in to confuse you. It does it right' (P2)*

*'In a PPI group, another panel they do events so I get that information from there then I use my input because other people are professionals there and I am just the layman but it nice for them to have me there where I can put my experience as a patients' (P5)*

### *Confidentiality/ Privacy*

Patients highlighted how they negotiated the information they shared. For example, P3 suggested that he got hold of information about another member of GMKIN but felt it was unfair to share this on a public space.

*'I can only speak personal point of view like X for example I mean I rang him and he answer me and 'I am in agony mate I cannot really talk, I will text you and that was all I got, terrible. I said to S yesterday but I could not put all that in a tweet or post or whatever it is unfair to him, if he wants to tell you he will tell you' (P3)*

P5 described an instance where he posted photos of patients taken at an event the organisations questioned him about patient agreement.

*'Have you asked patients about putting photos on? Yes I asked patients. They love it. That day I put photos on the comments saying thank you, can we use it' (P5)*

Privacy stopped patients from joining the Facebook group because they didn't want to share personal information.

*'...you always get some random on Facebook and I just don't really want them knowing every aspect of my medical health' (P9)*

### *Age*

In day to day conversation and discussion with patients it emerged that younger patients believed that GMKIN was mainly for older patients (Field notes). However, a respondent stated that:

*'You can't tell from the posts...Sometime, you can tell from profile picture other rather than that you can't really notice age from posts' (P10)*

P5 indicated that for patients to be very active (like the influencers) patients had to be unemployed, older and with a health issues. Although P11's perception was that the elderly were not using social media.

*'How old is x? Does he work or things like that. He seems to have lots of time you know what I mean. I don't know if he is a bit older or a bit younger I don't know, I am guessing he is a bit older...Not a certain type of person, no is bad to say, maybe you need to have something wrong with you' (P5)*

*'A lot of our patients don't use social media because they are elderly' (P11)*

#### *Quality of the information and trustworthiness of the source*

Respondents described that the information was of a good quality, including explaining what quality meant.

*'The writings and the poems and the way they describe and explain their situations it's exceptional I think!' (P13)*

*'Quality is ease of access in my ears, and part of it. I keep going back to Rob, part of it the research done, quality of the staff and like a fantastic magazine article, doing his own staff apart from other resources, another people feed in just increase your knowledge of the condition' (P3)*

One patient indicated that quality was not something one should question on social media sites as everyone has the right to give an opinion; sometimes those opinions from patients were less formal and easier to take notice of.

*'I don't question about the quality because every person had their right to post whatever they want' (P4)*

*'A lot of information I got from there is relevant it seems to be correct. Sometime (from a healthcare professional) it could be too prescriptive, that tends to be more like 'you got to do this' you got to do that whereas when it comes from somebody else is a little less formal so it makes it easy to read and makes it more willing to take it on board' (P10)*

#### *Technical issues*

Patients have indicated that there are technical issues

*'Or if someone saying I want to transfer I am doing the all way round I think. I will send myself an email and then I try to get that email but sometimes is does not always work' (P5)*

There are some specific to each mechanism, for example the GMKIN platform is slow the navigation can be improved and has too many functionalities, which makes it less intuitive:

*'The only thing is I found it slower than other websites I used ... that is the only thing'*  
(P9)

*'When I post onto the site is I two different ways to post...like you can post to your own wall or you can post blog'* (P6)

*'On the home page it has got the links to diet and whatever, rather than having to click into that if there was when you hover over it drops down in this section [...] that will make it slightly easier rather than having to go in and come out'* (P9)

On Facebook managing between post on personal wall and group is difficult, patient often post on their wall thinking that the whole group will see:

*'I tend to forget about it and I am going on main Facebook, I think I am a bit confused I think that If I am just putting on Facebook is going to go everywhere this is what I have been thinking'* (P5)

### **Chapter Summary - The emerging model**

Initially, when the study was designed, the GMKIN platform was intended to be the Social Media hub, although analysis of data identified that Facebook was at the centre of engagement. Usually, patients returned to Facebook after receiving a notification via mobile or email. The information shared on Facebook in the form of blogs and news stories created a linkage amongst Facebook and GMKIN platform. One patient used Twitter to retrieve information that was then posted as a news item on GMKIN.

Patients engaged with GMKIN often because they have a goal in mind. After their initial engagement point, the majority of patients suggested that they remained connected to GMKIN and only temporally disengaged. Whilst disengaged from GMKIN, they mentally remained connected with the application via the notifications, and taking the discussion offline (Inattention). The other facet of disconnection was decoupling, in which patients intentionally stepped out of GMKIN was a measure of protection or as a result of health issues. Inattention was only temporary, patients returned to the application a usually on a weekly basis, those more active returned on a daily basis. Disengagement was not a defined step with social media, instead it took two different modes (inattention and decoupling), which were influenced by several factors, such as environmental factors, health issues, and negativity. Despite this they were drawn back onto GMKIN because of sources such as sociability, information, patient's real stories and interactivity.

Key findings:

- Patients engaged with GMKIN differently. The most intense role was the influencer, who aims was to make GMKIN work; the second that of conversationalist, who created conversations; the third a browser (reading and collecting information). It is recommended that an intervention should share all three roles to exist, generate information and become sustainable
- The role of the manager of the intervention was crucial in developing the community of patients, identifying the leaders, influencing and training the leader
- The manager had different responsibilities among which monitoring ethical practice, identifying increased training of health professionals is needed to understand how to use social platforms and maintain a professional ethical profile
- The role of the leader was that of continuously curating information and focusing to make the intervention work
- The process of engagement was identified as different states: engaged, inattention, decoupling and re-engagement and each step was influenced by different factors
- Within the field of social media, users engagement influenced the success of interventions therefore it was crucial to understand various roles of engagement, the process and the factors

## CHAPTER 7: SOCIAL MEDIA MECHANISMS: WHAT WORKS FOR WHOM, WHY

### Introduction

This chapter presents the findings to evaluate what social media tools: Facebook, Twitter, blogging, forum, (mechanisms) work, and in what context to satisfy information need and increase self-efficacy (outcomes).

The previous chapter focused on the concept of engagement, which played a significant role in understanding other mechanisms; if patients don't engage would it be impossible to understand what works and assess outcomes. This chapter seeks to explore in more depth the role of social media mechanisms, exploring what it is that works (or not works), for whom and the reasons why. Although GMKIN was dedicated to a single patient group (renal), patients with a long term condition are likely to suffer from multiple illnesses (DH, 2012), which makes it possible to study mechanisms in the wider context.

The chapter examines data to explain and understand the CMOs 1-5 of proposition 1 identified in Chapter 3, to identify what mechanism is working and why.

- *SNS reflects real life relationships enabling patients to create a personal profile, access a network of networks, connect person to person in order to access information and social support (CMO1)*
- *Facebook is a source of information and social support having the potential to engage more active user (CMO2)*
- *Twitter is used as an outlet for satisfying information needs (CMO3)*
- *Blogs allow patients to narrate emotional experiences and contributes to information sharing, problem solving, alleviating emotional distress. Blogging is energy and time consuming (CMO4)*
- *Online communities are among the preferred social intervention in chronic disease management increasing patients' engagement with health interventions. The access to information and support influence positive health outcomes (CMO5)*

The first theme examines the impact of providing devices for people who did not ordinarily have online access, giving people access.



## Giving access

Seven patients with no access to internet had been given an Ipad, the role of the device perceived as a mechanism to get access to online resources, including GMKIN.

Two of the patients, who received an Ipad acknowledged that it was life-changing.

*'I had never drawn so much then I had these past. Well I suppose since I've got the Ipad, really. It's influenced me a lot and my life and it's helped me to sort of put away the troubles and stuff and just concentrate on the drawings' (P13)*

*'This is my lifeline [Ipad] even at home the TV is not on, this [Ipad] is everything in one and then if you don't want to watch anything at least you can look at someone else's feelings read their things on GMKIN and if you want to know medical things, diet things everything is in one place, just look you don't have to get bored' (P5)*

Other patients indicated that the Ipad was used for not only personal but also by the family.

*'Now, the wife and I are using it and she booked a holiday for her and her mate of it, I was watching her and all that, it is really good' (P2)*

*'It helped very much yes. I am mean I have all the events on there [...] I have the photos in here, I am the unit photographer' (P5)*

*'Just internet use, browsing, writing my blog, in a way I find it easy to type it on [...] watching stuff on catch up TV, easy if I am having a day when I am quite tired rather than get up and downstairs I can lie in bed put the headphone on. [...] news websites and reading little articles' (P9)*

The Ipad enabled patients to access healthcare information.

*'It has helped with my recovery because you just straight into it and go and have a look on the website and just read people's stories' (P9)*

*'Perfect size for looking at the website, everything is very easy, and very simple, and straightforward; and, it's, I mean I even downloaded a kidney app... although I'm not sure, I think I still got 'My organs' app' (P12)*

Receiving an Ipad gave patients the mechanism to access GMKIN that was their first point of engagement, which was crucial to their overall engagement and outcomes.

## Social Media mechanisms

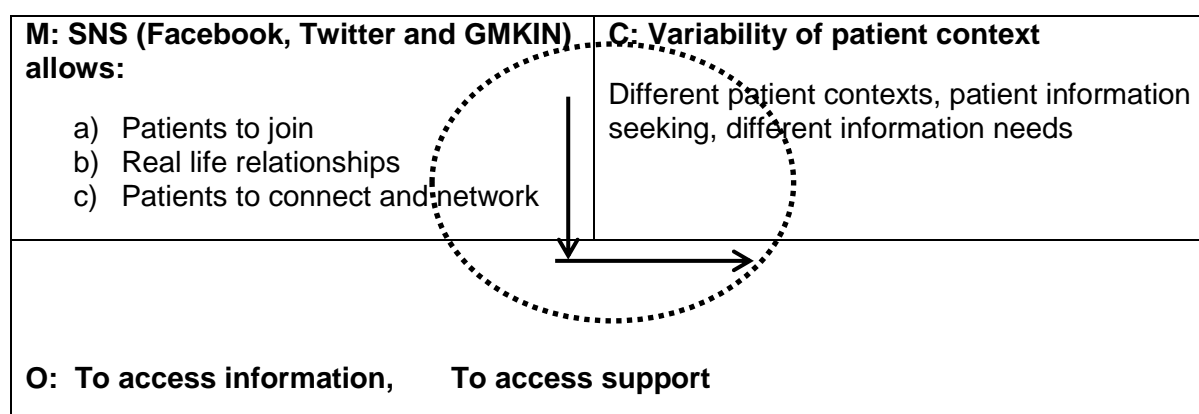
During the six months of managing GMKIN it became clear that not all mechanisms implemented, GMKIN Facebook, GMKIN Platform (blogging), Twitter and the GMKIN Platform (forum) contributed equally to patient engagement and the role of each one was examined. Each overarching mechanism (GMKIN Facebook, GMKIN Platform and Twitter supports various mechanisms presented in below. The decision to present data in such manner was influenced by existing tensions of what social media tools to be adopted as part of interventions and their role. The knowledge generated will influence practice in planning to adopt social media tools.

The aim through analysing the data was to refine the CMO 1-5 in order to attempt to develop an overarching theory. Each proposition is presented in a context, mechanism, outcome (C-M-O) structure drawing together evidence to indicate whether the theory is supported or not. Emerging mechanisms, contextual factors and outcomes are added. In line with realist evaluation, the challenging findings (what is not working) were examined.

### SNS role: CMO1

The middle range theory addressed in this configuration is the role of SNS. It was identified that *SNS reflects real life relationships enabling patients to create a personal profile, access a network of networks, connect person to person in order to access information and social support.* The CMO was configured (Table 26) then each component explored.

Table 26: SNS role - CMO1



### Context

At the initial point of engagement with GMKIN patients acknowledged their difficulties of accessing information in the past, related to the cause of the illness.

*'What caused this and what cause that (P10) and how the lack of information has influenced their condition I did not have much info that is why I think I developed so quickly' (P5).*

One patient indicated that in order to find information the first step was to;

*'...register an interest' (P3)*

In terms of medical information the vast majority of patients on dialysis indicated that they found information when on dialysis from;

*'...different doctors, nurses' (P4)*

However, the information received from the hospital was limited in terms of certain aspects such as diet:

*'...the sheet I was given it was just a paper with a list of foods to avoid and a list of foods that lowering potassium. It did say to take four portions of potassium a day, but it didn't tell you what a portion was and things like that' (P12).*

The internet plays a major role for the majority of respondents' information seeking behaviour. There was an indication that signposting to useful resources would be helpful.

*'The internet gives you all the information that you don't know regarding any medical condition. Again it's knowing where to look' (P8).*

However, the use of internet resources was not without risks according to patients beliefs of the mechanism;

*'...because you worry yourself' (P6)*

*'...you can get a fluttering heart' (P12)*

Another issue raised by P2 was the importance of health literacy:

*'If I see things on kidney I'll read it because it is for me, even if I go over my head I will try to read it' (P2).*

### *Mechanism*

Patients have suggested what is influencing them joining the platforms, which seem to have a dual purpose: personal and health use. It seems that is achieved by a dual purpose served by these platforms, which is achieved by Facebook:

*'A lot of people do not want to go on the website directly because they use Facebook for their personal purpose to chatting with the friends and do other stuff' (P4)*

*'Because the friends and the people I'm interacting with there have more in common with me than anybody on Twitter...and so it's much more personal' (P13)*

*'[On Twitter] I had fantastic conversations so beyond the kidney side of it' (P1)*

These platforms do not necessarily reflect real life relationships that would have developed.

*'The other one who I think socially would be unlikely to meet and connect before, but the other one is Jon. I really enjoy engaging with Jon partly because of his really complex background in terms of kidney disease and like of a character in Jon and I just find him interesting and some of them definitely I would not have been involved with outside this group' (P1)*

However, patients have indicated that they have made new friends through GMKIN:

*'A lot of people contact me and I contact them. I am now in connection with the Rochdale, a girl from there...she sends me poetry and I send her invitations to our group and things like that tells me what is happening there' (P5)*

*'They may message me or they may see something on Facebook and message me about it and these things' (P13)*

#### Outcome

In this context, GMKIN was seen as an outlet for information.

*'...if somebody will give me some ideas of what to eat, that will be of help' (P7).*

*'I've already seen two blog posts, which I read through and seemed quite interesting' (P10)*

A carer, who joined the GMKIN Facebook and then the research project, indicated that he had already benefited from GMKIN.

*'I didn't know where to get the medicine and you [GMKIN Facebook] told me that you can ring the ward, I rang them and they said come-on we will give you the supply' (P4).*

In addition patients identified gaining support.

*'Sharing common experience, understanding that what I perceive as being something that affected only me the thought process that stimulating me went unique' (P1)*

*'A lot of my mates are lorry drivers and I talk to them in a banter way it is good [Facebook Wall]' (P2)*

*'Some people might feel isolated with their condition 'why me' and then when you read other people is makes a community, he is the same, he is the same but he has got this I have not got this so it all comes down to how you view it' (P5)*

### *Refining CMO1*

There was a general consensus from patients that the information received offline was not fulfilling their information need and that by joining GMKIN they could access healthcare information and find support. It seemed that they preferred sites that had a dual purpose (personal and health). These mechanisms do not necessary reflect real life relationships but through them patients make new friends.

The challenge associated with SNS recognised by patients as Facebook was the level of personal detail circulated by members on personal walls. The group by being open on Facebook, patients were able to view not only posts from the GMKIN group members but from friends as well, which provided too much personal detail.

*'I think I am more tolerant of what people are posting on Facebook I don't always agree with it... I don't really enjoy some of the detail people are going to write down in social life' (P1)*

*'I don't know, I don't really get it to be honest...I don't know what they put, having my tea' (P6)*

*'I just got out of bed, then I went for a wash and I had a cup of coffee and I am going shopping to Primark and the kids are crying – for crying out loud get a life, you know what I mean, that is not communication that is boredom' (P8)*

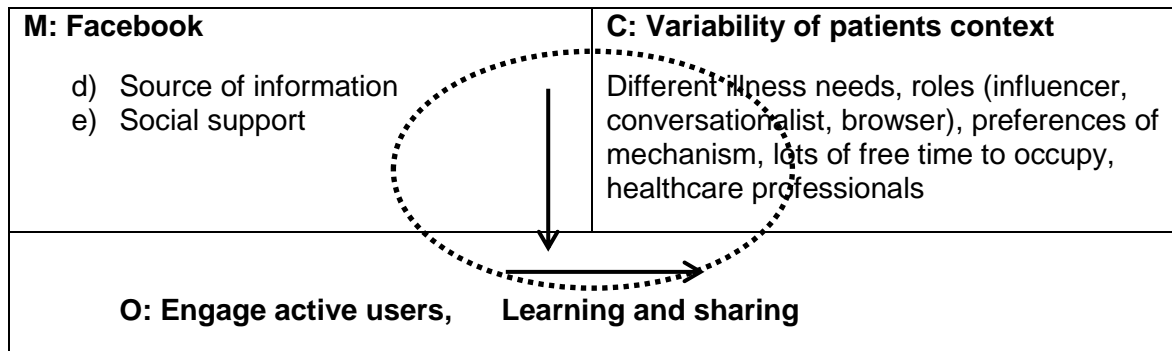
### *CMO1 – Role of SNS*

The information received offline does not fulfill patient information needs of patients seeking information (context) therefore they join SNS website in order to connect and network with other patients (mechanisms), which enable them to access information and support (outcome).

**The role of Facebook: CMO2**

The configuration addressed is the role of Facebook. That *Facebook is a source of information and social support having the potential to engage more active users*. The CMO was configured (Table 27) then each component are explored.

Table 27: The role of Facebook - CMO2



*Context*

It was identified there were various contexts of patients and different needs such as the fear of unknown.

*‘They are all absolutely terrified, it is fear of the unknown they don’t know what to expect they hear horrendous stories and stupid comments from the other people outside’ (P8)*

As a result of joining GMKIN patients took on various roles, those who want GMKIN to work and continuously post (the influencers), those who contribute to conversations by responding to post and posting themselves (conversationalist) and those who only read and collect information (browsing). Their roles contribute to the level of information generated and social support.

Patients preferred Facebook as a mechanism because it was reassuring or rewarding.

*‘And it’s reassuring to know that there is this bunch of people there that if I am struggling they are there...they’ve been through it and know what I’m talking about and not for sort of medical advice but how to live with it’ (P12)*

*‘It is so rewarding little things like someone click a like on a comment on Facebook. If someone posts a comment on a blog that I do that in my mind carries so much weight and emphasis’ (P1)*

Facebook was a platform that patients find easy to access, used and get a reply.

*'Facebook group is more immediate for me to post and get the answer quickly' (P4)*

*'Facebook is just an app on my phone it is a lot easier because I don't need to go to IE to find it is just there' (P10)*

*'Facebook just different way of doing it you don't need to try and explain certain things' (P7)*

*'Facebook is in front of you as you can see a lot of people post on the Facebook, I am guessing a lot more than they are on the website' (P6)*

Patients indicated that when they had a lot of free time and that Facebook helped them to occupy their time up to the point of becoming addictive.

*'I've got a lot of time in my hands. Especially when I'm at home because I don't work I have a hell of a lot of time in my hands' (P11)*

*'So, it occupies a lot of my time, so you can be looking for something and you are just lost in another world' (P5)*

*'Facebook is very addictive because people put things on and you get lost, and you put comments, and they have something else to say, I seems like a web' (P5)*

*'Subconsciously you don't know, like you pick up your phone and on Facebook and then you don't think you've been on Facebook' (P6)*

Patients have also indicated that they would benefit from healthcare professionals joining the group in terms of being reassured and receiving general advice.

*'There is someone there who understands the technicality of it much more comfortable, I'll much more express an opinion that was wrong and had someone there with authority behind them to actually correct me rather than engage in argument with someone you know who did not have that authority behind them so I do really do welcome the influx of medical profession into it' (P1)*

*'More direction than actual medical advice, because I feel if I wanted medical advice I will rather wait for my appointment' (P10)*

*'General advice that you can give but as far as medication or treatment not' (P8)*

In addition, healthcare professionals could benefits from joining.

*'They should look up the individuals and try and get an idea of what their life with dialysis or kidney disease or whatever' (P13)*

Patients had joined or looked at other groups on Facebook, locally, nationally or internationally. The other local group was smaller, as the manager of the group has indicated it:

*'Includes the dialysis unit only...like the nurses and few patients not everyone else can access unless I friend them so it is just what we share – but we don't share much' (P5)*

Patients found these groups useful to retrieve information which;

*'If you wouldn't see on these groups no one will know you don't find that information at the hospital, two new machines are coming out (P11) or this is occupying my time' (P8)*

However, patients indicated that they don't connect with the international and generally bigger groups.

*'I am not using much because is a lot of backbiting' (P11)*

*'I think a lot of the information that is put up on international group just doesn't apply to this country' (P13).*

They connect more with GMKIN:

*'I know more the Salford people you see' (P7)*

*'Information is coming from other units as well from different people' (P5)*

### *Mechanisms*

Patients indicated that Facebook was the central route to the intervention and that the mechanism was a source of getting information and a way to find social support.

One of the mechanisms identified was that Facebook was a source of information enabling patients to access information via links to blogs, news and research.

*'We do have links on Facebook through blogs, through news, you know a lot of new research...I read them through the links' (P11)*

*'I read the blog and that's it really, everything else is through Facebook' (P12)*



*'At the moment it has been mostly, I have looked on the blog and I have read what other people put in on there but I do go on Facebook and read more of them on Facebook' (P7)*

*'I got a lot of information from the group and a lot of articles to read these are the factors to influence me' (P4)*

As well as information patients indicated that on Facebook they find support and advice on how to live with the condition.

*'And it's reassuring to know that there is this bunch of people there that if I am struggling they are there...they've been through it and know what I'm talking about and not for sort of medical advice but how to live with it' (P12)*

*'On the Facebook group a number of people are opening asking for not only advice but comfort...they have overcome a lot of same hurdles that we all have too probably on all chronic conditions but we stick with kidney disease, we have to go through so much of it still appears to be unknown and someone posted yesterday the fear of the unknown and it is that fear of not knowing' (P1)*

Despite that the group focus was on how patients deal with the illness, they appreciated jovial conversations.

*'You can have a bit of a laugh and joke and that is all about it really, humorous. I know it is serious side, and lots of serious things are in obviously you need to make it a bit light hearted' (P2)*

*'I mean it is part of it you don't have to be thinking of dread and doom serious' (P3)*

*'At first, when I read conversations like that it was - oh my God this is what my life is going to be like - but then you start to see the jokes that people put up and you start to see the most humours side of it and people taking the mickey...that really helped me because it was seeing that even though this people were having problems getting the drug that they needed to live, you know all the difficulties' (P12)*

### Outcomes

Data generated from patients indicated that GMKIN Facebook remained the most powerful tool to engage patients. The group was used by 13 out of 14 participants. One of the patients indicated that the Facebook group was active compared to the other mechanisms:

*'Facebook is active, you are not going to go on GMKIN site all the time just because is probably quite slow. Facebook is in front of you as you can see a lot of people post on the Facebook' (P6)*

Patients suggested that Facebook is good platform to attract new users to the group:

*'It is a good way to influence the people to tell the people that it is a group you can consider' (P4)*

Indeed, as patients highlighted the group was expanding.

*'I am pleased it is growing the way it is, I think when I arrived there were about 20 others involved and now 120 users at one stage I didn't think it was going there but seem attracted a number of people recently, it seems (perhaps my perception) to be influx of young people on there...medical professional' (P1)*

*'Group is expanding now more and more health professionals, more and more people are coming from different hospital' (P4)*

*'You get new members coming on and when I get my alerts saying welcome then I go on...is just nice to welcome and greet them saying we are here, you need to talk I am here' (P5)*

### *Refining of CMO2*

The theory is supported by the GMKIN findings. In addition it was found that Facebook does not only provide access to information, advice and support but also comes with an element of fun, which patients actively engage with. Despite this the mechanism is not without challenges. The challenges highlighted demonstrated what it is about Facebook that is not working to keep patients actively engaged.

A significant issue with the group on Facebook, merely for patients new to the condition, was the information shared, which could be overwhelming and contributed to patients decoupling from GMKIN.

*'Discussing things like the drugs that they were on, or having discussions about the problems that they were having like getting supplies delivered...I really, really struggled and I got to the part where I was talking to my partner one day and I was considering phoning you up and saying: No I don't want it' (P12)*

*'Just one of them was saying that they were really off colour and could not get out of the house for few days...that is when I stop reading' (P7)*

And that one solution would be to have tailored groups for each stage of the illness:

*'I think the only way you would do it realistically would be to have almost like a pre dialysis group and a dialysis and transplant group, which, if that would work or not I don't know. I kind of made it more so that the people who are accessing it are the people who are at stage four or five onwards. I mean, I've been told that I may have as much as a couple years...but again that has helped me' (P12)*

In addition, one patient suggested that repeated negativity was a reason for not posting on the group:

*'If people are continually moaning if you feel sorry for them first and help and give a bit of advice and you realise they are no really taking that advice and what they do moaning and after a while you think, no I can't be bothered and you get to a stage something' (P8).*

Likewise having a medical background stopped members from posting advice.

*'I have to be careful if they know I am medically qualified they start asking me medical questions and advice and I can't give them the advice because I am not their doctor' (P8).*

Another reason for not posting on the group was that of preferring more face to face communication.

*'I don't ever post on Facebook I don't use it because I am more of a face to face I will rather speak to someone face to face' (P6)*

Furthermore, patients were not sure what to write when the stories were sad.

*'Because I am a positive person and I don't know what to write when someone is down and upset' (P6)*

*'And you feel guilty commenting sometimes because the person is worse than you, what can you say to him – you cannot really say anything. What can you do? Sometimes you don't comment? No because, I feel a bit sad for him' (P2)*

On Facebook users have to sign using real identity, and by connecting with the group they fear that friends and other contacts are able to access their health information. Therefore, as P9 suggested some patients preferred to remain anonymous.

*'I will join that, I was a little worried I did not want too, I am under anonymous name when I am blogging and that is just because of work [...]. You always get some random on Facebook and I just don't really want them knowing every aspect of my medical health' (P9)*

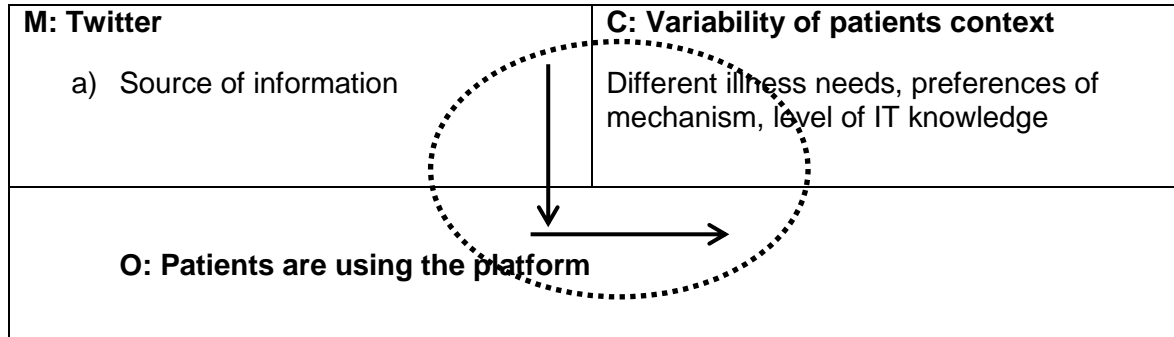
**CMO2 – Role of Facebook**

Variable attitudes to dealing with self-disclosure, and disclosure by others, in an online conversational setting (context) allows conversations among participants, the use of humour and supports coping (mechanisms) leading to more community engagement, feeling part of active learning and sharing (outcomes).

**Role of Twitter: CMO3**

The CMO3 addressed in this configuration is the role of Twitter. It was identified that *Twitter could be an informal outlet for information sharing with a high potential reach*, configured in CMO (Table 28), and then each component is explored.

*Table 28: The role of Twitter – CMO3*



**Context**

Data from patients indicated that Twitter was not a platform with which patients could easily interact or connect. Two patients (P5, P13), users of Twitter prior to the study progressed towards being more active on Facebook.

*'It was just a natural progression really because it was GMKIN and then it was the Facebook and I thought well, why not! [...] Twitter's, more... they're not friends, they're not family, you know. They're more really media people who would try to get across their own agenda, you know. If it's not authors flagging their books it's people*

*with eating disorders or recovery. They're in recovery eating disorders or they're celebrities. It's totally different platform to Facebook' (P13)*

P7 and P11 progressed to open an account on Twitter but were not actively involved, whereas. P13 was using it occasionally (Table 23).

In terms of preferences, amongst other tools, Facebook and GMKIN Platform, only one person highlighted that:

*'If I had to lose the website and Facebook probably I would not shed a tear but really I would not like to lose Twitter... [GMKIN] has opened my eyes to the parallels and the immediacy of it...I can't imagine life without it' (P1).*

All those patients (P1, P3, P4, P13) that used Twitter indicated good technical and digital skills at baseline.

#### *Mechanism*

Data from patients highlighted that Twitter was an informational resource.

*'For information you know, see who can follow up, Twitter round there you can chase' (P3)*

*'Twitter is in the sense understandable and unusual medium but I do think that it's limiting what they can find out themselves because the information is there' (P1)*

In addition to information, Twitter was perceived as a tool that enabled conversations with other users, or as a platform seen as an open medium, which gave patients the opportunity to follow medical staff.

*'I had fantastic conversations beyond the kidney side of it but often come back to it with people like Y and others like that are tweeting and re-tweeting links to my blogs now and putting comments on the twitter about the contents of the blog [...] which is about essentially kidney related problem but they have then linked it to other things' (P1)*

*'I think I just enjoy working within the Twitter environment I just find it much more focused and I do really find it more rewarding than Facebook, because the Facebook group is closed I think limits it' (P1)*

*'...the MRI renal team is on Twitter, the surgeon, who did the operation is on the twitter and all the surgeons...and the MRI transplant team the whole group is on*

*there [that is why there is pressure] to use the Twitter because these people are not using Facebook' (P4)*

In terms of potential reach to media, Twitter was highlighted as a good medium to advocate for GMKIN. Indeed, P3 highlighted:

*'They are all on Twitter I saw that Elaine from look northwest. I exchanged messages with Elaine so I thought great: I am mentioning GMKIN. Of course she said brilliant' (P3)*

### *Outcomes*

The majority of patients indicated that they have not used Twitter or used it very little (Table 23). The medium was actively used by one patient and only occasionally used by others but has the potential to reach a wider audience.

### *Refining CMO3*

The theory is partially supported. Indeed Twitter was seen as an open medium that enabled patients to follow medical staff, access information and engage in conversations with reach in terms of advocacy to the media but not necessary to patients.

Patients also indicated that there were challenges associated with the tool, such as being technically restrictive and difficult to use.

*'Probably it is the way its set up and I just can't get my head around it. I am used with Facebook and know what which way it works and everything just can't figure get my head around the way twitter works' (P7)*

*'I think because is more restrictive... None of them are trying to write about events and what events are coming on and the amount of characters whereas the Facebook is does not matter' (P10)*

In addition to that patients have expressed that Twitter was aimed at celebrities and media people.

*'Twitter's, more... they're not friends, they're not family, you know. They're more media people really, who would try to get across their own agenda' (P13)*

*'Is good to see what celebrities are doing, I am not interested certainly' (P6)*

*'They always say all the stars are on there...'* (P7)

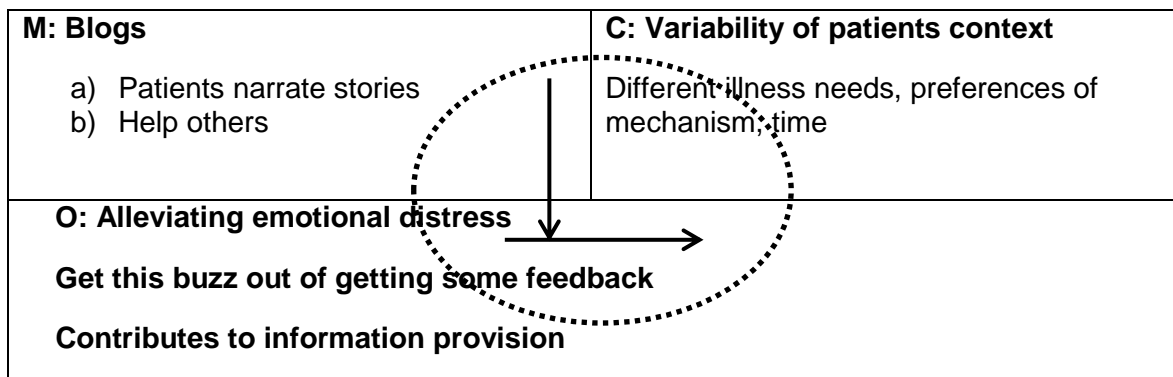
*CMO3 – Role of Twitter*

Patients with variable needs and preferences of tools, who are proficient with using IT (context), take part in in conversations with other users, follow medical staff and become advocates of specific causes (mechanism) leading to more active engagement of a wider audience (outcome).

**Role of blogs: CMO4**

This configuration focus was the role of blogs. It was identified that *blogs allow patients to narrate emotional experiences and contributes to information sharing, problem solving, alleviating emotional distress. Blogging is energy and time consuming.* The CMO was configured (Table 29) then each component explored.

Table 29: Role of blogs - CMO4



*Context*

Data gathered from patients on the use of blogging mechanisms was indicative of the fact that blogging and the website were less accessed compared to Facebook. Only eight patients had written blogs, although the majority had read the blogs.

Blogging was a lengthy process that not all patients embark on. For those that did they indicated that the blogging process was time consuming, some spent from two hours to two or three days to write blogs.

P1 indicated that the blog has to be mentally prepared.

*'I need to mentally prepare for a blog, sometimes the process is quite quick but other times I have to go through the process in my head for few days before hand before I commit anything to a blog' (P1)*

Editing, refining and ensuring not to miss anything were among the time consuming factors. There was an indication of editing the day after writing the blog and that considering carefully what to write was important.

*'I think I will come back the next day and check it' (P10)*

*'Wording things, when I word things [...] think that is not right [...] It will let me look stupid [...] ...is just pride I suppose' (P7)*

Conversely to the blogs, Facebook was considered to be shorter.

*'Short and sweet [...] you don't need to try and explain certain things' (P7)*

Patients' who blog have concerns of how their blog was received. One patient associated posting with:

*'Stepping out into the sky and the result could be that they would be crash landing or somebody would actually support me' (P13)*

Patients who believed their condition was not as bad compared to others in the group expressed concerns of posting positive stories.

*'I am always cautious about that when I am writing them because I don't know how people feel when I read mine' (P10)*

Experience of being with the illness seemed an inhibition to write a blog.

*'It's often I don't feel like I've got anything to offer because the people who are on GMKIN are mostly more advanced' (P12)*

### *Mechanisms*

The reason patients were writing blogs was a perceived belief that the information shared was helping others.

*'I am thinking that there are others out there who are struggling and is it helping them to see somebody getting [...] or is it more not helping them so is one of them I am always cautious about that when I am writing them because I don't know how people feel when I read mine' (P10)*

*'You can help them as well sometimes. If they're having a hard time you may be through the same situation and come out at the other end' (P1)*



There was also an indication that by blogging, patients were writing about their own experience with living with the condition and its challenges.

*'I get ideas from all sorts of things I suppose – some of them are literally past experiences spring into my mind and I will develop that theme, but always try to look it back so people understand where I am coming from [illness associated with stigma] I wanted to make other people understand that they didn't have to sit there and live with it...Those are some of the motivations and entirely on personal level it has helped come to terms with what I gone through' (P1)*

### Outcomes

Patients highlighted that blogs were informational resources regarding patients experiences.

*'I read a lot of them. I read about X and all that, he is a good writer. I read lots of them I think there are all right. That X he is very good, he is picking a lot of things up [...] good reading' (P2)*

*'I read the other people blogs and other ideas more then I don't post myself because the other people have information' (P4).*

*'I would say, on the actual GMKIN site on website, I don't really use it, except to read the blogs...I think that's the biggest part of the website. Because is interesting to find out other people's feelings as well as what they're going through' (P11)*

*'So it's really blogs I like to read and what's going on in people's lives' (P13)*

*'I remember reading one blog from a girl...and that was really...honest and truthful and I remember thinking I wish I could write like that and I didn't think I would be able to because I'm very controlled' (P12)*

Bloggers mentioned the benefits of writing blogs patients feel an element of catharsis.

*'I do feel as though I am getting things off my chest. Part of that is due to the way I dealt with CKD at the start where I just ignored the problem until I could no longer ignore it, and admitted in a number of forums that is the biggest mistake I made in my life' (P1)*

*'Just writing all down really helps...I think if my story can help anybody else then that will make me worthwhile like the decisions I had to make and the way I approached it helps anybody else that obviously is brilliant' (P9)*

*'That was the first time that I have been honest with myself about how I was feeling and it was really to get it off my chest. I felt relieved, because I got it out, and also worried, because I got it out and people could see it' (P12)*

*'And it was quite therapeutic because it was like I was coming out after so long and I didn't know the response I'd get, you know and that was a bit frightening' (P13)*

Another stimulus that patients were gaining from blogging was given by the feedback and interaction they are gaining as a result of posting the blog.

*'One of the other stimulus for doing them is I really get this buzz out of getting some feedback from it. It is an indication of my perceived growth and self-confidence that if I committed something like that which is part of me something that in the past probably kept to myself or just close friends' (P1)*

*'I think if I have done the first blog and no one commented on it I would have not bothered doing another one because...when you get really nice comments back and people found it helpful said thanks for doing that obviously they taken the time and effort to read and post something back is just polite to make sure they know how you are getting on' (P9)*

*'When you put a post on there the comments back are always very supportive and very friendly, I mean I tend to expect that nobody is going to read or nobody is going to comment on but when people do there is actually make you think that is was worthwhile and is that that makes you want to carry on' (P10)*

#### *Refining of CMO4*

The process of blogging was time consuming hence not many patients were blogging. Those who write blogs confirmed that blogging enabled them to narrate emotional experiences, which in turn alleviated emotional distress. Blogs were sources of information that patients read and gained benefits from.

Blogging was not without limitations, indeed a patient spoke about the blogs compared with Facebook. In his perception the website and blogging was technically restrictive.

*'I think the website is a different thing from the group, because the group you can open it and post anything you want, whereas on the website you can't just click anywhere and start posting' (P4)*

In addition, it was difficult to read blogs that were too long.

*'When they [blogs] are very long because my concentration starts going, my sight, the words start disappearing. And yes I got glasses for reading but I even so with the glasses' (P5)*

#### CMO4 – Role of blogs

The variability of patients' needs, preferences for tools and their availability (context) allows patients to narrate emotional life experiences and support others in a similar condition (mechanism) contributes to information provision, alleviation of emotional distress and positive feelings (outcome).

#### **On-line Communities: CMO5**

In this configuration the role of online communities (OC) was explored. It was identified that OC was among the preferred social intervention in chronic disease management increasing patients' engagement with health interventions. The access to information and support influenced positive health outcomes.

In the context of this study, the proposition was not supported. The OC created on GMKIN, which was the forum was not been used by patients, with only couple of attempts to post on the forum. Patients strongly indicated that the forum on GMKIN was replaced by the Facebook group. This configuration would be supported if online communities on Facebook were observed. However, for the purpose of this study the community studied was the forum underpinned by evidence that forums were effective interventions.

Almost half of the patients suggested that Facebook replaced the need for the forum because of convenience that everyone was on Facebook.

*'Everyone goes to the Facebook like is not thinking about it must go to the Facebook and might just see maybe you don't scroll through GMKIN like is Facebook' (P6)*

*'Maybe because people are generally more on Facebook and then they will do that, you have it on your phone, I go on Facebook more than anything else even though I don't post much, it's the ease of access.'* (P9)

*'It seems a lot more going on the Facebook page but maybe because that is the one I am always get the email about' (P10)*

*'What I see with the forum is more like questioners, is more a question, then an*

*answer whereas with the Facebook page you can do that but you can do other things as well...have a good day kind of thing. You won't do that on the forum' (P11)*

*'I think Facebook has kind of become its own forum and message board and things like that. It's Facebook has replaced all of that, and I think the only thing that forums or message boards have over Facebook is the, who you are, you can choose what you want to say' (P12)*

Perhaps, as P13 indicated a more explicit description of forums and their role within the intervention would have contributed. Furthermore, a better strategy to engage patients to use the forum was required to overcome the issue highlighted by P10.

*'I don't know what people expect from the forum. So until I get a definition of the forum, I wouldn't know what to post on there...'* (P13)

*'I had a look a I but there wasn't many posted on there so I was not bothered. But then again if everybody thinks there is nothing on there not point posting them' (P10)*

#### CMO5 – On-line Communities

The convenience and usability of Facebook (context) replaced the need of patients to use the forum (mechanism) leading to OC not working in this particular context (outcome).

### Chapter Summary

The middle range theories CMO 1-5 were tested and evaluated to identify what social media tools work and why. The detail of the contextual factors, the mechanisms and the outcomes contributed to an increased understanding of how each theory operated in real life. Patients highlighted the need for social media platforms to access information and find support. Although these mechanisms did not necessary reflect the relationships they would make in face to face real life, but provided opportunities to open up their minds through GMKIN networks to make different and new friends.

Facebook remained the preferred medium to use for most patients to find information and gain social support, as well as having fun, which in return actively engaged them. Its dual purpose contributed towards Facebook being the central route for everything. Facebook was a platform that was easy to access and use via an app on the phone or browser, occupying patients times up to the point of becoming an addictive. For patients being part of the group and accessing the stories of other patients with a similar condition was both reassuring and

rewarding. However, there were challenges associated with Facebook which at personal level included the level of detail some people post on their wall. In the medical context respondents indicated that the information posted on the group was overwhelming to the point that they stopped using it.

Patients who repeatedly post about the same negative issues influenced the replies they received. One patient, who was medically trained, expressed concerns about other group members asking him medical questions, which in his perception was inevitable. One more reason for not posting was that of not knowing what to say when reading negative stories. The one respondent, who had not joined the Facebook group, acknowledged that the main reason associated with that was privacy and that people from work may be able to see. Patients indicated they used other groups but they connected better with GMKIN because it was a local group.

Twitter was a platform used by only a couple of patients. It was primarily a mechanism that provided access to information. In comparison with Facebook patients were able to follow the medical staff on Twitter, overall the platform was considered more open. Despite that Twitter was not working for everyone because it was restrictive and used mainly by celebrities.

The GMKIN platform was mainly used by patients for the blogging, with more experienced patients more prone to blog, but they still expressed concerns on how their blog was received. In addition, most patients indicated that the blogs because of their informative nature being true reflections of people's lives. Technically, blogging can be restricted by the platform usability. In addition in terms of accessing the information on the blogs, patients find lengthy blogs difficult to read. However, the process of blogging alleviated emotional distress and stimulated feedback and interaction.

The forum was not used because most of the discussion happened on GMKIN Facebook, which seemed more accessible and usable for patients. Perhaps a different strategy was needed to stimulate the patients to use the forum.

#### Key findings and refined CMOs

- Facebook is the mechanism that allow access to information, social support and fun, which in return actively engages users
- Twitter is a mechanism that allows patients to follow medical staff, access information and engage in conversations with reach in terms of advocacy to the media but not necessary to patients

- The process of blogging is time consuming hence not many patients are blogging. Thus, who write blogs, have confirmed that blogging enable to narrate emotional experiences, which in return is alleviating emotional distress. Blogs are sources of information that patients read and gain benefits from.
- In the context of GMKIN, online community (as the forum) was not used by patients. Instead they prefer Facebook

The final findings chapter, identifies the impact and the key difference made by GMKIN on those patients involved, primarily focusing on the difference GMKIN has made on information provision and self-efficacy, why, how and for whom.

## CHAPTER 8: POSITIVE AND NEGATIVE OUTCOMES IN REAL LIFE

### Introduction

The five CMOs tested in the previous chapter related to the mechanisms of social media. SNS allowed patients to join the mediums, connect with one another in order to access information and support (CMO1). Facebook enabled patients to access support, information and have a good time, which in return is actively engaging patients (CMO2). Twitter was only working for a specific cohort of patients, who were not interested in making friends. In their perception, the medium was perceived as an open medium, used as an information outlet, communication and advocacy for GMKIN (CMO3). Blogging enabled patients, who were more experienced and wanted to help others, to narrate information (PGI), which alleviated emotional distress (CMO4). Facebook was the preferred OC not the forum (CMO5).

In this chapter, the attention is turned to examine the key outcomes of the study within individual contextual CMO patient cases. It explores the data generated from longitudinal patient interviews and self-efficacy scales (General Perceived Self-Efficacy Scale [GSE] and Self-Efficacy [CSE] for Managing Chronic Disease 6-Item Scale) across two time points to evaluate the overarching impact of the study intervention primarily on the satisfaction of patients information needs (O1), impact on self-efficacy (O2). The analysis of data by individual patient cases provided various CMO configurations for specific contexts, highlighting both positive and negative real life impact outcomes. Eight, four positive and four challenging, varied scenarios are presented to demonstrate different outcomes for different people, in different contexts:

- Satisfaction of information need (P3)
- Overwhelming of information (P12)
- Increase in self-efficacy (P5)
- Decrease in self-efficacy (P10)
- Increased confidence to consider employment (P2)
- Moderating challenges (P13)
- Using information to make changes (P7)
- Social media is not for everyone (P6)

First an overview is presented regarding the CMOs that information needs are satisfied through using social media (O1), self-efficacy is increased and other outcomes were identified.

## Overview of Satisfaction of information need (O1)

Patients have indicated that the information retrieved from GMKIN has broadened their knowledge about the condition, living with the condition and treatment options.

*'Curiosity, natural curiosity about the condition about its implications, to be quite honest with you I did not know the difference between HD and PD, I do now, but even before dialysis, that was it, I did not realise that were different forms of dialysis and this is something I picked up – just an example there are many things I picked up' (P3)*

*'I think it's kind of triggered me to go and look at other things, and go and find out things, and I've learnt things that I didn't know; like now, I know that there is, you can do home dialysis, which I never thought of' (P12)*

Biomedical information helped patients recognise symptoms and long term implications.

*'Like I said I didn't realise that the pains in my legs was due to my kidneys until somebody was writing it on. Silly, little things like that crop up makes you realise how bad you are. Because me personally I don't feel like I have anything wrong even though I have been told that I am in a bad way I don't feel it' (P7)*

*'The long term effect of kidney disease is one of those things you don't really know about...I read yesterday a link to her [patient] own blog, about anti-inflammatories, which I found quite interesting because I suffer a lot with sinus problems and I take anti-inflammatories so it is bad for kidney...but they never tell you why, so I found out...I have been fine I have used them before so to take them again will not be too bad, but reading the post its best not to' (P10)*

In addition, patients specified medical advances, which gave patients hope for better treatment.

*'In America I read about them pipes that they put around your arms, they were good. A lot of information in there seems to be American to be truthful nothing in Britain is coming out...everything is very much American that is one issue, when you are reading you know is not going to happen over here for ages. It is not giving me any hope, but they are getting the idea somebody will pick it up over here and they will say we cannot do that... it is too expensive' (P2)*



Patients had a high regard for the information gathered by reading other patients stories, which contributed to a better understanding of their condition and how it may affect them.

*'Just to see how is getting on really... because we all having to have one day, that is what you thinking' (P2)*

*'I have learnt this from a lot of people listening to their story that in relative terms my journey has not been easy but it's been absolutely a piece of cake compared to what other people gone through and that's made me realise perhaps my quality of life is better than what I was perceiving it beforehand' (P1)*

The influencers and conversationalists as a result of engaging with GMKIN contributed to PGI. The information generated was grouped in knowledge about the condition, biomedical information, medical advances and patient stories. The PGI contributed to the satisfaction of information need, about the condition, treatment options, symptoms and long term expectations, and other patient experiences.

#### Key findings - Satisfaction of information need

The information generated from GMKIN satisfies patient's information need (supporting CMO6). The satisfied needs included:

- Information about living with the condition, treatment
- Recognition of symptoms and long term expectations
- Patients experiences

### **Overview of self-efficacy trends (O2)**

This study aims to understand the difference GMKIN made in terms of outcomes such as increasing patient self-efficacy in managing their chronic condition and/or general self-efficacy.

The data from self-efficacy instruments was analysed initially to determine the score, the mean of the six items. The higher the score the person demonstrated higher self-efficacy. The t-test was performed to determine for if the results were statistically significant across the patient cohort (baseline and follow up). The small sample size was unsuitable for any further statistical test, the CSE and GSE scores were used to inform the discussion within the patient interview in context. Indeed the interviews raised questions regarding the stability and reliability of such measures. The full results are presented in Tables 30-32.

According to the analysis of the quantitative data 13 out of 14 patients (Table 30) indicated an increased (+) in self-efficacy at least for one of the instruments compared from baseline to six months later, with one patient measuring a decrease in self- efficacy. It is worth noting that patients who reported suffering from depression before or at the point of joining GMKIN (P1, P5 and P12) six months after joining their self-efficacy had increased across all domains.

*Table 30: Self-efficacy trend for CSE and GSE*

| Patient | GMKIN Role               | Ipad access | Age group | Modality     | Gender | CSE | GSE  |
|---------|--------------------------|-------------|-----------|--------------|--------|-----|------|
| P1      | <i>Influencer</i>        |             | 51-60     | Transplant   | M      | +   | +    |
| P2      | <i>Browsing</i>          | YES         | 51-60     | Dialysis     | M      | +   | +    |
| P4      | <i>Browsing</i>          |             | <30       | Carer        | M      | +   | +    |
| P5      | <i>Browsing</i>          | YES         | 41-50     | Dialysis     | M      | +   | +    |
| P12     | <i>Browsing</i>          | YES         | <30       | Pre-dialysis | F      | +   | +    |
| P8      | <i>Browsing</i>          |             | 61<       | Transplant   | M      | +   | Same |
| P6      | <i>Browsing</i>          |             | <30       | Transplant   | M      | +   | -    |
| P14     | <i>Browsing</i>          | YES         | 31-40     | Dialysis     | F      | -   | +    |
| P13     | <i>Browsing</i>          | YES         | 51-60     | Dialysis     | F      | +   | -    |
| P7      | <i>Browsing</i>          |             | 61<       | Pre-dialysis | F      | -   | +    |
| P3      | <i>Conversationalist</i> |             | 61<       | Pre-dialysis | M      | -   | +    |
| P11     | <i>Conversationalist</i> | YES         | 41-50     | Dialysis     | M      | -   | +    |
| P9      | <i>Conversationalist</i> | YES         | 31-40     | Pre-dialysis | F      | +   | -    |
| P10     | <i>Conversationalist</i> |             | <30       | Pre-dialysis | F      | -   | -    |

Table 31: The Self-Efficacy for Managing Chronic Disease

|                | P7   |      | P2   |      | P11  |      | P9   |      | P8   |      | P14  |      | P13  |      | P6   |      | P4   |      | P5   |      | P1   |      | P10  |      | P12  |      | P3   |      |
|----------------|------|------|------|------|------|------|------|------|------|------|------|------|------|------|------|------|------|------|------|------|------|------|------|------|------|------|------|------|
|                | B    | 6bln | B    | 6bln | B    | 6bln | B    | 6bln | B    | 6bln | B    | 6bln | B    | 6bln | B    | 6bln | B    | 6bln | B    | 6bln | B    | 6bln | B    | 6bln | B    | 6bln | B    | 6bln |
|                | 9    | 8    | 4    | 4    | 8    | 3    | 8    | 2    | 8    | 10   | 5    | 3    | 10   | 10   | 10   | 10   | 9    | 10   | 4    | 4    | 7    | 8    | 10   | 8    | 6    | 8    | 8    | 8    |
|                | 8    | 8    | 5    | 6    | 8    | 5    | 5    | 3    | 8    | 10   | 7    | 4    | 10   | 10   | 10   | 10   | 8    | 9    | 4    | 5    | 6    | 8    | 10   | 9    | 8    | 8    | 7    | 7    |
|                | 10   | 9    | 3    | 5    | 10   | 8    | 2    | 1    | 9    | 10   | 6    | 5    | 9    | 10   | 8    | 10   | 10   | 9    | 3    | 4    | 6    | 8    | 10   | 9    | 5    | 9    | 9    | 8    |
|                | 9    | 9    | 5    | 7    | 8    | 3    | 2    | 9    | 8    | 10   | 6    | 7    | 10   | 10   | 10   | 10   | 10   | 9    | 3    | 4    | 7    | 9    | 10   | 9    | 7    | 8    | 9    | 7    |
|                | 9    | 8    | 6    | 4    | 10   | 9    | 10   | 9    | 10   | 10   | 7    | 6    | 9    | 10   | 10   | 10   | 9    | 10   | 4    | 5    | 7    | 8    | 10   | 10   | 8    | 10   | 7    | 7    |
|                | 8    | 5    | 5    | 5    | 10   | 9    |      | 10   | 10   | 10   | 5    | 5    | 9    | 10   | 10   | 10   | 10   | 10   | 5    | 8    | 8    | 9    | 10   | 10   | 4    | 9    | 8    | 9    |
| Ttest p value: | 0.08 |      | 0.46 |      | 0.01 |      | 0.79 |      | 0.03 |      | 0.14 |      | 0.08 |      | 0.36 |      | 0.7  |      | 0.03 |      | 0    |      | 0.04 |      | 0.03 |      | 0.47 |      |
| mean           | 8.83 | 7.83 | 4.67 | 5.17 | 9    | 6.17 | 5.4  | 5.67 | 8.83 | 10   | 6    | 5    | 9.5  | 10   | 9.67 | 10   | 9.33 | 9.5  | 3.83 | 5    | 6.83 | 8.33 | 10   | 9.17 | 6.33 | 8.67 | 8    | 7.67 |

Table 32: The General Self-Efficacy Scale results

|               | P7     |      | P2   |      | P11  |      | P9     |      | P8      |      | P14  |      | P13  |      | P6  |      | P4  |      | P5     |      | P1  |      | P10   |      | P12   |      | P3  |      |   |
|---------------|--------|------|------|------|------|------|--------|------|---------|------|------|------|------|------|-----|------|-----|------|--------|------|-----|------|-------|------|-------|------|-----|------|---|
|               | b      | 6mth | b    | 6mth | b    | 6mth | b      | 6mth | b       | 6mth | b    | 6mth | b    | 6mth | b   | 6mth | b   | 6mth | b      | 6mth | b   | 6mth | b     | 6mth | b     | 6mth | b   | 6mth |   |
|               | 1      | 4    | 3    | 3    | 3    | 4    | 4      | 4    | 4       | 4    | 3    | 3    | 3    | 1    | 4   | 3    | 4   | 4    | 1      | 3    | 3   | 4    | 4     | 4    | 4     | 3    | 3   | 3    | 3 |
|               | 2      | 3    | 2    | 3    | 2    | 3    | 4      | 3    | 4       | 4    | 2    | 3    | 3    | 1    | 4   | 3    | 2   | 3    | 2      | 3    | 3   | 3    | 3     | 3    | 3     | 3    | 3   | 3    | 3 |
|               | 1      | 3    | 3    | 3    | 3    | 3    | 4      | 3    | 4       | 4    | 3    | 2    | 2    | 2    | 4   | 4    | 4   | 4    | 1      | 3    | 3   | 3    | 4     | 3    | 2     | 3    | 4   | 3    |   |
|               | 1      | 4    | 3    | 3    | 4    | 4    | 4      | 4    | 4       | 4    | 3    | 3    | 2    | 1    | 4   | 4    | 4   | 4    | 2      | 3    | 4   | 4    | 4     | 3    | 3     | 4    | 4   | 4    |   |
|               | 2      | 4    | 3    | 3    | 3    | 4    | 4      | 4    | 4       | 4    | 3    | 3    | 2    | 2    | 3   | 4    | 4   | 4    | 2      | 3    | 4   | 4    | 3     | 3    | 3     | 4    | 3   | 4    |   |
|               | 1      | 4    | 3    | 3    | 4    | 4    | 4      | 3    | 4       | 4    | 2    | 3    | 3    | 3    | 4   | 4    | 4   | 4    | 2      | 3    | 4   | 4    | 4     | 3    | 3     | 4    | 4   | 4    |   |
|               | 2      | 3    | 2    | 3    | 4    | 4    | 4      | 4    | 4       | 4    | 3    | 4    | 2    | 4    | 4   | 3    | 3   | 3    | 1      | 3    | 4   | 4    | 4     | 3    | 3     | 4    | 4   | 3    |   |
|               | 2      | 4    | 2    | 3    | 3    | 3    | 4      | 3    | 4       | 4    | 2    | 3    | 2    | 3    | 4   | 4    | 4   | 4    | 2      | 3    | 4   | 4    | 3     | 3    | 2     | 3    | 3   | 4    |   |
|               | 1      | 3    | 3    | 3    | 4    | 4    | 4      | 3    | 4       | 4    | 2    | 3    | 2    | 3    | 4   | 3    | 3   | 4    | 2      | 3    | 3   | 4    | 3     | 3    | 3     | 3    | 3   | 4    |   |
|               | 1      | 4    | 3    |      | 4    | 4    | 4      | 3    | 4       | 4    | 3    | 4    | 2    | 1    | 4   | 3    | 4   | 4    | 2      | 3    | 3   | 3    | 4     | 3    | 3     | 3    | 3   | 3    |   |
| means         | 1.4    | 3.6  | 2.7  | 3    | 3.4  | 3.7  | 4      | 3.4  | 4       | 4    | 2.6  | 3.1  | 2.3  | 2.1  | 3.9 | 3.5  | 3.6 | 3.8  | 1.7    | 3    | 3.5 | 3.7  | 3.6   | 3.1  | 2.8   | 3.4  | 3.4 | 3.5  |   |
| ttest p value | 0.0000 |      | 0.05 |      | 0.06 |      | 0.0023 |      | #DIV/0! |      | 0.03 |      | 0.61 |      | 0.1 |      | 0.1 |      | 0.0000 |      | 0.1 |      | 0.008 |      | 0.002 |      | 0.6 |      |   |

Data retrieved from self-efficacy questionnaires enhanced the findings that emerged from the interviews. Patients indicated that, as a result of engaging with GMKIN and reading other's stories (vicarious experiences) their self-efficacy had increased.

*'I imagine is has done [increase in self-efficacy] because you take an interest in things, it is another interest to give you will – say you fed up doing anything nothing in general at all, you leaving down anyway, you can go and reading things and it is good. You can even read things that you have read before' (P2)*

*'It has in everything sometimes if I am struggling a bit and there are others out there somebody just reading somebody else's what they are going through it helps makes you feel better' (P10)*

*'I think it helped me that he is going through so much and has dealt with the condition for such a long time and lived a positive normal life' (P9)*

In addition it gave them confidence and a purpose, believing it could help others.

*'It has given me purpose... it has given me more focus. I have not allowed things like fatigue or lack of concentration to stop me. It has given me a motivation that was missing before that motivation is primarily to help others. I am feeling like genuinely helping other people, I think that is the essence of what we are like human beings this gives us the opportunity, GMKIN gives the opportunity to do it' (P1)*

*'My only blog if I write a blog and it helps one person it is worth it and more than one person commented on it so that was probably my only goal which I think I achieved' (P9)*

*'It helps me forget my problems, to help others, and makes me appreciate my luck more that I can help others while having this condition so it is not all dull and gloom you have to get up and do it' (P5)*

The conversationalists, especially blog posters benefitted from social persuasion from fellow patients, which positively influenced their self-efficacy.

*'I think that is it when strangers are kind of asking how you are and wanting to know how you are doing and posting comments like 'you know you have been an inspiration, you doing very well' and all that it means a lot because my friends have a bit a vested interest' (P9)*

*'Oh, it's just feeling part of a group of people. You know I suppose because I've had the kidney disease now for... what...10 years! It makes me feel a bit as if I know what I'm talking about, you know' (P13)*

*'I love the interaction and love the human side of it and I think while at first that was what I found difficult it's actually become the most reassuring bit' (P12)*

#### Key findings – Self-efficacy

The information generated from GMKIN contributed to an increase in self-efficacy (supporting CMO 8). Self-efficacy was increased when they engaged with GMKIN and their information needs was satisfied. They benefited from vicarious experiences, perceived confidence gained from helping others and social persuasion.

Access to information (PGI) empowered patients and reduced their perceptions of being different, which contributed to increase in self-efficacy.

#### Overview of other associated outcomes

As well as increased self-efficacy, patients experienced other psychological benefits from being engaged with GMKIN, including increased confidence and feeling generally better.

*'It's almost been like a snowball effect, because once I've got over the kind of the shock and I dealt with things I recognised how the community on GMKIN was actually really helpful...and because I'd dealt with my issues to do with my kidneys I felt comfortable going to Liz and saying "Yes, I want to be involved", and because I've been doing things at the Young Adult Renal Network and things like that that's increased my confidence' (P12)*

*'I don't think I would have engaged with her before GMKIN I would not have felt confident enough in myself to be able to hold my own in a conversation with someone who clearly knows a lot about not just programme management but also renal problems and that is given me enormous satisfaction but again added to the boost in self-confidence' (P1)*

*'I think he posted how you are getting on that is really nice that people out there is definitely helped from that point of view in terms of boosting my confidence back up, boosting my self- esteem' (P9)*

Some patients stated that they were feeling better as a result of being engaged in GMKIN conversations.

*'Oh, only in my drawing I suppose. Yeah! I still don't think I'm up to much or worth much or have anything to offer apart from the drawing which isn't really that bigger deal but if it makes people happy that's the little bit I take from it' (P13)*

*'It has in everything sometimes if I am struggling a bit there are others out there somebody just reading somebody else what they are going through it helps make you feel better' (P10)*

*'If someone posted that it is good for me I am feeling more energetic so I will trust even in this sense' (P4)*

Giving Ipads to people contributed to their access and engagement with GMKIN, especially for P2, P5 and P13; with P2 and P5 demonstrating an increased self-efficacy for both instruments, across all domains. P2 as a result of gaining access had accessed information, increased IT skills and applied for jobs. P5 had accessed information, occupied his time better, realised that overall his health situation is better compared to fellow patients.

A number of patients reported that they were now considering employment.

*'Entertaining the idea of getting some proper employment again and that would be an achievement I never thought I do certainly giving the past 10 years in my life already didn't think I could get to that point again' (P1)*

*'I applied for two jobs one with the kidney association, one of them I had to write things down, like an email' (P2)*

A younger patient felt the need to tailor GMKIN more to the younger generation, and got involved with the younger adult group.

*'I realised that it does engage people and is a huge help, and I think I wanted to help tailor that a bit more to make it more so that other people like me and younger people could engage with it as well' (P12)*

#### Key findings – Additional Outcomes

The information generated from GMKIN also increased confidence, and generally improved well-being.

Giving access to patients enabled their engagement with GMKIN and informational

resources, which in return contributed to increase in their self-efficacy

Three patients, who increased their self-efficacy were now considering seeking employment

The remainder of the chapter brings together real life patient scenarios for the most significant cases, both challenging and positive in nature, in order to highlight how different patient contexts and mechanisms influenced outcomes.

### **Real life patient scenarios**

The real life outcome scenarios presented reflect the overarching outcomes that emerged. Satisfaction of information need was an outcome that most patients indicated. Similarly, 13 patients have indicated an increased self-efficacy at least either generally or specific to their chronic condition. Since enrolling onto GMKIN, three patients indicated that they sought employment, joined research and/or patients support groups (P1, P2, P12), two of these had received an Ipad (P2, P12). Four patients highlighted that as a result of being part of GMKIN and by using the information they made life-style changes, and managed their condition better to preserve the kidney function (P2, P7, P10, P12).

### ***Satisfaction of information need – CMO (P3)***

The patient had joined GMKIN being guided by another member of the group (Table 33). He has a number of other long term illnesses, which limits his activities. He acknowledged that recognising the need is the first step to find information and that in the past he had found information though different offline mechanisms such as the doctor or leaflets.

*Table 33: CMO configuration P3*

#### **Patient Context**

Male (74) pre-dialysis diagnosed with CKD since 1998, other co-morbidities. Unemployed but has attended computer courses. Developed friendship talking outside GMKIN. Goal: Joined to communicate with other kidney patients.

- *[illness] 'Because of my co-morbidities because like the doctor said to me: co-morbidities [name], which contributes to the kidney'*
- *[illness impact] 'When they first diagnosed me he said you are 58 you finish work as well...and when you are used to doing that and do your best it is psychologically 'I am useless'*
- *[information seeking] 'register an interest you can get if you request'*
- *[finding info before GMKIN] 'Leaflets, medical pages of daily mail quite good, compressive...The nephrologist very good he explained everything went through everything'*
- *[offline issues] 'My medication was wrong. It didn't affect me – I've got a copy from the GP and looked through and thinking what is this?...you don't expect this at this level mixing up*

|  |
|--|
| <p><i>medications</i></p> <ul style="list-style-type: none"> <li>• <i>[Goal] 'Obviously to see what is happening, to be honest it has become part of me in the sense because as you see I can't run out and dig the garden but I can run onto GMKIN and spend a happy time'</i></li> </ul>   |
| <p><b>Mechanism (What / how)</b></p> <p>Conversationalist role:</p> <p>Active use of GMKIN Facebook group and GMKIN Platform</p> <p>Use of Twitter</p> <p>Forum is not working</p> <p>Notifications</p>  |
| <ul style="list-style-type: none"> <li>• <i>'Obviously I got more and more involved in it since its form, I mean it was Jon that guided me'</i></li> <li>• <i>'Well, I don't bother much with anything apart from GMKIN. I mean occasionally I went to Twitter and got couple of nephews and nieces and not spoken who them for a while and contacted them and one or 2 other people, I used to drop off particular groups you know...but other than that is GMKIN'</i></li> <li>• <i>[Facebook] 'I put comments and chatter and keep in touch with people to join the laughs, they inevitable the lighter side you know and taking the serious stuff'</i></li> <li>• <i>[Twitter] 'The same through GMKIN that raised my interest more and shall we say GMKIN caught me back...for information you know, see who can follow up, twitter round there you can chase. I mean last night a couple of things that I noticed like I say P1 was there, he is everywhere like a bad rash he is exchanges with the nurses you know and just had a quick look there just things like that'</i></li> <li>• <i>[feedback] 'If it something more serious, one of P1 information or something like that I have added stuff on the website I commented through there'</i></li> <li>• <i>[Forum] 'I think is just the fact that virtually a lot of stuff that goes through Facebook, I just seem to reply there and then its ust convenience. I mean I suppose if you are logging straight into GMKIN direct then it will be a different matter, it will be using the forum and all that more often – I don't know I suppose'</i></li> <li>• <i>[Notifications] 'After I've been on here (mobile) and you sending the message and every day I look in because I do my banking ... and I check all emails using Google, you know the separations using 3 categories headings with GMKIN in the middle is right there'</i></li> </ul> |
| <p><b>Outcome</b></p> <p>Satisfaction of information need</p> <p>Learnt about the disease and learnt about treatment</p>   |
| <ul style="list-style-type: none"> <li>• <i>[medical information] 'Curiosity, natural curiosity about the condition about its implications, to be quite honest with you, I did not know the difference between HD and PD, I do now but even before dialysis that was it I did not realise that was different forms of dialysis and this is something I picked up – just an example there are many things I picked up'</i></li> <li>• <i>'I mentioned about EPO and transplant and little bits you pick up interchanging with other people somebody was worried about something, someone more experienced like Jon, P1 replies so you learn in between'</i></li> <li>• <i>'I have learnt so much I didn't know before about kidney disease you know dialysis and different forms of dialysis'</i></li> <li>• <i>'Quality of ease of access in my ears, and part of it... keep going back to P1, part of it the research done, quality of the stuff and like a fantastic magazine article, doing his own stuff apart from other resources, and other people feed in just increases your knowledge of the condition'</i></li> </ul>   |

The patient started the journey into GMKIN to see what is happening and as result, now, spends quality time, likely to be a result of the sociability. He is retrieving information from



Twitter and acknowledged that the forum is not as convenient as Facebook, where most of the discussion happens.

*The sociability element of Facebook is a result of my strategy as a manager to form a friendly environment (Field note: 15/09/2013)*

The patient has acknowledged my influencing role:

*'And your flowers, I mean it is part of it you don't have to be thinking of dread and doom' (P3)*

Notifications played a role in keeping in touch with GMKIN and the information shared. The patient acknowledged that through GMKIN he had learnt about the condition, its implications and treatment.

**Information overwhelming – CMO (P12)**

P12 level of self-efficacy increased for both tests. The results of CSE and GSE were statistically significant. At baseline P12 indicated that she was new to the condition and her knowledge was limited (Table 34).

Table 34: CMO configuration P12

|   |
|---|
| <p><b>Patient Context</b><br/>         Female (27) pre- dialysis, with diabetes, reported suffering from depression. New to CKD. Unemployed. Received an Ipad to access GMKIN.</p> <ul style="list-style-type: none"> <li>• <i>[limited knowledge] 'I think, it was the fact that I could see people having discussions on GMKIN that they knew what they were talking about between themselves, but I didn't because I didn't understand what the drugs were what this was, that was'</i></li> <li>• <i>[occupy time] 'I'm waiting at the doctors for an appointment I start to click on and have a look through'</i></li> <li>• <i>[limited connection] 'I don't feel like I'm particularly part of the community on GMKIN'</i></li> </ul>  |
| <p><b>Mechanism (What / how)</b><br/>         Browser role<br/>         Occasional use of GMKIN Facebook group and GMKIN Platform<br/>         Notifications</p> <ul style="list-style-type: none"> <li>• <i>[information] 'People put up on the Facebook group things like - I've read such a thing on the website - and I go and have a look, but my main interaction has been with Facebook'</i></li> <li>• <i>[information] 'A photo of dialysis or something like that and that was the first time I've seen it'</i></li> <li>• <i>'I just kind of go on to GMKIN to have a quick look around and now and again I read the blog'</i></li> <li>• <i>[trust] 'I think there is got to be a level of trust there to start opening up on groups. And, I think the trust comes from people being open and honest'</i></li> <li>• <i>[sociability] 'love the interaction and love the human side of it and I think while at first that was what I found difficult it's actually become the most reassuring bit'</i></li> </ul> |
| <p><b>Outcome</b><br/>         Information overwhelming</p>   |

Some of the information shared was overwhelming  
Decoupling  
Re-engaging

- *'At first, when I read conversations like that it was "oh my god this is what my life is going to be like"'*
- *[decoupling] 'I had about 6 to 8 weeks where the only time I'd go would be when someone posted and I get the notification, and I'd click on it to see what they posted, but I wasn't going through the site and looking at comments and engaging or anything like that with it.'*
- *[re-engaging] 'And then, I started to turn a corner with it when I realised that just because the Facebook group was generally made of people more advanced than me that actually underneath it all, it's the same issues I have'*

Despite joining GMKIN she did not feel part of the community. She used GMKIN Facebook and the website, mainly as a result of getting notifications. The main issue with using GMKIN was the overwhelming of information.

*The patient, reported suffering from depression indicated that she found difficult to accept the information shared on GMKIN about the complications, risks and symptoms that go with declining kidneys up to the point of giving up on GMKIN. As a result I sent an email back to acknowledge that feeling overwhelmed is part of the process and there was no problem if she was not engaging with GMKIN (Field note: 29/07/14).*

The patient acknowledged how notifications triggered reconnection with GMKIN information and socialisation, despite feeling overwhelmed her self-efficacy levels increased for both tests.

### **Increased Self-efficacy – CMO (P5)**

P5 has received an Ipad, which he referred to as his *lifeline* and gave him *freedom*. After joining GMKIN, he made an account on Facebook, which was the main mechanism contributing to his self-efficacy. Through GMKIN he was part a community, which can be accessed at a convenient time (Table 35). He explained how accessing other people stories helped him realise he is not doing too bad compared to others. Apart from GMKIN he mentioned life-experiences as contributors to increase in self-efficacy.

*P5 has had episodes of depression in the past and posted couple of comments about that on GMKIN (Field note: 2014)*

Table 35: CMO configuration P5

|  |
|--|
| <p><b>Patient Context</b></p> <p>Male (45) on dialysis, diabetic, reported struggling with depression. Employed, initially struggled with the use of IT but now finds a way around. Received an Ipad to access GMKIN. Joined GMKIN because it is convenient and can get a voice.</p>   |
| <ul style="list-style-type: none"> <li>• <i>[community] 'GMKIN has helped me to stay connected to people [...] A lot of people contact me and I contact them'</i></li> <li>• <i>[convenience] 'It is very convenient I mentioned that earlier, I can do it from home, hospital, I've got four hours there'</i></li> <li>• <i>'So by having this Ipad I think I got freedom, freedom to get away'</i></li> </ul>  |
| <p><b>Mechanism (What / how)</b></p> <p>Browser role<br/>Occasional GMKIN Facebook and website, active use of Facebook for personal purpose<br/>Satisfaction of information need<br/>Repeated negativity<br/>Long blogs</p>  |
| <ul style="list-style-type: none"> <li>• <i>[engage with information] 'Facebook first then there will be a link to GMKIN'</i></li> <li>• <i>[notifications] 'People put their stories on... do they? And then I get alerts on my mobile saying welcome to so and so person and then they have a story'</i></li> <li>• <i>[information -people stories] 'I manage better because of the other people stories and things like that when you compare yourself you think you are doing much better than other people [...] when you read other people is makes a community, he is the same, he is the same but he is got this I have not got this so it all comes down to how you view it'</i></li> <li>• <i>[blogs] 'When they are very long because my concentration starts going, my sight, the words start disappearing'</i></li> <li>• <i>[life experience] 'GMKIN influence but the life experiences as well'</i></li> </ul> |
| <p><b>Outcome</b></p> <p>Increase in self-efficacy (general and chronic condition) (CSE p=0.03 and GSE p= 0.0000)</p>  |
| <ul style="list-style-type: none"> <li>• <i>Depression you get when you are alone and when you are thinking too much, I used to do 13 hours before even when I was on dialysis then you I used to go there and nothing you can do and you just think about house, about social life and you get depressed. But now [...], through GMKINI got involved with citizen scientist they put the post on and all that made me occupied with everything mainly the Ipad'</i></li> <li>• <i>'Before I did not even use my phone [...] I upgraded my phone as well. I think I have upgraded my life'</i></li> </ul>  |

During the interview he indicated that depression is a result of seclusion, whereas now, by being part of the GMKIN community gave him a different outlook to life. His self-efficacy score was statistically significant for improved general self-efficacy and improved self-efficacy with respect to managing his chronic condition test.

**Decrease in self-efficacy – CMO (P10)**

P10 has joined GMKIN and her main goal was to show other patients that despite illness things can still be done. In her social life she is secluded and since baseline had periods of

not feeling well, which impacted on her outdoor activities. She was more comfortable with blogging on GMKIN platform and engages with Facebook mostly through notifications. The information retrieved from GMKIN has given her the *extra push to keep fighting and make positive changes to manage health* (Table 36).

Table 36: CMO configuration P10

|  |
|--|
| <p><b>Patient Context</b><br/> Female (27) pre-dialysis. In employment. Proficient with IT (after blogging on GMKIN has decided to do own blogging platform. Cycling and involved with outdoor activities.</p>   |
| <ul style="list-style-type: none"> <li>• <i>[loneliness] 'I keep my-self and I don't tend to networking at the moment'</i></li> <li>• <i>[illness] 'I have been ill, of the races that I do this year I have actually completed one or 3 events just because I have been unwell, not necessarily kidney related but I didn't think that feeling unwell make such a difference'</i></li> <li>• <i>[goal] 'The biggest goal is to show other people that is possible that even if you are suffering from illness you can still get out there and still do things'</i></li> </ul>   |
| <p><b>Mechanism (What / how)</b><br/> Conversationalist role<br/> GMKIN platform mainly<br/> Facebook through notifications<br/> Blogger</p>   |
| <ul style="list-style-type: none"> <li>• <i>[comfortable with GMKIN platform] 'I feel a bit more uncomfortable writing things to them where as I find it easier to write on the GMKIN website about things'</i></li> <li>• <i>[notifications] 'The Facebook page is quite good because I get the email notifications when somebody posted something on there so because I read on my email I don't necessarily check Facebook always check the GMKIN page [platform]'</i></li> <li>• <i>[feedback] 'When you put a post on there the comments back are always very supportive and very friendly...that makes you want to carry on [blogging]'</i></li> <li>• <i>[Blogs] 'Only when I am feeling a little unwell, or a bit tired or a bit fed up then it helps to go and have a look at it'</i></li> <li>• <i>[information – people stories] 'It is good to read somebody's else even if they are not doing very much...but you can still see – it just gives you that little bit extra push to keep fighting I suppose'</i></li> <li>• <i>[information –biomedical] 'read yesterday a link to her own blog, about anti-inflammatories which I found quite interesting because I suffer a lot with sinus problems and I take anti-inflammatories so it is bad for kidney...but there never tell you why so I found out...I have been fine I have used them before so to take them again will not be too bad but reading the post no, it is best not to.'</i></li> </ul> |
| <p><b>Outcome</b><br/> Decrease in self-efficacy (general and chronic condition) (CSE p=0.01 and GSE p=0.04)</p>   |

However despite reporting positive outcomes from GMKIN, P10 scored a decrease in self-efficacy for both scales. She explained that it this was as a result of being ill and feeling less in control.

*'Because I have been ill... (and that she was unaware) that feeling unwell made such a difference' (P10)*

**Increased confidence to consider seeking employment – CMO (P2)**

P2 joined GMKIN and expressed his motivation to gain new skills to manage technology. He received an Ipad and two hours of training on how to use the Ipad, email, the apps settings as well as debugging skills if things will go wrong (Table 37). As a result the patient stated in the log

*'I enjoy the training yes I do... yes I did enjoy using the Ipad' (blog [log], 25/11/2014).*

Table 37: CMO configuration P2

|  |
|--|
| <p><b>Patient Context</b><br/>Male (58) on dialysis for 3.5 years and diabetic. Unemployed. Low IT skills. Wanting to improve at using technology. Has received an Ipad to gain access</p>   |
| <ul style="list-style-type: none"> <li>• [IT skill] <i>'Not very good. I must admit. Not brilliant'</i></li> <li>• [goal] <i>'I expected to be a silver surfer'</i></li> </ul>   |
| <p><b>Mechanism (What / how)</b><br/>Browser role<br/>Using GMKIN Facebook group and occasionally the GMKIN platform<br/>Offered training to use the Ipad, email, and apps.</p>  |
| <ul style="list-style-type: none"> <li>• <i>ROLE] 'If I am on Facebook and it is a bit quiet I pop into that [GMKIN] and see who is coming on, because not a lot of people are on all the time there are good things coming on and I do read, I read everything that goes on'.</i></li> <li>• <i>[training] 'You mentioned before that you are afraid of breaking things. Yes, you know when you are pressing and nothing happens you think what is going on here? Better turning off, you know what I mean and leave it then coming back'</i></li> <li>• <i>[self-efficacy] 'I imagine is has increased because you take an interest in things, it is another interest to give you will – say you are fed up doing anything nothing in general at all, your feeling down anyway, you can go and reading things and it is good. You can even read things that you have read before'</i></li> </ul> |
| <p><b>Outcome</b><br/>Applied for 2 jobs<br/>Increase in self-efficacy (not significant) (CSE p= 0.45, GSE: p=0.05 )</p>   |
| <ul style="list-style-type: none"> <li>• <i>'I applied for 2 jobs on the kidney association, one of them I had to write things down, like an email interview really so I managed through that and send things it was alright. I did not get the job though [...] It was good experience, I never done that before'</i></li> </ul>  |

In addition to gaining digital skills, the patient had increased his self-efficacy from baseline to 6 months. He had indicated that taking an interest on things and the information gained from GMKIN (patients' stories) had contributed to this. As a result, the patients had increased confidence to apply for a job through the Ipad.

### **Moderating Challenges - CMO (P13)**

This patient scenario highlights the various levels of decisions that moderators of social media interventions have to take and how the decisions may influence the level of patient engagement with the intervention (Table 38).

Table 38: CMO configuration P13

|   |
|---|
| <p><b>Patient Context</b><br/>         Female (55) on dialysis, reported suffering anorexia. Was referred to GMKIN by her consultant. Goal was to know what is happening in the kidney world. Received an Ipad to access GMKIN. Submitted a blog for moderation, which included indicating she wanted to stop dialysis.</p>   |
| <ul style="list-style-type: none"> <li>• <i>I know it's my choice in writing what I have but I would appreciate your opinion, if you think it's wise in posting (Field note, 08/17/14)</i></li> <li>• <i>I have spent 5 weeks without support and I am supposed to be seeing my therapist this Friday (Field note, 08/18/14)</i></li> </ul>   |
| <p><b>Mechanism (What / how)</b><br/>         Browser role<br/>         Has used GMKIN Facebook, GMKIN platform, Twitter</p>  |
| <p>Key actions (field notes):</p> <ul style="list-style-type: none"> <li>• <i>P13 was left without a therapist for 5 weeks and as a result of being overwhelmed has decided to write a blog expressing her thoughts and feelings. The blog was posted on a Sunday evening, followed by an email sent by P13 to say that the blog was submitted for moderation. As a result I contacted the moderation team to discuss the implications. The decision was to inform the local kidney patients' association (HKPA) and psychologist services from local renal hospital.</i></li> <li>• <i>The HKPA has contacted the medical team, including patient own consultant, who initially referred P13 to GMKIN intervention. I then discussed with the consultant, who indicated that there is nothing to worry about P13 and we discussed a good strategy to inform the patient. The consultant has indicated that a friendly and human approach will be a better way to write the email rather than using a formal tone. The patient understood the decision; however she felt that I should have discuss the issues with her first before contacting the medical team. As a result she decoupled from GMKIN (Field note, August 2014)</i></li> </ul> |
| <p><b>Outcome</b><br/>         Decoupled from the Facebook group</p>  |
| <ul style="list-style-type: none"> <li>• <i>Yeah, it did! It did influence my attitude towards GMKIN but it's not to say that it's influenced like "I'll never go back!" but it has influenced it! Because I don't feel like I could give, like I said I can't give the support that I feel, or the commitment that I feel I should. Until I feel that, I can't go back but it doesn't mean to say that that will last forever, well I hope that it won't.'</i></li> </ul>  |

The learning that occurred as a result of what happened influenced the GMKIN moderation strategy.

*The GMKIN policy was updated to clearly include when post are not made publish*

*It was felt that the first level of action should include sending an email to the patient with details about local support. In cases where the patients and medical team details are known (not anonymous bloggers) the second step is to discuss with the team (consultant) before escalating the case (Field notes, August 2014).*

### **Using information to make changes – CMO (P7)**

P7 is newly diagnosed to her CKD condition and she joined GMKIN as a result of not getting offline access to information and to socialize (Table 39).

Table 39: CMO configuration P7

|   |
|---|
| <p><b>Patient Context</b><br/> Female (68) pre-dialysis, with diabetes. Unemployed. Low IT skills. Joined GMKIN to find information and mix with people. Has joined local KPA committee.</p>  |
| <ul style="list-style-type: none"> <li>• <i>goal</i>] ‘somebody will give some ideas of to eat will be of help and to genuinely mix more’</li> <li>• <i>[information seeking]</i> ‘It is hard to find it was hard to find until I started going to the meetings I found it very hard to find information of any type’</li> <li>• <i>[information about the condition]</i> ‘from my daughter mainly – about the kidney I knew nothing, it is information mainly through my daughter since I was told’</li> </ul>   |
| <p><b>Mechanism (What / how)</b><br/> Browser role<br/> Has used GMKIN Facebook, GMKIN platform</p>   |
| <ul style="list-style-type: none"> <li>• <i>[activity]</i> ‘I browse a lot, I’ll answer certain people if I can but if I don’t know I just look at what other people have said [...] do collect a lot of information’</li> <li>• <i>[notifications]</i> ‘I look on Facebook anyway I look on Facebook most days so sometimes it does not come up because I am on it. If I am not on it, it will come up notifications and I will look up then’</li> <li>• <i>[learning]</i> ‘that way you learning more by people actually speaking out right to you and saying what is going on’</li> <li>• <i>[satisfaction of information need]</i> ‘...like I said I didn’t realise that the pains in my legs was due to kidneys until somebody was writing it on. Silly, little things like that crop up makes you realise how bad you are.’</li> <li>• <i>[information overwhelming]</i> ‘you get people asking questions and this questions, that questions and especially when it comes to their kids that I don’t like’</li> </ul> |
| <p><b>Outcome</b><br/> Made changes to preserve the kidney condition</p>  |
| <ul style="list-style-type: none"> <li>• <i>[changes]</i> ‘Just one of them was saying that they were really off colour and could not get out of the house for few days because they could not move and the kidneys were causing all this problems and that is when I stop reading [...] then I try to put what they have said into my own mind to stop me doing certain things I should not do to help to keep my kidney function, it daft little things like that makes me stop and realise change this.’</li> <li>• <i>[changes in diet]</i> ‘Watching and listening to what they all saying has helping me to sort my life out by not eating this and not touching that and if they tell you not to do it don’t do it’</li> </ul>   |

Her activity on GMKIN involved mainly browsing and collecting information. She has indicated how the stories shared on GMKIN, did at one time contribute to her decoupling from GMKIN.

*'I stop reading because I don't want to know the problems if you like' (P7)*

However, the real stories of living with the condition made her make changes in diet to preserve the kidney condition.

### **Social Media is not for everyone – CMO (P6)**

P6 is a young, transplanted patient and joined wishing to have a positive input. He acknowledged during the interview that GMKIN is not working for him because he prefers more a face to face approach and he does not connect with the community because in his perception it is made of mainly older people, without a job (Table 40).

*'I think that it is good, is good that he gets involved so much. Does he work?' (P6)*

Table 40: CMO configuration P6

|  |
|--|
| <p><b>Patient Context</b><br/>Male (21) transplant patient, employed. Prefers real friends and face to face interaction. Joined GMKIN to chat with people and motivate them</p>  |
| <ul style="list-style-type: none"> <li>• <i>[goal]' I'd like to go on there give a bit more motivation out tell people it is not all so bad have a positive input'</i></li> <li>• <i>'I am more of a face to face I will rather speak to someone face to face which is why I enjoy the mentor role at hospital'</i></li> <li>• <i>'But is does get me when people sit on the phones all the time.'</i></li> </ul>  |
| <p><b>Mechanism (What / how)</b><br/>Occasional use of GMKIN resources,<br/>Predominantly <i>browsing</i><br/>posted couple of blogs<br/>GMKIN (social media) not working for him personally</p>   |
| <ul style="list-style-type: none"> <li>• <i>[Twitter] 'No, it is not for me. I don't know I don't like it. I don't like Twitter, [...] I have everything else but I run Twitter for my company it is boring. It is good to see what celebrities are doing, I am not interested certainly not going on it for a bit.'</i></li> <li>• <i>[level of engagement] 'To read, I am a reader just to absorb information, I don't like to share my information, that is mine'</i></li> <li>• <i>'So every day I see it [Facebook posts] because it is always on my notifications. I get to see what people are putting on and everything else'</i></li> <li>• <i>'I would not say I have used it as I should have done. Because sometime I don't know I don't use social media in general'</i></li> </ul> |



- *'Yes because I don't feel like going on and say 'are you going for a pint tonight or who is fancying going out for a drink or walk or do something because everyone is going to have a bad back or bad episode I don't know gangrene... but you know what I mean though?'*

**Outcome**

Decoupled from the intervention / only occasional use.

- *'I don't say I am observer. I don't observe what is the word? P6 does not care about social media'*

## Chapter Summary

This chapter aim was to identify the overarching outcomes of the study and context specific outcomes. It began with a section summarising the key outcomes for satisfaction of information need and self-efficacy, followed by other outcomes that emerged from the study.

The findings presented within the scenarios focused on giving context specific examples of CMO configurations for both key positive and negative study outcomes.

### Key Outcomes - Positive and negative

- 13 patients reported increased self-efficacy for at least one domain
- Patients, who reported a form of depression increased self-efficacy across both domains
- The vicarious experiences, confidence gained from helping others and social persuasion (through PGI), contributed to increased self-efficacy
- Patients reported other psychological experiences (increased confidence and feeling better) and three reported considering seeking employment
- Information could be overwhelming, more for patients new to the condition but for others patients reported making better self-management behaviour changes
- The positive effects of GMKIN were not able to override the impact of prolonged illness
- Moderation influenced the level of patient engagement with GMKIN
- Social media did not work for everyone, with some preferring face to face interaction

The main outcomes included satisfaction of information need, as well as providing overwhelming information, increased self-efficacy, consideration of seeking employment and site moderation challenges.

The key findings from the chapter included:

- GMKIN contributes to satisfaction of information needs for all levels of engagement

- Information retrieved from GMKIN (patients' stories) in addition to other factors like life experience contributed to increased self-efficacy
- The information retrieved from GMKIN can be overwhelming to patients, however in some cases, they have made life changes to preserve themselves against the illness
- Patients reported access to information, life experiences and increased self-efficacy gained as a result of engaging with GMKIN alleviated to some degree their feelings of depression
- Moderation of groups requires a strong moderation policy and team of healthcare professionals.

The findings that emerged from chapters 6-8 will be further discussion in the next discussion chapter, which situate the findings from the realist evaluation study within the general realist synthesis and review literature context to extend and expand new knowledge and theory.

## CHAPTER 9: DISCUSSION

### Introduction

The aim of the study was to develop interventions using social media (GMKIN) and then test out propositions and mechanisms that trigger change. The focus was particularly surrounding how patients with a long term condition engage with GMKIN to generate information, and the effect of that on satisfying their information need and increase of self-efficacy. The social media tools included in this study (SNS, blogging and OC) were not studied in isolation but as a unity under the GMKIN intervention, which included GMKIN Facebook group, GMKIN Twitter, GMKIN platform (blogging and the forum). The CMOs were tested using knowledge gained from a real life patient experiences, a novel approach used in this study. Previously research has evaluated one or two types of social media at one time; certainly there is no current research evidence that evaluates a myriad of social media mechanisms in the context of health.

The findings highlighted that engagement, an overarching mechanism crucial to trigger other changes, takes different modes (engagement, inattention, decoupling and re-engagement), each mode influenced by a variety of factors. In addition the levels of engagement emerged as a three tier process: influencers, conversationalist and browsing. In social media interventions, emphasis should be placed on stimulating and sustaining engagement, a crucial influencer of other health and social outcomes. Each platform played a different role in engagement and information generation, which in turn supported the proposition that social media satisfied patient information needs (Proposition 1). Finally, engagement with GMKIN and satisfaction of information needs triggers an increase in self-efficacy and other reported outcomes, dependent on context (Proposition 2).

This chapter draws together and discusses the main conclusions from the realist synthesis, in an attempt to better understand the role social media can play within a health context, extending what is known within the existing evidence. The purpose of the chapter is to map the findings that have potential implications for health care professional practice using new knowledge gleaned from GMKIN and the realist synthesis. Four key themes emerged as crucial influencers to create a positive impact that warranted discussion:

- The engagement process: variability of patient's roles and contexts
- The role of mechanisms: what works for whom, why
- The emerging outcomes: satisfaction of information need and self-efficacy
- Connecting up: recommendations for practice

## **The engagement process: variability of patient's roles and contexts**

Engagement was a concept highly regarded in health and the wider contextual literature, usually referring to when adherence was not achieved (Christensen et al., 2009; Calder et al., 2009). In this setting, it was recognized that social media has the potential to unfold new opportunities to patients engagement resolving existing issues (Hardiker & Grant, 2011). Indeed, applying the technical knowledge gleaned from O'Brien & Toms (2008) to develop the GMKIN platform in practice facilitated an opportunity, using realist synthesis methodology, to test out existing engagement theory in a healthcare context.

### ***The engagement process***

The engagement process which emerged from GMKIN took four different modes: engagement, inattention, decoupling and re-engagement. Fundamental to engagement were patients' goals. At the initial point of engagement patients had a goal in mind, which were often influenced by motivations or interests (O'Brien & Toms, 2008). Within GMKIN patients explained how they were motivated to support other patients and to gain new knowledge about coping with the condition. In addition to that they had a vested interest in knowing what was happening in the renal community, as well as feeling like they had a voice.

Patients remained engaged with social media and that was triggered by a number of factors, namely attention, novelty, interactivity, information and sociability, some theoretical factors proposed in the O'Brien & Toms (2008) engagement theory in this study observed working in practice within GMKIN. Perceived interactivity was considered to have no impact on user satisfaction and implicit engagement, for those users no longer wanting sustained communication with members of a network (Shipps & Phillips, 2013). However, interactivity within GMKIN was identified as a twofold concept including conversations or feedback and system interactivity. This contrasted with O'Brien & Toms (2008) theory, who perceived interactivity and feedback as two separate influential factors of engagement. Previous research identified that feedback was connected with interactivity being a significant indicator of interactivity, where the communicators can be human or computer (Kiousis, 2002).

O'Brien & Toms (2008) proposed that interest (in the form of stories or intellectual interest in presentation) was a sustained factor of engagement. With GMKIN, the information in itself arose as a stronger influencer of engagement, overriding interest. The information generated within GMKIN moved beyond patient stories to include biomedical information, and presenting new medical advances. Patients identified that information was the main

contributor to remaining engaged. Indeed, social media was acknowledged as a mechanism that facilitated patient generated content (Merolli et al., 2013; Applebaum et al., 2013). The informational support has been identified as a motivator of users joining online groups in order studies (Buchanan & Coulson, 2007; Mo & Coulson, 2010; Welbourne et al., 2013).

Another dimension identified within GMKIN as an influencer of engagement was sociability. On GMKIN, sociability was seen as someone's ability to engage, converse, listen and create friendship with other members, feeling comfortable with the platform in terms of both, technically and social networking. This enabled the construction of conversations. A level of openness was required, in order to be comfortable in disclosing information in a way that was authentic. Javornik & Mandelli (2013) defined the social dimension as complex experiences, which resulted from interaction between an individual involved into a community, as well as the surrounding context. Virtual socialisation allows a patient with a chronic disease, who can experiences both peer and social rejection, to become part of social communities (Chan & Dicianno, 2011). It encompasses the *'collective purpose of the community, the goals and roles of its members, and policies and rules defined to foster social interaction'* (Demiris, 2006: p185).

Inattention and decoupling emerged as two separate modes of disengagement in this study. Both were related to O'Brien & Toms (2008) disengagement phase theory; however there were differences among what was perceived and what actually occurred within 'real life' disengagement. O'Brien & Toms (2008) perceived disengagement was associated with users' internal decisions to disconnect or a result of external environmental factors. The theory suggests that internal decisions to disconnect seemed more appropriate with decoupling from the system, whereas the environmental factors were related more to inattention. In 'real life' the concept of inattention occurred as a temporary phase, in which people despite being disengaged remained connected as a result of notifications they received and read, or discussing the information received from GMKIN outside the media. Task inattention, a *'transient disengagement of attention from the dynamic features of the task'* (Cheyne et al., 2009: p99), is influenced by stimulus and could be affected by incidental factors, performance errors and near-misses (Cheyne et al., 2009). An example described by P1 was *'still trying to do my walking during the day but even then I crank up the volume on my laptop so I can hear messages'*. Patients decoupled from GMKIN influenced by factors such as overwhelming information, health issues or negativity. Similar to Cheyne et al. (2009), the decoupling occurred as a result *'conscious processing from online environmental sensory information as attention is directed inward to thoughts and feelings'* (p100).

Notifications emerged as a strong influencer of re-engaging patients with GMKIN, after decoupling and task inattention. For example, the CMO (P12) configuration was indicative of how notifications contributed to re-engagement after decoupling, whilst CMO (P5) was re-engagement after inattention. Reminders have previously been found to contribute to an upsurge of use of online interventions in web interventions (Nordfeldt et al., 2010).

Time, age, health literacy, confidentiality and privacy, the quality of information and technical challenges were influencing factors of engagement. A patient indicated that those who were not in employment were more likely to engage in conversations and become influencers of the community. Despite younger patients' perceptions that older patients were more prone to use GMKIN, age did not in fact influence the level of engagement, with patients aged over 60 years sharing the conversationalist role. This challenged previous evidence that found patients below the age of 50 were more likely to engage in conversations (Chan & Dicianno, 2011).

Patients indicated that health literacy influenced the level of posting and digesting of the information, indeed as previously acknowledged patients only use information if they can understand it (Sarasohn-Kahn, 2013). Information quality emerged as an important factor influencing engagement. It was linked to the personal experiences of members, the information curated (research, links to resources) and presentation, similar findings by Oh & Worrall (2013). Interestingly, the findings of this study highlighted that it was more likely for patients to absorb and apply informal information from GMKIN as opposed to prescriptive information gathered from healthcare professionals.

Privacy was linked to engagement, mainly to Facebook, having to use a personal profile to join the group was linked to fears of breach of their privacy, exposed in other studies (Applebaum et al., 2013). Those who feared becoming part of GMKIN on Facebook have used the GMKIN platform with an anonymous profile, where they could write blogs and post comments. Therefore it was crucial to provide multiple communication channels, which patients can choose from and meet their preferences and needs.

Technical issues (usability, access, challenge) were factors that patients indicated that it influenced engagement. The familiarity of Facebook addressed existing challenges on technical issues; therefore it was the most popular platform engaged with and by the most active patients, reinforced by other studies (Merolli et al., 2013). However, the variety of posting capabilities within these platforms was confusing for patients and training should be designed to better explain how these work.

The factors identified in the engagement model highlighted and extend the evidence base of information on what influences engagement.

### ***Variability of patient roles***

Social media was previously associated with various levels of engagement in creating and distributing content (Javornik & Mandelli, 2013). The findings emerged from this study highlighted that patients engaged with GMKIN and that happened on different levels, the highest level of contribution (influencers), mid-level of contribution (conversationalist) and low level (browsing). These levels were not a segmentation of a particular group; often those in higher groups shared all three levels. Similar categories have been described previously as posters and lurkers (Demiris, 2006; Rau et al., 2008; Petrovic & Petric, 2014) or a more complex classification is that of sharing, co-developing, learning, socialising, and advocating (Brodie et al., 2011). However, the influencer on GMKIN shared more responsibility than just advocating, involving almost all other processes. The influencer fulfilled the taxonomy created by Brodie et al. (2011); their role involved co-creating and sharing information, socialising and advocating whilst learning new knowledge from the members. In addition, unique to this influencer role was that of wishing to make the community work. The role was more comparable to that of an opinion leader, *'the individuals who were likely to influence other persons in their immediate environment'* (Katz & Lazarsfeld, 1995:p3; cited by Uzunoğlu & Misci Kip, 2014). Within social media environments, more specific Facebook groups and blogging, the influencer role was significant in creating an environment, which stimulated conversation and empowered members by observing, analysing and posting content.

The conversationalist role was shared by those users, who were active posters, in the form of writing a blog, starting a discussion or providing feedback (Bernoff, 2010). Their role on GMKIN was crucial to influencing members' engagement by providing feedback and keeping the conversation going.

Another level of engagement identified on GMKIN was that of browsing. This role was associated with reading and collecting information (Thackeray et al., 2013), which contributed to their learning (Gray, 2004). In previous literature the role would be comparative to a lurker or a passive member of the community (Nonnecke & Preece, 2000; Preece et al., 2004). The browsing mode was a predominant role within GMKIN. The findings complemented previous research which indicated that those who prefer to browse through information do not engage in conversations. They account for more than half of members (Nonnecke & Preece, 2000), which was similar in GMKIN case. Browsers share

the same values and are familiar with the information and conversations as much as the conversationalist and influencers (Schneider et al., 2013). Despite benefiting from the information shared on GMKIN, the passive role was preferred when patients did not feel they had sufficient experience of the illness and had joined primarily to gain new knowledge. Patients sharing this role demonstrated a benefit of an increase in self-efficacy similar to the influencer and conversationalist (Mo & Coulson, 2010), which contradicted the suggestion that social interaction was not linked to behaviour change (Thackeray et al., 2013). Similarly with CoPs the domain of learning and increase in knowledge is distributed over a period of time (Wenger et al., 2002). Members (at all levels of engagement) initially join the community as newcomers and over time they become familiar with the norms of the community. As a result they start to become more involved making the community work (Lave & Wenger, 1991), especially at conversationalist and influencing levels.

### ***The health engagement model***

The main purpose of this study was not to create a new model of engagement, instead the focus was on understanding how patients engaged with GMKIN and what were the influential factors, building on existing theory through applied research. However, analysing the data, new patterns emerged related to the process of engagement (Figure 9). This combined knowledge from literature applied to brand communities and social networking (Bernoff, 2011; Brodie, et al., 2011), ecommerce, web-searching Webcasting, and gaming (O'Brien & Toms, 2010) in an attempt to map similarities within healthcare.

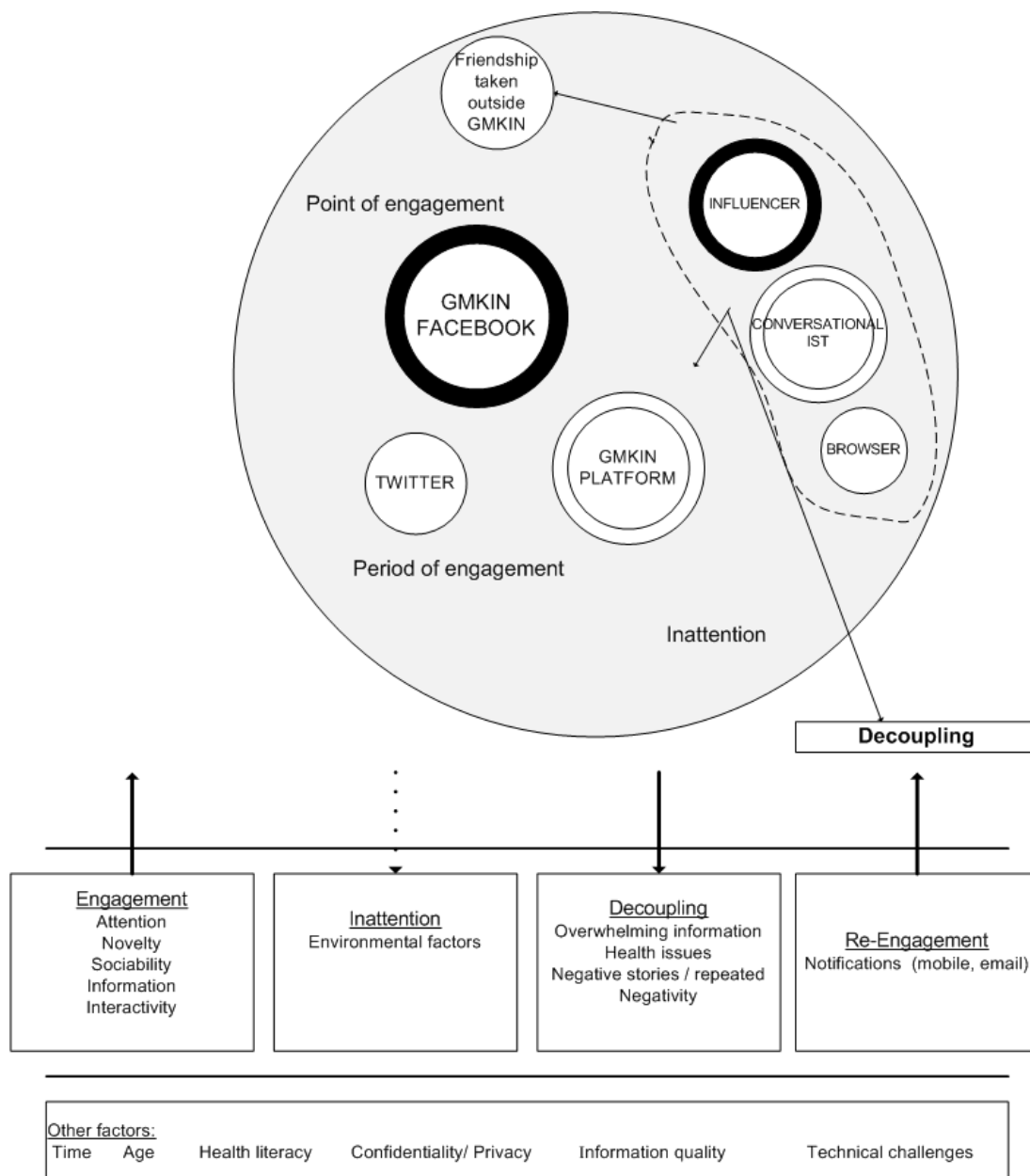
Different modes of engagement were established: engagement, inattention, decoupling and re-engagement. Although, this model provided limited information of the point of engagement, because patients had not dropped in; instead they joined GMKIN since the early phase of development. Further research is needed to establish the factors that influence the point of engagement. Within this new model it describes the process and how Facebook contributes as a first point to engagement. Facebook remained the central route that patients take to engage with GMKIN resources, involving the most active users. The GMKIN platform was less accessed (directly) by patients. In addition, those with an account only on GMKIN Platform preferred this route because of the ability to create an anonymous account to openly share feelings (Chung, 2013). Twitter was used to retrieve information, which was posted as news items on GMKIN.

Existing literature on health engagement has been measured using mostly the total number of unique visits to website features and the length of time spent on a site (Merolli et al., 2013; Lawlor & Kirakowski, 2014) which is more relevant to the concept of participation



(Poorrezaei & Heinze, 2014). Other attempts include the use of Theory of Planned Behaviour (Ajzen, 1991) to predict user intentions to continue to use Facebook (Al-Debei, 2013). However, the validity of TPB was questioned for studies involving people with a long term condition (Sniehotta et al., 2013). The area in which O'Brien & Toms (2008) developed their engagement theory focused on searching the web, ecommerce, Webcasting, and gaming, which was not entirely focused on social networking, and its social interaction element (Shippis & Phillips, 2013).

Figure 9: The Health Engagement Model



The engagement model developed from this study involved behavioural, emotional and cognitive functions that constructed a positive and quality user experience with technology, influenced by attributes of: '*challenge, aesthetic and sensory appeal, feedback, novelty, interactivity, perceived control and time, awareness, motivation, interest, and affect*' (O'Brien & Toms, 2008: p949). The results from the analysis of engagement with GMKIN support and dismissed some of factors identified in O'Brien & Toms (2008) model. It takes forward the attention, novelty, and interactivity, but also includes additional factors that primarily influenced engagement that of sociability and information. Furthermore, the evaluation of the theory in health identified that health issues directly influenced disengagement (decoupling) and exposed the valuable role of notifications to promote re-engagement. Usability and challenge were combined with time, age, health literacy, information quality and confidentiality under technical challenges.

Unique to this model was the addition of three specific new forms of engagement (influencer, conversationalist and browsing), which indicated the extent to which patients engaged with GMKIN. Within the field of social media, users influence the success of interventions (Glasgow et al., 2007, Christensen et al., 2009; Poirier & Cobb, 2012; Archambault et al., 2012).

In summary, patients engaged with GMKIN often because they have a goal in mind (O'Brien & Toms 2008). After their initial engagement point, the majority of patients suggested that they remained connected and only temporarily disengaged. Whilst disengaged from GMKIN, they mentally remained connected with the application via the notifications, and took the discussion offline (Inattention). The other facet of disconnection was decoupling, in which patients intentionally stepped out of GMKIN as a measure of protection or because of health issues. Inattention was only temporary, patients returned to the application at least on a weekly basis, whereas those more active returned daily. Disengagement was not a defined step within social media, instead it took two different modes (inattention and decoupling), influenced by several factors. Patients disengaged because of environmental factors, health issues, and negativity, but were often persuaded back onto GMKIN because of sources such information generated from patient's real stories.

The model extends the social element of the O'Brien & Toms' (2008) engagement theory, which lacks emphasis on social interaction. Sociability was a new factor that directly influenced the phases of engagement. In addition the O'Brien and Toms' model did not consider the level of engagement or how much patients contributed, which again were crucial elements underpinning the activity in GMKIN and use of social media. The additional levels of engagement enhanced the model outlining the extent to which patients engaged. It

focused on the behavioural aspect of engagement highlighting motivational factors (Van Doorn et al., 2010), emotional and cognitive processes (O'Brien & Toms, 2008; Javornik & Mandelli, 2013) and the social dimension, demonstrating levels of interaction among individuals in the community (Javornik & Mandelli, 2013).

### **The role of mechanisms: what social media mechanism works for whom, and why**

Middle range theories were the highest level of abstraction of social phenomena, known as simple theories (Boudon, 1991) indicating how mechanisms work in contexts to trigger outcomes (Pawson & Tilley, 1997). The middle range theories identified through the extensive realist review were tested and refined using data collected and observed within GMKIN (CMO1-5). The results highlighted the mechanisms work in specific contexts, providing outcomes and challenges. However it was impossible to identify all-encompassing variables that apply in all social processes (Boudon, 1991), which was why the context specific CMO configurations provided real life patients scenarios of positive and negative outcomes generated from the applied research of GMKIN. Although GMKIN encompassed a single patient group (renal), these patients had a long term condition and were likely to be suffer from multiple illnesses (DH, 2012), which made it possible to study mechanisms in the wider context of long term conditions. The middle range theories are critically discussed to expose a family of potential working mechanisms.

The data retrieved from respondents was indicative of the fact that GMKIN was an informational resource, the main information being generated by patients who engaged with the different mechanisms. The CMOs identified five different configurations:

- the role of SNS in allowing patients to join and connect with fellow patients to access healthcare information and find support (CMO1)
- the role of Facebook as a source of information, support and pleasurable experience which engages more active users (CMO2)
- the role of Twitter in engaging patients (CMO3)
- the effect and role of blogging in triggering information generation (CMO4)
- the role of forum (CMO5)

The configurations were revisited in turn in an attempt to establish a working framework identifying what works for whom and why, proposing key contextual factors, mechanisms, outcomes and key challenges, discussed in the wider context.

### ***The role of SNS (CMO1)***

The information received offline does not fulfill patient information needs of patients seeking information (context) therefore they join SNS website in order to connect and network with other patients (mechanisms), which enables them to access information and support (outcome).

Patients with a long condition often suffer from various complications and multiple illnesses (DH, 2012), and providing information that meets the need of patients remains a challenge (Ormandy, 2008; Schinkel et al., 2013), mainly as medical staff have minimal time to respond to their queries (Haase, & Loiselle, 2012). The findings from the current study suggested that patients had unmet needs, which is why they turned to GMKIN to seek information, findings supported by previous research (Griffiths et al., 2012).

Social Networking Sites enabled patients to join this site, connecting with other members (Ellison et al., 2007). Patients had to engage with the site to gain any benefit from the platform. As identified above in the Health Engagement Model patients engage if they have a goal in mind (O'Brien and Toms, 2008), and gaining new knowledge was a goal indicated by patients. In addition to joining the sites, patients indicated a level of friendship, a sociability factor emerging as a result connecting and engaging with fellow renal patients. As previously acknowledged users with intimate relationships were more predisposed to communicate with one another (Shin & Lee, 2012). As a result of joining social networking platforms, connecting and developing friendship patients reported outcomes such as access to healthcare information and support (Bacigalupe, 2011; Kata, 2012; Rogers et al., 2011; Merolli et al, 2013).

Patients reported increased perceived support as a result using GMKIN, a finding supported by previous studies (Solomon et al., 2012; Richardson et al., 2010).

- Key contexts to take forward were: variability of patients with a long condition, with unmet informational need, who register interest to seek information
- Key mechanisms were joining social networking platforms, and connecting to develop sociability
- Key outcomes included access to healthcare information, and support
- Key challenges associated with SNS (recognised by patients as Facebook) were the level of personal detail circulated by members on personal walls

## ***Role of Facebook (CMO2)***

Variable attitudes to dealing with self-disclosure, and disclosure by others, in an online conversational setting (context) allowed conversations among participants, the use of humour and supported coping (mechanisms) leading to more community engagement, feeling part of active learning and sharing (outcomes).

Social media allowed users to be engaged at different levels in creating and distributing content (Javornik & Mandelli, 2013). As a result of patients engaging with social media sites various levels of engagement resulted: influencer, conversationalist and browsing. Each level influenced the level of information generated and support. Facebook was an easy to use mechanism, rewarding and reassuring when conversations happens, a view supported by Kim & Vender (2014), which fulfilled patients free time, up to the point of addiction.

Patients perceived a partnership existed between patients and healthcare professionals on Facebook GMKIN, which brought benefits to both parties. Patients perceived the role of healthcare professionals as an authority, which could intervene when there was misinformation. There was a level of expectancy of general advice (not medical) and signposting. At the same time, medical professionals by being part of the group gained knowledge on how patients lived with the condition. The patient's perceptions were different to those who were medically trained (P8), who believed that patients expected medical advice. No previous literature was identified that supported the two opposing views, existing evidence highlighted that patients preferred interventions managed by medical personnel, who ensured the quality of the information (Armstrong et al., 2007; Applebaum et al., 2013). However, it emerged that a partnership between the two was preferred, where learning occurred for both parties. Other studies have called for increased collaboration between patients and healthcare professionals on social media (Van de Belt et al., 2012).

A further context related finding was that patients joined GMKIN Facebook group and other renal groups to occupy time and retrieve information but engagement was minimal because of issues associated with these groups, including negative discussion (backbiting). This was an interesting finding, which strengthened the local partnership, which these patients preferred compared with other groups.

Another unique element of this study was the role played by Facebook to engage patients in mixed interventions like GMKIN. Patients indicated that the mechanism was perceived like a central route to information. Most patients reported using Facebook, which in their opinion

was a source of information and social support. Previous evidence suggests that Facebook plays a major role on information provision and support (Chan & Dicianno, 2011; Merolli et al., 2013). The information retrieved through links and posts widened their knowledge about the condition, biomedical aspects and medical advances, which were patients information needs (Ormandy, 2008; Astin et al. 2008; Van Weert et al., 2013; McNair, 2013). It became evident after six months of following the study participants that patients placed a great emphasis on the patient experience of living with the condition information.

Patients perceived Facebook as a mechanism that allowed them access to light hearted conversations, which were beyond the doom and scary discussion about the disease. Somehow, the humour and conversations outside the illness alleviated the distress caused by posting information about the illness. Previous research found that patients' posting about their own condition was correlated to increased level of stress (Shaw et al., 2008; Welbourne et al., 2013). This was a strategy adopted by the researcher and influenced by the work of Kim & Oh (2009) who highlighted that humour was an evaluation factor of user satisfaction within online communities. In addition the community manager acting as influencer stimulated conversations and sociability crucial factors for engagement, also identified by Lai & Chen (2014).

A significant issue with the group on Facebook, usually for patients new to the condition, was the information shared, could be perceived as overwhelming (CMO P12). Previous studies have acknowledged that it was normal to feel overwhelmed (Ormandy, 2008), especially when the information was readily available (Adams, 2010). Through GMKIN it was found that by acknowledging to patients that their feelings were normal influenced their decision to temporarily decouple from GMKIN but re-engage as a result of notifications received. Another potential practical solution proposed by a patient was to have groups for each treatment modality (pre-dialysis, dialysis, and transplant). Repeated negativity did stop those with contradictory views posting (Guan, 2006). Although some patients did not post if they were unsure what to write, some preferred to remain anonymous (hence using the GMKIN Platform) to be able to openly share their emotions (Chung, 2013). It was envisaged that social media was not working for everyone and that there were individuals who preferred more face to face communication.

- Key contexts to take forward were: variability of patients with a long condition, attitudes to dealing with self-disclosure, and disclosure by others and different engagement levels
- Key mechanisms were: conversations among participants, use of humour and social support

- Key outcomes included leading to more community engagement, feeling part of active learning and sharing
- Key challenges associated with overwhelming of information, repeated negative experience associated with illness, difficult to maintain anonymity, in favour of face to face contact

### ***Role of Twitter (CMO3)***

Patients with variable needs and preferences of tools, who are proficient with using IT (context), take part in in conversations with other users, follow medical staff and become advocates of specific causes (mechanism) leading to more active use of Twitter.

Twitter was a platform that patients did not prefer to use. It was a mechanism preferred by the influencers (community leader) and those who reported good IT skills (occasional use of the medium) to follow and engage in conversations and retrieve information. The remaining users either had an account but only used it occasionally or were not interested to join Twitter.

Previous research (Scanfeld, 2010; Bonetta, 2009; Lee & Kim, 2014) suggested that Twitter is mainly an informational resource and not a social network, which applied to GMKIN as well. The findings indicated that users engaged in conversations contributing to constructing new connections but not to the extent to which friendship is formed: *'Facebook you can keep it within family and friends. And so it's much more personal. So I think it will always be Facebook over Twitter for me'* (P13). Unlike the Facebook group, which was closed to protect patients' confidentiality, Twitter was open with potential to reach a wider audience.

Despite the potential of Twitter to be used as an information outlet for information sharing (Scanfeld, 2010), or for conversations and sociability (Zhao & Rosson, 2009; Lee & Kim, 2014) and follow medical staff, it did not actively engage patients. However, the mechanism could be used to advocate GMKIN. Patients who were not actively using Twitter had stated that the main reason was the technical challenge, it was difficult to understand. A previous study suggested that technology gratification (easy of using technology) influenced the continual use of the platform (Liu & Rogerson, 2012). Twitter was perceived by patients as a media predominantly used by celebrities and media people with an agenda.

The influencers (the community leader and myself) organised a training sessions for use of Twitter, which patients we not able to follow. One of the patients suggested organising a face to face training session.

- Key contextual factors included the influencer (community leader), who was comfortable in using Twitter and able to follow and engage in conversations
- Key mechanisms triggering engagement were informational resource, engaging in conversations, following medical staff and advocating
- Key outcomes were engaging wider audience
- Key challenges were technical issues and useful for thus interested to follow celebrities and people with an agenda

### ***Role of blogs (CMO4)***

The variability of patients' needs, preferences for tools and their availability (context) allows patients to narrate emotional life experiences and support others in a similar condition (mechanism) contributes to information provision, alleviation of emotional distress and positive feelings (outcome).

Patients prevailing circumstances influenced the process of blogging. Existing literature was indicative of the fact that blogging was time and energy consuming, often patients felt fearful of how others were judging their feelings and behaviours, and negative opinions (Ressler et al., 2012), factors echoed by GMKIN bloggers. In addition patients' experience with the illness contributed to the level of posting and those new to the condition felt unequipped to post. This was a result of GMKIN being used by patients at different stages of their illness, on different treatment modalities.

The findings from this study indicated that the process of writing blogs, despite being an onerous task, allowed patients to narrate their stories. Patients' bloggers indicated that writing blogs has helped them to release emotional tension whilst helping others in a similar condition. Furthermore, the meaningful conversations generated among members of the GMKIN community as a result of feedback had a therapeutic effect, reflecting similar findings within other studies (Nardi et al., 2004; Chung & Kim, 2008; Marcus et al., 2012; Schatell, 2013; Merroli et al., 2014).

The blogs posted by patients contributed to the patient generated content (Savolainen, 2011), which in return has helped to fulfil patients' needs for information. However, patients



indicated how technical challenges influence their use of blogs. It was suggested that written blogs should be shorter for patients to read as their attention span and visual impairment could affect the reading process.

- Key contextual factors highlighted that blogging required time, influenced by a patients' illness experience
- Key mechanisms were helping fellow patients, allowing patients to narrate their stories
- Key outcomes included the release emotional tension, therapeutic effect, and patients generated content
- Key challenges of concentration called for shorter blogs

### ***Role of forum (CMO5)***

The convenience and usability of Facebook (context) replaced the need of patients to use the forum (mechanism) leading to OC not working in this particular context (outcome).

The online community created on the GMKIN (the forum) has not been used by patients. This contradicted existing evidence which acknowledged that online communities were the most widespread peer to peer communities contributing to information provision and support (Eysenbach et al., 2004; Buchanan & Coulson, 2007, Coulson et al., 2007, Malik & Coulson, 2010), improving patients health outcomes and self-efficacy (Merolli et al., 2013). In this context the GMKIN Facebook replaced the need to have a forum. Although if a forum was deployed the community manager could emphasise more the role of the forum, as well as offer training to enhance use.

### ***Key connection elements***

Connections were dependent on the setting and external constraints (Greenhalgh et al., 2009) such as: variability of patients context such as time, beliefs about mechanisms being addictive, collaboration with healthcare professionals, familiarity with technology, communication and sociability skills, their unmet needs and interest to seek information (Table 41).

A key element to realist evaluation is that of mechanisms, which indicates the logic of an intervention, the behaviour and relationships of the intervention responsible for change (Pawson & Tilley, 1997, Pawson & Tilley 2004; Pawson 2005). The power of mechanisms

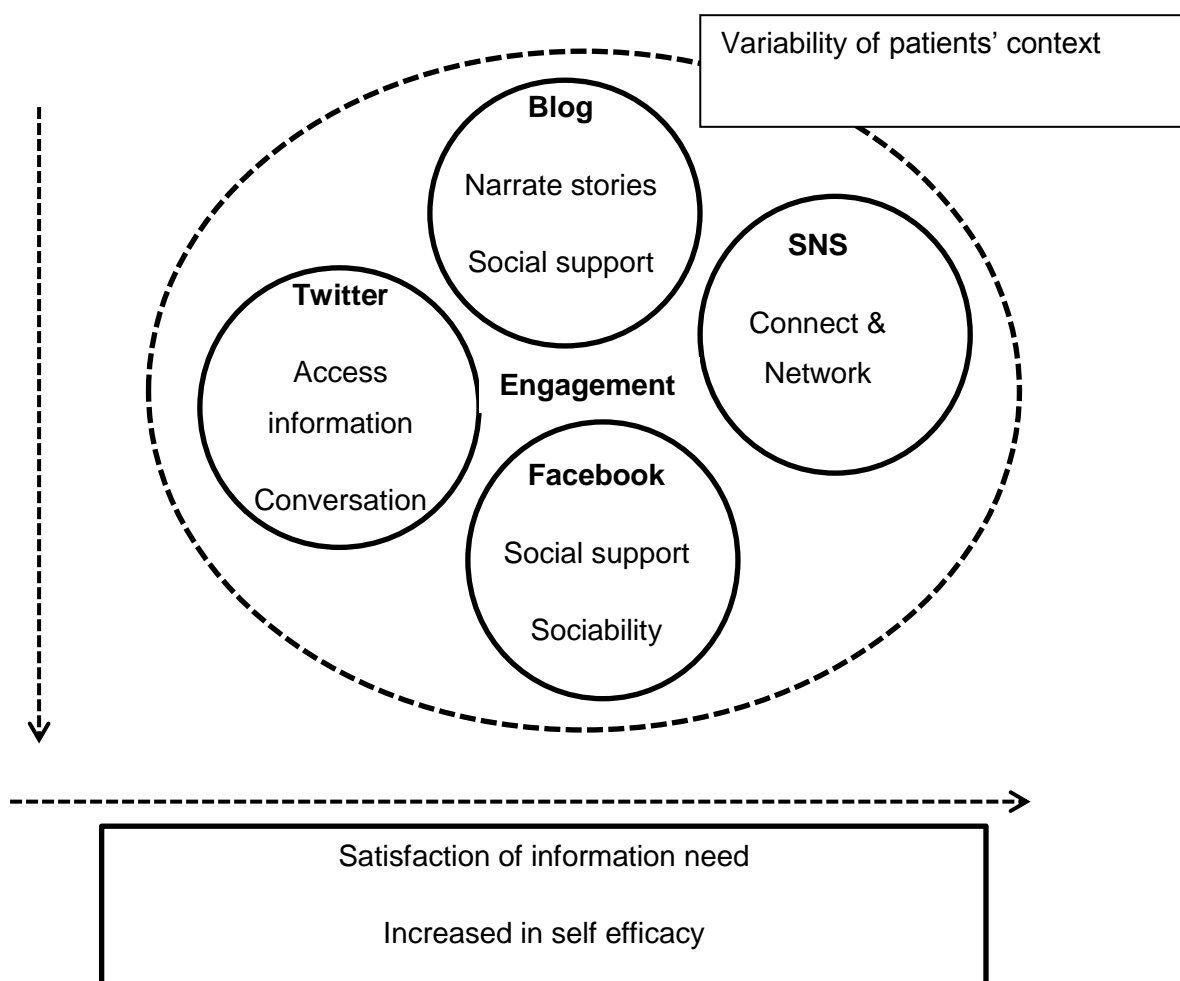
was that of connecting the gap between theory and implications for practical recommendations (Goicolea, 2012). The outcomes were the sum of mechanisms working in a specific context (Pawson & Tilley 2004).

*Table 41: Key connection elements*

| CMO  | Context  | Mechanism   | Outcomes  | Challenges  |
|------|--|---|---|---|
| CMO1 | variability of patients with a long condition, with unmet informational need, who register interest to seek information  | to joining social networking platforms, and connecting to develop sociability     | access to healthcare information, and support                             | level of personal detail  |
| CMO2 | levels of engagement, patients have free time to occupy, use Facebook, which is easy to use, rewarding and reassuring and additive, partnership with healthcare professionals, use of local and other renal groups | source of information, social support and sociability                             | engagement of active users  | overwhelming of information, repeated negativity, not sure what to write, anonymous, prefers face to face |
| CMO3 | influencer (community leader), who was comfortable in using the medium and able to follow and engage in conversations  | informational resource, engage in conversations, follow medical staff, advocate   | engage wider audience   | technical issues and useful for thus interested to follow celebrities and people with an agenda           |
| CMO4 | blogging requires time, patients' illness experience   | Blog stories are helping fellow patients, allow patients to narrate their stories | release emotional tension, therapeutic effect, patients generated content | shorter blogs   |

CMO1 to CMO4 were interconnected (Figure 10). CMO1 and CMO2 had almost a roller-coaster effect; patients to benefit from information, social support and sociability initially join the SNS (Facebook) (CMO1). These platforms enable patients to create accounts, connect and network with other patients synonymous with findings from Chan & Dicianno (2011). This was triggered by them acknowledging their information needs and registering an interest (goal) (O'Brien & Toms, 2008; Ormandy, 2008). By joining the interventions, patients gained access to information, advice and support (Merolli et al., 2013).

Figure 10: Connecting CMOs



P10 summed up each role within GMKIN intervention:

*'It's almost like, if you imagine like a university campus, Twitter is like the notice board and then Facebook is the student union and then the website is like the resource library. So it kind of depends on what you are looking for' (P10)*

Among these Social Networking platforms, Facebook was the central route to social support, sociability and the information available on the group and links to other resources (GMKIN Platform), which engaged more active users (CMO2). Patients' levels of engagement, structure of the platform, potential partnership with healthcare professionals and other groups were contextual factors that influenced the amount of social support, sociability and the information available.

Twitter worked for patients with good IT skills, keen to promote themselves and their cause. It allowed them access information, engaged in conversations and connected to medical staff (Scanfeld, 2010; Zhao & Rosson, 2009) but did not necessary foster friendship (Lee & Kim, 2014). It is used more to advocate the intervention and did not engage active patients in conversation. The influencer used the medium to push information generated on GMKIN and gain new information to supply on GMKIN (CMO3).

GMKIN platform allowed patients to write the blogs. The process of generating information was influenced by contextual factors such as patient experience with the illness and time to dedicate to the writing and editing process. The process of creating and sharing blogs was influenced by motivational factors such as willingness to helping others contributes to the conversations and feedback received. The level of feedback posted on GMKIN formed part the strategy tested by the community manager to influence engagement. Comments on existing blogs were encouraged through the influence of other members. The evidence from GMKIN indicated that posting comments during periods of silence brought the community alive and stimulated more conversation. Patient bloggers reported therapeutic outcomes such as tension release and the stimulus from feedback, and for the wider GMKIN outcomes, it contributed to patient generated information. Indeed previous research highlighted that blogs contribute to information generation (Ressler et al., 2012; Merolli et al., 2013) (CMO4). A finding unique to this study was that forums were not working when an intervention included Facebook as a resource (CMO5).

### **Satisfaction of information need**

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|--|
| The information generated on GMKIN (PGI), in the form of patients stories satisfied patient's needs, namely information about living with the condition, treatment options, recognition of symptoms and long term expectations |
|--|

Social Media was seen as an online technology and a social revolution (Downes, 2005; Kaplan & Haenlein, 2010; Schneiderman et al., 2011), therefore apart from the technology, the social element was equally as important. In this context, GMKIN activity demonstrated that for health interventions to be successful, three levels of engagement (influencer, conversationalist and browsing) had to occur in order to stimulate sociability, learning, socialising, and advocating but more importantly creating and distributing content (Javornik & Mandelli, 2013).

The role of users, who were browsing, was important because the size of the network influenced the diffusion of USG (Thompkins & Rogerson, 2012). Each platform played a different role in engaging patients (CMO1, CMO2, CMO3, CMO4). As a result of engaging with GMKIN, patients created shared and accessed information, satisfying information needs. The needs were primarily information on the treatment and condition, symptoms and expectations and self-management, reflecting needs exposed in previous research (Astin et al. 2008; Van Weert et al., 2013; McNair, 2013).

Wilson (2006) suggested that the inability to satisfy cognitive needs (disclosure of need) triggers affective needs such as fear. Through the GMKIN intervention it was revealed that patients return to social media, more often to the Facebook group, fearing of not knowing what was happening. By engaging in conversations with fellow patients, the fear was alleviated. Despite that the information from peers was ranked lower with patients finding it a useful source rather than expressed as a direct information need (Ormandy & Hulme, 2013), the majority of patients accessing GMKIN indicated how they benefited from accessing experiential information from peer stories, similar to Vennik et al. (2014).

It was noted that patients were unaware of information deficits or they deferred a need (Ormandy, 2008). The study findings exposed information deficit when a patient highlighted not knowing about different forms of treatment till they had read it on the site. Others measured themselves against patient stories and realised they were not doing too bad (CMO P5). The CMO (P7) provided an example of how patients deferred a need by choosing to ignore the process (decoupling from GMKIN). Despite decoupling from the intervention they made changes to their lifestyle to preserve the condition, based on the information found. Indeed, Ormandy (2008) found that managing the CKD condition was one of patients' main information priorities, and the findings are strengthening the view that information from social networking is used for diagnosis, self-management and monitoring of treatment (Griffiths et al., 2012). Patients acknowledged the biomedical information shared on the GMKIN intervention, with information shared about the medical condition and medicine contributing to the satisfaction of unrecognised needs (CMO P7 and CMO P10). Furthermore, the exchange of information that occurred within the community supported learning, a key role of a community of practice. By being part of the community and disclosing information patients learnt about their illness and how to maintain health.

Cole (2011) vision of information need as a process of searching for information, metaphorically seen as going through a tunnel has implications for designing systems to provide information to patients, the theory mandating strong aesthetic and affective system

components. The fact that the GMKIN Platform, used for blogging, was developed using O'Brien & Toms' (2008) theoretical propositions with emphasis on aesthetics, could have positively influenced the searching and location of information.

### **Impact on self-efficacy and other outcomes**

The engagement with GMKIN and satisfaction of information need, contributes to an increase in self-efficacy and increased well-being through vicarious experiences, perceived confidence gained from helping others and social persuasion

The data retrieved from respondents was indicative of the fact that GMKIN was an informational resource, the main information being generated by patients who engaged with the different mechanism. The CMOs described earlier presented five different configurations, which together contributed to patients' satisfaction needs. Throughout the study, other overarching outcomes tested included increased self-efficacy as a result of engaging with GMKIN and satisfying their information need. Current evidence provides mixed views on social media contribution to positive health outcomes. Lawlor & Kirakowski (2014) highlighted that active participation was not directly linked to positive effects on illness, whereas Roblin (2011) found similar to GMKIN that social media did increase self-efficacy.

According to Bandura (1997) individuals draw on four different types of sources to discern self-efficacy: enactive mastery experience, vicarious experience, social persuasion, and physiological and emotional state. Enactive mastery experience was linked to prior experiences, such as experiences in contributing to GMKIN and receiving positive feedback, which increased patient confidence in their ability to help other patients. The findings from GMKIN suggest that patients built on skills which increased their self-confidence, such as the community leader (P1) in his role as influencer described how achieving tasks on GMKIN contributed to his increased self-efficacy. Vicarious experiences or access to other stories influenced self-efficacy (Bandura, 1997). Browsing through GMKIN content in the form of blogs or posts on Facebook (patient's stories) directly contributed to a patients' increase in self-efficacy (CMO P5). Patients indicated that seeing other people's stories had given them a new outlook to life; reducing negative perceptions of being different (Armstrong, 2007). P1 sums up the benefits of access to vicarious experiences:

*'I think that it is a key lesson for people going into it, virtually everything you come across someone else has gone through, someone else has learnt from' (P1)*

Receiving feedback was part of the social persuasion influence on self-efficacy (Bandura, 1997). The positive feedback posted by conversationalists on GMKIN Platform and GMKIN Facebook has encouraged patients not only to engage in posting but encouraged their self-efficacy perceptions. The final source of self-efficacy pinpointed by Bandura (1997) was that of physiological and emotional state, which were more linked to physical activities not pertinent to GMKIN.

The qualitative findings were reinforced and strengthened by the quantitative scale measures. It emerged that 13 out of 14 patients reported an increased self-efficacy from at least one of the instruments, and almost half reported an increased self-efficacy in both instruments (chronically ill self-management and general health self-management). P1, P5 and P12 (patients with self-reported depression) measured a statistically significant increase in at least one domain. These findings confirmed previous evidence which has acknowledged the benefit of social media in increasing self-efficacy of patients suffering from depression (Bessi re et al., 2008; Merolli et al., 2015). Furthermore P7, P8, P9, P11 and P14 reported significant increase in self-efficacy. The results of the study indicated that increased self-efficacy was not directly linked to the age or diagnosis. Similarly, the level of posting did not influence self-efficacy, all levels and types of users reported benefit gains (Mo & Coulson, 2010; Merolli et al., 2015). Self-efficacy was independent of the context of each patient, (apart from the three patients with self-reported depression) and findings suggested that the progression of the illness may negatively influence and undermine a person's self-efficacy (P10). Interestingly P10 joined GMKIN having their goal: *'to show other people that is possible that even if you are suffering from illness you can still get out there and still do things'*. The patient suggested that she did not envisage that being ill had affected her ability to engage in outdoor activities.

According to previous research it is not clear whether increased self-efficacy contributes to health outcomes. Whilst increased self-efficacy has been correlated to better management of symptoms and better quality of life (Pitt et al., 2013; Teixeira et al., 2015) other studies report contradictory results (Griffiths et al., 2007; Olander et al., 2013). According to the GMKIN study patients indicated better health outcomes, however it was not clear if that was a result of increased self-efficacy. For example CMO P5 suggested that depression was a result of social isolation and by being involved in GMKIN gave him a different perspective on life, although no direct connection can be inferred. P1, who reported a statistically significant score in self-efficacy, reported enormous benefits in terms of self-confidence, self-esteem and feelings of self-worth. P10 despite a decrease in self-efficacy scores identified that after reading other patients' stories she *'feels better'*.

The GMKIN findings indicated that 3 patients (P1, P2 and P12) intended to seek employment as a result of their activity or receiving information to satisfy their needs which could be linked to their involvement in GMKIN, as a result of which they increased confidence and self-efficacy, a finding unique to this study and an outcome of social media. In addition, GMKIN patients as a result of the information retrieved, reported changes in the way they self-managed their illness (Griffiths et al., 2012).

The evidence of social outcomes emerged through GMKIN, a concept supported by very limited empirical evidence other than a study by Merolli et al. (2015) who reported social outcomes such as enjoyment of life and positive relationships with others. The affiliation with the community identified social benefits among which trust, social camaraderie, friendship, and affection through light and friendly conversations (welcoming messages), social support and the human side (such as showing pictures of my garden). The result from GMKIN highlighted the bonds created amongst members. Putman (2000) previously introduced the concept of bridging and bonding social capital. In the context of GMKIN both types of connection emerged; some of the patients stated that the connection with the community was primarily to exchange useful information (bridging) whereas other reinforced the bonding (affection, emotions) emerged as a result of engaging with peers (bonding social capital). In previous studies weak ties were more prevalent (Hampton, 2002; Ellison et al., 2007; Tufekci, 2008); social capital was found to support reducing stress (Mikal et al., 2013) and support better quality of life (Kavanaugh et al., 2005).

### **The influencing roles – practical recommendations**

The debate around engagement of patients is not over yet. Generally studies report that users of social media are passive and that communications and engagement remain a challenge (Merolli et al., 2015). This study provided an alternative view to the engagement of users, which was practically tested, and positive results determined through empirical research. The GMKIN intervention not only demonstrated that patients engaged in conversations and produced and shared patient generated information but this remained sustainable beyond a six month period. Iriberry & Leroy's (2009) model proposes that a community is developed in four stages: inception, establishment, maturity and death (Millington, 2012). A community is mature when 90% of the activity is produced by users (Millington, 2012), which occurred on GMKIN. The content and the interactions were produced by members stimulated by the influencer. This was attributed to a number of factors; stimulating engagement, trustworthy information, and revising operating policies.



### ***My role in stimulating engagement and sustainability***

GMKIN was successful in engaging patients over a longer period and that was a result of a strategy adopted after reviewing existing evidence (O'Brien & Toms, 2008; Brodie, et al., 2011; Uzunoğlu & Misci Kip, 2014) and my experience gained from previous social media projects. The knowledge was applied to GMKIN, an intervention which combined key social media mechanisms. The GMKIN community is continuously growing with plans to expand the work across Greater Manchester and a national franchise of local groups.

As a web developer and researcher I was influenced in my efforts to create a sustainable community influenced by CoP concepts (Lave & Wenger, 1991; Wenger, 2002). The GMKIN community is currently self-sustainable; the members gradually have become familiar with the community of practice and its norms introduced at the development and building stages. The patient leader (in the apprenticeship role), who joined the community as a newcomer (initially engaging in peripheral participation) gained experience and learnt from my practice and continuous discussions contributing to the growth, establishment and now sustainability of GMKIN.

The development of the community on Facebook occurred in three distinct stages:

- The first stage focus was to increase the community users and that was achieved by sending email invitations (where email addresses were available), and advertising through attending local events and educational days at local hospital.
- The second stage was more complex and consisted of creating an interactive environment that stimulates conversation, socialisation, and empowers other members (conversationalist), achieved by observing, analysing and posting content. In order to develop meaningful relationships among users, stimulating light discussions (by posting content and photos) and trust (by being open and involving members in decisions about the group)
- Finally, it was crucial to identify, support and train patient and patient and future community leaders (influencers). Continuous interaction with the community leader was required to offer support and empower through honesty, trust openness and friendly suggestions, the core element of the relationship being trust.

A crucial contributory factor was ensuring the privacy and confidentiality of the Facebook group members. The group began by being open then disclosure of personal and familial

stories influenced the decision to close the group. Although not envisaged, after closing the group on GMKIN an increase in contribution was noted.

The GMKIN platform was needed to house blogs, news and comments on blogs (feedback). The system enabled patients to register with an anonymous account and be open to allow sharing through other channels (Facebook and Twitter). Whilst developing the system my experience and usability and user testing was helpful to take efficient and quick decision. The role of Twitter on GMKIN was appreciated more by the patient leader, who retrieved information from Twitter to create blogs and news stories and push GMKIN information (blogs) to the wider Twitter community. I envisaged that Twitter would contribute to establishing GMKIN within the health professionals and media context through advocacy and following, which triggered an increased awareness of the brand. Indeed GMKIN as a new intervention has become a renowned brand within the renal and nursing communities on Twitter.

Another important role I had on GMKIN was to provide training to the members involved on how to use social media. I focused primarily on privacy, anonymity and general technical advice. I made myself available to patients who needed advice and reinforced that my role was to help with technical aspects, problems and offer training.

New knowledge gleaned from the continual practical testing of the intervention provided evidence and increased awareness of important factors that influenced and stimulated engagement, which included:

- The deployment of mix communications channels and stimulation of engagement through the user's preferred mechanisms was recommended, with the development of the intervention being user centred and not technologically driven (Laranjo et al., 2015).
- Identify the user's preferred mechanisms and push content via those channels, within GMKIN Facebook was deemed as the most preferred platform which seemed the central route to other resources.
- Trust of the information shared on social media platforms is subject to controversy (Hocevar, et al., 2014). Previous evidence identified that if individuals had concerns over information, believing that the information was false they refrain from sharing (Li & Sakamoto, 2014). From patients' perspective the information shared on GMKIN was less formal and easy to read making it easier to take on board, trusted from a local reliable source (P3, P10).

### ***Revisit operating policy***

Patients indicated how beneficial it was to have clinicians involved in GMKIN. Guidelines, policy, ethical procedures, which often undermine the benefits brought by these tools, should change to include guidelines from real life projects. This was reflected in my work undertaken in collaboration with INVOLVE (National Institute for Health Research, 2014), who acknowledged the lack of such interventions, to develop guidance on patient involvement using social media (<http://www.invo.org.uk/wp-content/uploads/2014/11/9982-Social-Media-Guide-WEB.pdf>). It did not come as a surprise when medical staff perceived the relationship with patients as inevitably focused on health information and not as a partnership, from which both parties were learning about the condition. GMKIN Facebook has become a popular venue for health professionals to join and a further study is required to seek their perceptions about the benefits gained from the group.

Healthcare professionals and other parties involved in this type of interventions should treat social media platforms as a mechanism to connect and communicate with patients and not be intimidated by these 'friendship' venues. Guidelines advise professionals not to accept friendship requests from patients, and that they should not use the information retrieved from online interaction, despite contrasting evidence on the benefit (George, 2013; Moubarak, 2013).

Instead, medical staff should receive training to understand Facebook privacy settings and ability to create groups with whom specific information is shared. Having the experience of running GMKIN, I would strongly suggest that the adoption of social media should be treated as an intervention, in which all offline rules (privacy, confidentiality) are maintained. In Facebook health discussions should take place on closed groups to protect that and policies should ease their tone providing a balanced view on risk and benefits indicating how social media technologies could be positively adopted (George, 2013).

### **Strengths and limitations**

This study received the 'best poster' for innovation accolade at the British Renal Society 2014. In addition, it was considered one of the most innovative and empirical studies within the UK by INVOLVE, who included GMKIN as a case study within their guidance on how to actively involve people in research. The study enabled a deeper understanding and provided in-depth knowledge on how to use social media as an intervention to enhance patient information provision, networking and communication. It has proven through practical implementation and testing of theoretical models that social media interventions, in which

engagement was a crucial component, can trigger positive health and social outcomes. The intervention was developed using both theoretical constructs within a user-centred philosophy. The components were based on extensive research, combining evidence from a variety of research fields beyond health to gather useful concepts, develop and refine middle range theories. The practical running of GMKIN for six months gave a clear indication of why patients engaged, how and why and what was the role of each platform in stimulating engagement and achieving positive health outcomes. The experience and knowledge gained from deploying and running GMKIN has contributed alongside using a mixed methodology to refine the theories and create new knowledge to extend existing theoretical models.

Throughout the course of the study and managing GMKIN from inception to an established community, a number of challenges occurred, which were mitigated with the input of my supervisors and growing experience.

### ***A real world exists but is perceived differently***

By nature, I am neither a journal keeper nor a very good writer; I am a thinker and an observer, which was a gain in terms of making GMKIN work through careful observations and application of influencing strategies to the detriment of my writing. In this light the philosophical stance of this study was suitable. According to critical realism, knowledge is gained initially at empirical level (experience gained from GMKIN), which then was expanded to actual knowledge (refining and development of theory).

The use of realist synthesis was a powerful approach that directed the methodology of the study (Pawson & Tilley, 2001). It enabled the search of evidence to include grey literature and from a variety of fields to strengthen the theoretical underpinning of the study. In this complex social media phenomena, which varied in scope and terminology (Kietzmann et al., 2011), the iterative process allowed decisions to be made based on findings (Pawson et al., 2005), including grey literature as well as predecessors of Web 2.0 with an element of social interaction (online communities). The process added strength to the study, mainly contextual in which a call for flexible qualitative methodologies was needed to understand the concept of engagement beyond quantitative linear causal models (Gambetti & Graffigna, 2010). Likewise the qualitative methods facilitated in depth knowledge of the social phenomenon and gathered views from various disciplines (Gambetti & Graffigna, 2010).

The quantitative tools strengthened the measureable difference GMKIN made in terms of self-efficacy and added depth to the discussion with each patient. There were limitations to

the questionnaire used as patients indicated that measuring self-efficacy in that way was not something they agreed with. More precisely they felt that self-efficacy was affected by mood and by measuring at a six month difference, it may not reflect the reality of the whole period. Indeed the small numbers of the study and primarily the focus on context made further analysis not useful. However, for the purpose of this study it added an element of reassurance that the self-efficacy reported in interviews was supported by quantitative findings.

The use of diaries (logs) intended to record users' frequent visits to GMKIN and the benefits gained, was not an efficient method. The limited data gathered from the diaries was of little use to the research because of patient's did not complete them (Green et al., 2006). A different method was required to track that specific data, but a diary could have added rich data which could have been discussed within the interviews.

The realist synthesis despite providing an opportunity for innovation left the novice researcher open to a wide range of difficulties in conducting research (Greenhalgh et al., 2011). The limited support on the inclusion criteria in the nursing field, where emphasis was given to qualitative appraisal of manuscripts, left the researcher seeking answers on how to refine the middle range theories in the context long term conditions. To overcome this issue a complex programme theory approach used by Pearson (2012) was selected and facilitated a degree of order and structure to follow.

The lack of clear guidance on how to design CMO relationships and separate context, mechanism and outcomes created a continuous agony over refining and refining the developing theories (Rycroft-Malone et al., 2010). It became clear that the findings of the study could be presented in so many different ways and precisely that was a limitation of the chosen methodology. Whilst conducting a realist review it was crucial to know when to stop reflecting and refining to the finest level of abstract, which for me was a clear drawback and even now I feel I stopped for the purpose of this report and that further correlations could be synthesized.

Given that experience is something ones gains by doing, I feel I have made enormous progress in understanding realist evaluation and how to find logic in the disconnected world of middle range theory, where a real world exists but is perceived differently at individual context (Meads et al., 2014). For me, a web developer, finding the logic among disconnected objects such as CMOs was crucial, and added an extra level of complexity to the research.

### ***Transcribing and analysis***

The transcribing process proved an onerous task mainly for a novice researcher. A significant issue was for a researcher with English as a second language to transcribe verbatim interviews from a local Salford dialect. It involved stopping and replaying several times to make sense of data. Despite that, the benefit of having to transcribe and highlight at the same time, helped enormously in making connections in the early phases of analysis. If the exercise would be repeated data would have been extracted from the start in a CMO configuration for each case.

### ***Time management***

Certainly, developing, technically maintaining and managing an online intervention was not a 9-5pm role (INVOLVE, 2014). Technically, it required working around the clock in order to maintain security, safety and access. Socially, it involved working closely with GMKIN community, monitoring and adding content to influence engagement. In practical terms that means verifying notifications with no delay (mainly when the GMKIN Facebook community was open), checking IP addresses for every member registered on GMKIN platform to limit security risks, verifying and publishing blogs. In addition users' engagement within the site was monitored to understand their preferences and be able to find content that stimulates discussions. I was passionate about the topic and the task involved, hence I have invested a vast amount of time, which I had not envisaged. It was recommended that further research studies should involve a community manager, which is trained to perform the role I undertook and that should be separate from the researcher and research duties, managing a longitudinal mixed method study at the same time was a huge challenge.

### **Chapter Summary**

The focus of this chapter was to connect the findings of this study, which draw on three different areas of research: engagement, information provision and self-efficacy. The theories tested in this chapter were a result of extensive literature review, from different areas of research and practical application. It provided clear evidence of the impact of social media interventions to address previous methodologically weak evidence, which predominantly involved correlations among platforms and not in-depth longitudinal and practical applied research.

The study highlighted that by having a comprehensive evidence based strategy the most challenging concepts in online interventions, which is patient engagement and sustainability can be overcome and achieved.

This study generated a Health Engagement Model, which collates knowledge from literature brand communities and social networking (Bernoff, 2011; Brodie, et al., 2011), ecommerce, web-searching Webcasting, and gaming (O'Brien & Toms, 2010) to transfer theory and test within healthcare. The emerging new model highlights that engagement takes four different modes: engagement, inattention, decoupling and re-engagement, influenced by different factors among which information and sociability. Unique to the model was the different levels of patients' engagement, influencer, conversationalist and browser which were crucial to sustained engagement.

Clarifying that for interventions to work, engagement was required, the study adds to the field of knowledge surrounding information provision acknowledging that patients engaging with social media interventions contribute to patients' generated information which in turn satisfies patients' information needs. Furthermore, almost all patients engaged in GMKIN, who accessed sources of self-efficacy such as enactive mastery experience, vicarious experience, social persuasion reported positive outcomes.

## **CHAPTER 10: CONCLUSIONS AND FINAL REMARKS**

### **Introduction**

This final chapter draws together the concluding remarks on the contribution of this study to highlight the impact of social media on the field of engagement, information provision and self-efficacy. The ultimate goal of the thesis was to contribute to knowledge and strengthen the evidence of the impact of social media on patient information provision, communication and networking. This study is unique in combining key social media tools and identifying what tools works for whom and its purpose. The use of a variety of social media tools (mechanisms) the context of chronic conditions has triggered social and health outcomes. That was a result of a successful engagement strategy, application of existing knowledge and continuous learning, which has numerous implications for practice. The future direction of GMKIN and recommendations for practice and further research are presented, the strategy for dissemination proposed.

### **GMKIN research and recommendations**

The primary aim of this study was to develop a social media intervention to enable generation of healthcare information to patients with a chronic illness and measure the impact on satisfaction of information need and self-efficacy. Directed by a realist methodology it aimed to understand the overarching mechanisms (Facebook, Twitter, Blogging and online communities) and as instruments of driving change in the context of chronic illness. There was a clear need to conduct a study guided by both theory and its application in practice. It was clear from the focused realist review on long term conditions that there was limited existing evidence available and the need for empirical studies.

The adoption of the realist synthesis (theory of causal explanation) was needed to understand the complex social media phenomenon (Kietzmann et al., 2011) and address existing methodological issues. It allowed the inclusion of grey literature from various disciplines and focused on mechanisms as drivers of changes in a specific context (Pawson & Tilly, 1997), connecting the gap between theory and practical implications (Goicolea, 2012).

The research on GMKIN has given a twofold view: applying theory onto practice to develop GMKIN and the engagement strategy; and develop theory from practical experience. Using evidence from existing literature (Steps 1 to 4 of the realist synthesis) an intervention was



developed and theories tested. As a result new theories were developed using evidence from a model on an intervention that works.

This has implications for practice, generating understanding of the role of each mechanism and engagement strategies, which are summed up below. In addition policy changes are required to adapt to the unprecedented expansion of social technologies in healthcare. Furthermore, health professionals could benefit from knowledge generated from GMKIN in a number of ways.

### ***Organizational and process learning and impact***

The key elements that stand out from my thesis are the propositions tested and how each mechanism works differently to patient's engagement:

- Patients lacking access to information are able to join SNS and connect to one another to find information and network
- Facebook because of information shared, social support and sociability (pleasurable experience, humour, and trust) is leading to community engagement, active learning and patients' generated information
- Twitter allow patients (mostly with good IT skills) to follow medical staff, access information and promote GMKIN to a wider audience, creating a recognised brand
- Blogs enable patients to narrate emotional life experiences which in return is alleviating stress, influences further engagement (information provision) via feedback received and positive feelings
- An online community, namely the forum, was not working in the context of GMKIN, which are contradictory to previous results. It seems that the Facebook community replaced the need of a forum

One of the unpacked overarching mechanisms was that of engagement. The importance of engagement in health suggested in various studies (Glasgow et al., 2007, Christensen et al., 2009; Poirier & Cobb, 2012; Archambault et al., 2012; Merolli et al., 2015) likewise in other disciplines (Gambetti & Graffigna, 2010; Javornik & Mandelli, 2013). The model developed in this study extends O'Brien & Toms (2008) theory by including elements from social interaction and information provision. Different modes of engagement were established: engagement, inattention, decoupling and re-engagement. The influencers of the process of engagement were: attention, novelty, sociability, information and interactivity. Another facet of engagement was that of disengagement, which took two different modes:

inattention, triggered by environmental factors and decoupling, resulted in overwhelming information, health issues and negativity. An interesting finding is that notifications influence re-engagement.

It was argued that in the field of social media the three identified levels of engagement (influencer, conversationalist and browsing) are needed for other outcomes to occur. Clear connections were underpinned among the members' activity of learning and sharing on GMKIN and CoP legitimate peripheral participation concepts (Lave & Wenger, 1991).

The role of influencer (community manager) was crucial to trigger engagement and that is a result of a number of tasks:

- Influencing conversations by posting various content
- Encouraging relationships among users using light discussion, supporting leaders, be open and trustworthy
- Observing the blogging activity and recognising when further engagement was needed and stimulated the leader to post comments
- Maintaining confidentiality of the Facebook group and in general be considerate of trust and privacy
- Involving users in taking decisions related to the community (close the group, accept medical professionals)
- Creating a sustainable community with leaders which sustain GMKIN by curating and posting information and keeping the conversations going

In addition to understanding the mechanisms, this study adds to knowledge on the impact of social media by highlighting the outcomes, namely: satisfaction of information need, increased self-efficacy, seeking employment and positive changes to illness management.

- The information retrieved from social media contributed to patients' satisfaction of information needs.
- The information distributed and retrieved from GMKIN and social support contributed to an increase in self-efficacy. Patients draw from enactive mastery experience (positive feedback as a result of posting), vicarious experience (other patients stories) and social persuasion (positive feedback, conversations), which are sources of influence of self-efficacy. Patients reported changes in the way they managed their condition as a result of information retrieved from GMKIN in the form of experiential stories or biomedical information.

- The affiliation with the community identified social benefits among which trust, social camaraderie, friendship, and affection via light and friendly conversations (welcoming messages), social support and the human side.

### ***Policy impact***

The influence of GMKIN and this innovative research was already sensed at national level. Other communities have started to learn from GMKIN. The research has influenced other projects at the local hospital and further collaboration was established to promote renal research among patients.

- The collaboration with INVOLVE has indicated the authority established by GMKIN in the field of social media and patient involvement. This was also reassuring in terms of sustainability; GMKIN has emerged in less than two years from a zero base renal community as an established brand generating interest from other online communities and renowned organizations in the renal field.
- However, more needs to be achieved in terms of establishing policies, which provide a balanced view on risk and benefits indicating how social media technologies could be positively used (George, 2013).

### ***Healthcare professionals impact***

The results from GMKIN are indicative of the information sharing and the learning which occurred as a result of patient disclosure of personal information and content curation. The robust evidence generated from this study also highlights the positive social and health outcomes which resulted from peer to peer interaction. Although, previous research argues that the relationships formed online are mostly weak ties current findings indicate that bonds among patients have been formed, which contribute to engagement and peer to peer support. Finally, local initiatives based on local values, connections and a sense of belonging seemed important characteristics which made GMKIN influential and sustainable.

### ***Risks and challenges***

The field of social media is not without challenges. This study highlighted challenges associated with engagement and identified ways they may be overcome. The uppermost challenge was that of engagement and sustainability, and the proposed solution was to

stimulate engagement via the influencers with clear evidence based strategies. Other challenges were associated with the mechanisms.

### **Dissemination**

The findings of this study are to be compiled in to summary reports and communicated to the research participants, organisations in the renal field, healthcare professionals and other parties interested. There is no doubt that it will be beneficial for patients to know the difference they make when engaging in the process of generating information, which hopefully will continue to stimulate their engagement. In addition it will help to clarify some of their concerns in posting positive stories, when negativity was an element of decoupling from GMKIN.

Other organisations in the renal field have already been contacted to expand GMKIN and offer employment opportunities to patients. It will also allow them to reach out to patients and establish relationships with two way communication.

There is a need to develop stronger partnerships with medical professionals therefore seminars will be considered to disseminate the findings of this study and highlight the impact GMKIN has achieved. An online training model is planned to offer evidence based education regarding the use of social media in health.

### **Conference presentations**

The findings of this study have already been presented at Salford Media festival conference and accepted as oral and poster presentation for British Renal Society. Other conferences and events will be planned on a local, national and international level.

### **Peer reviewed publications**

A minimum five peer reviewed publications are envisaged to emerge.

- A paper drawing on the ethical challenges associated with social media
- A methodological paper drawing on the patients perceptions of the usefulness of self-efficacy scale in longitudinal studies
- Sharing experience or pushing information out to stimulate people – the influencers of sustaining engagement with social media.
- The experiential application of realist synthesis within this research field
- Explore communities of practice concepts: legitimate peripheral participation and duality and situated learning concepts)

## **Further research**

The researcher is planning to expand the area of research and seek further clarification of concepts for example online identity and partnership among healthcare professionals and patients in generating information. Further research is needed to understand the role of social media in influencing patients with a chronic illness to seek employment. The engagement model requires further testing in alternative health contexts to allow for wider generalisation. Partnership is already established to develop a model, which will qualitatively test the engagement model, facilitating wider confirmation and trustworthiness of the current findings and similarities with brand communities.

## **Concluding remarks**

The study has achieved what it set out to do. The realist methodology brought together evidence from various disciplines, and refined them in the context of long term conditions. It moved beyond the main aim of the study to understand what social media mechanisms works for whom and why, to provide clear insight on the engagement processes and the variability of patient engagement.

This research also influenced my personal beliefs and outlook on life. As a web developer I have had very little contact with chronically ill patients. During the first months of this research I felt overwhelmed with the challenges of the chronic condition, but have since learnt to appreciate not only the difference an intervention such as GMKIN can make to people's lives but understand the real meaning of context. I have always been interested in research with real life impact and this research has offered me the chance to be involved in areas, which I am passionate about: social media, sociability and impact. Seeing patients' positive transformation during the six months of the intervention was way beyond my expectations.

## Appendix 1: Search Strategy

30/06/2012 - Main strategy

*(social media OR social networking OR social network OR social networks OR social network\* OR facebook OR twitter OR microblog OR microblogging OR microblogs OR microblog\* OR video share OR video sharing OR video shar\* OR YouTube OR linkedin OR blog\* OR podcast\* OR content communit\* OR discussion board OR discussion board\* OR wiki\* OR forum\* OR discussion forum OR online support group OR web 2.0 OR health 2.0 OR medicine 2.0 OR med 2.0 OR virtual health OR Second Life) AND (health OR patient OR nurs\* OR doctor\* OR clinic\* OR physio\* OR occupational therap\* OR allied health prof\* OR SLT OR speech therap\*) AND (information shar\* OR communication OR communicat\* OR networking or information provi\* OR connecting or engagement or involvement) AND (“selfcare” or self-care or “selfefficacy” or motivat\*) AND (“longtermcondition” or long term condition or LTC or chronic or ckd or kidney)*

### Details

| Databases (n=)  | Screening / inclusion  |
|---|--|
| <ul style="list-style-type: none"> <li>• Web of science: 80</li> <li>• Scopus: 3</li> <li>• Science direct 467</li> <li>• Pubmed: 338</li> <li>• Medline: 23</li> <li>• Cinhal: 12</li> </ul> | <p><u>Total</u>: 879 manuscripts</p> <p><u>Read abstracts</u>: 879, included 143</p> <p><u>Read full</u>: 143, excluded 117</p> <p><u>Included</u>: 26</p> |

26/06/2014 Updated search

### Details

| Databases (n=)   | Screening / inclusion   |
|--|---|
| <ul style="list-style-type: none"> <li>• Web of science: 2</li> <li>• Scopus: 1</li> <li>• Science direct: 171</li> <li>• Pubmed: 106</li> <li>• Medline: 37</li> <li>• Cinhal: 6</li> </ul> | <p><u>Total</u>: 323 manuscripts</p> <p>Read abstracts: 323, included: 23</p> <p>Read full: 23</p> <p>Included: 6</p> |

## Appendix 2: Gmkin Testing

### Testing of home page navigation

| Navigation             |                                 |                             | Functional | Log Errors |  |
|------------------------|---------------------------------|-----------------------------|------------|------------|--|
| Homepage               |                                 |                             | ✓          |            |  |
| Blog                   | Patient blog                    |                             | ✓          |            |  |
|                        | Staff blog                      |                             | ✓          |            |  |
|                        | Carer blog                      |                             | ✓          |            |  |
|                        | Young adults blog               |                             | ✓          |            |  |
| GMKIN Members          |                                 |                             | ✓          |            |  |
|                        | Your story                      |                             | ✓          |            |  |
|                        | GMKIN friends                   |                             | ✓          |            |  |
|                        | Members                         |                             | ✓          |            |  |
|                        | Activity                        |                             | ✓          |            |  |
| Forum                  |                                 |                             | ✓          |            |  |
| Groups                 |                                 |                             | ✓          |            |  |
| Your health            | What is CKD, what causes it     | Treatment options           | ✓          |            |  |
|                        |                                 | Medication                  | ✓          |            |  |
|                        |                                 | Your diet and nutrition     | ✓          |            |  |
|                        |                                 | Balancing fluid intake      | ✓          |            |  |
|                        |                                 | Your fitness                | ✓          |            |  |
|                        |                                 | Living with kidney disease  | ✓          |            |  |
|                        | Social activities and lifestyle |                             | ✓          |            |  |
|                        | Holiday experiences             |                             | ✓          |            |  |
|                        | Advice                          |                             | ✓          |            |  |
|                        | Renal patient view              |                             | ✓          |            |  |
|                        | Locate services                 |                             | ✓          |            |  |
|                        | Eat well-food recipe            | Recipes                     | ✓          |            |  |
|                        | Young adults                    | About young adult           |            | ✓          |  |
|                        |                                 | YA section timeline         |            | ✓          |  |
| Young adults news      |                                 |                             | ✓          |            |  |
| YA information         |                                 | Activities for young people | ✓          |            |  |
|                        |                                 | Pregnancy/abortion clinics  | ✓          |            |  |
|                        |                                 | Substance abuse/addiction   | ✓          |            |  |
|                        |                                 | Sexual health               | ✓          |            |  |
|                        | Eating disorder services        | ✓                           |            |            |  |
| Research SRFT          |                                 |                             | ✓          |            |  |
| Join Hope KPA          |                                 |                             | ✓          |            |  |
| About us               | GMKIN POLICY 2014               |                             | ✓          |            |  |
|                        | Research                        |                             | ✓          |            |  |
|                        | Contact us                      |                             | ✓          |            |  |
|                        | Help                            |                             | ✓          |            |  |
| Link to Youtube video  |                                 |                             | ✓          |            |  |
| Stop video             |                                 |                             | ✓          |            |  |
| Login                  |                                 |                             | ✓          |            |  |
| Register               |                                 |                             | ✓          |            |  |
| Facebook link          |                                 |                             | ✓          |            |  |
| Reply to comments      |                                 |                             | ✓          |            |  |
| Live activity          |                                 |                             | ✓          |            |  |
| Blogs tag cloud        |                                 |                             | ✓          |            |  |
| Join GMKIN on Facebook |                                 |                             | ✓          |            |  |
| Share this page        |                                 |                             | ✓          |            |  |
| Latest Tweets          |                                 |                             | ✓          |            |  |

### Appendix 3: General Self Efficacy Scale

| Statement  | 1               | 2           | 3               | 3            |
|--|-----------------|-------------|-----------------|--------------|
|  | Not at all true | Hardly true | Moderately true | Exactly true |
| I can always manage to solve difficult problems if I try hard enough                 |                 |             |                 |              |
| If someone opposes me, I can find the means and ways to get what I want              |                 |             |                 |              |
| It is easy for me to stick to my aims and accomplish my goals                        |                 |             |                 |              |
| I am confident that I could deal efficiently with unexpected events                  |                 |             |                 |              |
| Thanks to my resourcefulness, I know how to handle unforeseen situations             |                 |             |                 |              |
| I can solve most problems if I invest the necessary effort                           |                 |             |                 |              |
| I can remain calm when facing difficulties because I can rely on my coping abilities |                 |             |                 |              |
| When I am confronted with a problem, I can usually find several solutions            |                 |             |                 |              |
| If I am in trouble, I can usually think of a solution                                |                 |             |                 |              |
| I can usually handle whatever comes my way   |                 |             |                 |              |

Schwarzer R, Jerusalem M. Generalized Self-Efficacy scale. In Weinman J, Wright S, Johnston M. (eds). *Measures in health psychology: A user's portfolio. Causal and control beliefs*. Windsor, UK: NFER-NELSON, 1995: 35-37.



## Appendix 4: Self-Efficacy For Managing Chronic Disease 6-Item Scale

We would like to know *how confident* you are in doing certain activities. For each of the following questions, please choose the number that corresponds to your confidence that you can do the tasks regularly at the present time.

1. How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do?

|                         |   |   |   |   |   |   |   |   |   |    |                      |
|-------------------------|---|---|---|---|---|---|---|---|---|----|----------------------|
| Not at all<br>confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Totally<br>confident |
|-------------------------|---|---|---|---|---|---|---|---|---|----|----------------------|

2. How confident are you that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?

|                         |   |   |   |   |   |   |   |   |   |    |                      |
|-------------------------|---|---|---|---|---|---|---|---|---|----|----------------------|
| Not at all<br>confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Totally<br>confident |
|-------------------------|---|---|---|---|---|---|---|---|---|----|----------------------|

3. How confident are you that you can keep the emotional distress caused by your disease from interfering with the things you want to do?

|                         |   |   |   |   |   |   |   |   |   |    |                      |
|-------------------------|---|---|---|---|---|---|---|---|---|----|----------------------|
| Not at all<br>confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Totally<br>confident |
|-------------------------|---|---|---|---|---|---|---|---|---|----|----------------------|

4. How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do?

|                         |   |   |   |   |   |   |   |   |   |    |                      |
|-------------------------|---|---|---|---|---|---|---|---|---|----|----------------------|
| Not at all<br>confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Totally<br>confident |
|-------------------------|---|---|---|---|---|---|---|---|---|----|----------------------|

5. How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce you need to see a doctor?

|                         |   |   |   |   |   |   |   |   |   |    |                      |
|-------------------------|---|---|---|---|---|---|---|---|---|----|----------------------|
| Not at all<br>confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Totally<br>confident |
|-------------------------|---|---|---|---|---|---|---|---|---|----|----------------------|

6. How confident are you that you can do things other than just taking medication to reduce how much you illness affects your everyday life?

|                         |   |   |   |   |   |   |   |   |   |    |                      |
|-------------------------|---|---|---|---|---|---|---|---|---|----|----------------------|
| Not at all<br>confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Totally<br>confident |
|-------------------------|---|---|---|---|---|---|---|---|---|----|----------------------|

Lorig KR, Sobel, DS, Ritter PL, Laurent, D, Hobbs, M. Effect of a self-management program for patients with chronic disease. *Effective Clinical Practice*, 2001; 4: 256-262.

## Appendix 5: Informed Consent

### Informed consent

Version: 2: 14.03.13

Date: \_\_\_\_\_

Participant Identification Number \_\_\_\_\_

**Study Title: Impact of Social Media for information provision, networking and communication**

Name of Researcher(s): Cristina Vasilica

*Please tick box*

|   |  |
|---|--|
| I confirm that I have read and understand the information sheet (03.13 SMH-A3version2) for the above study and have had the opportunity to ask questions.   |  |
| I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected.  |  |
| I understand that my name and involvement in the study will remain confidential.  |  |
| I understand that any personal information about me such as my email contact address will not be shared outside of the study team and will only be used for this research (unless I have given instructions to be placed on a separate mailing list). |  |
| I understand that the information I provide could be used as part of the final study report or journal publications but any comments used will not be identifiable to me.   |  |
| In understand that the interviews will be tape recorded and transcribed   |  |
| I agree to take part in the above study   |  |

\_\_\_\_\_

Name of Participant

Date

Signature

Cristina Vasilica

\_\_\_\_\_

\_\_\_\_\_

Name Researcher

Date

Signature

(SMH-A5version1)

## Appendix 6: Interview Guide

### Prior to interview

- Review of logs (engagement and activity)
- Overview of general paradata (activity, blogging, commenting, main activity) to reflect and explore within interview (activity diagram)

|                                  |  |
|----------------------------------|--|
| Context                          | Age and illness<br>Partnership with healthcare professionals   |
| Mechanims                        | <p>On a tipical day can you explain how you began your journey with GMKIN? Why? What factors initiated that. Where do you start? Which is your favourite tool? Before you began the activity, did you have any expectations or goals in mind? What were they?</p> <p>Was your activity a voluntary or mandatory activity for you? What was it about it that made you continue to use GMKIN? How or why did you decide to stop using the activity? Was the presence of a person/many important to you? Why? Was interactivity important? Why? Did you develop affection for GMKIN? Why? Have you been infleunced by other people advocating the GMKIN? Why? Have you found yourself listening to the others in the group? Can you explain in more details how you listened? Does the local aspect of gmkin made any difference to your engagment? Can you explain why? Have you made friends from GMKIN? Do you chat? Can ou explain other factors that infleunced your engagement with GMKIN</p> |
| PGI                              | Looking a the diagram you read posted blogs, commented and replied? What factors influenced that?  |
| Satisfaction of information need | Can you explain how engagement with GMKIN satisfied an information need.   |
| Outcomes                         | Discussion around the self-efficacy and the questioinnaire responses. What differnce GMKIN has made?<br>What other changes can you recall after using GMKIN and a given time?  |
| Reflection                       | Reflecting back on your diagram is there anything else you would like to share   |
|                                  | <p>What did you like best?</p> <p>What did you not like or would you change?</p> <p>What suggestions do you have for us?</p>   |

## Appendix 7: Patient Information Sheet

### Patient Information Sheet

Date: \_\_\_\_\_

#### Research Study: Participant Information Sheet

#### Demonstration Project: Impact of Social Media for information provision, networking and communication

#### *What is the purpose of the research project?*

The purpose of this project is to explore how social media can be used to provide instant information for patients with a long term condition to understand how they engage with online information and what difference it makes to their lives and illness management.

#### *What would I have to do if I agree to participate?*

- If you agree to participate you will agree to take part in all aspects of the research including
- Complete three surveys at the beginning, mid-point and final point of the study
- Engage with the Social Media Hub and write a monthly diary blog
- Take part in three interviews that will be held at the beginning, mid-point and final point of the study.

#### **Survey Information Details**

It should take about 5 to 10 minutes to complete a survey to gather information about current behaviour, how you cope with your illness, physically and mentally. This will be repeated at 6 and 12 months.

#### **Blog Diary Information Details (online summary or diary)**

If you agree to participate, you will need to agree to engage with the Social Media Hub (SMH) on a minimum of a weekly basis (at least 10 minutes/week) a blog (an on-line summary) about your overall experience with the SMH, your communication with other patients/healthcare professionals, how you found the information and the difference it made to you.

#### **Interview Information Details**

- You will be asked to take part in an interview that will be no longer than 2 hours. The first interview will be done face to face. The follow-up further two interviews will be held using a method that works best for you, (maybe over the telephone, using skype, or face to face).
- During the interview, further information about your overall experience with the SMH, your communication with other patients/healthcare professionals, how you found the information and the difference it made to you will be gathered. Some aspects of your engagement with SMH will be explored in more detail to understand whether it made a difference to you.
- The interviews are tape recorded, transferred to a safe computer / laptop and transcribed by the researcher.

#### **How much time do I have to spend on the project?**

You will be required to engage with the Social Media Hub at least 10minutes/week to discuss with other patients and keep a blog about your experience.

You will have to spend a maximum 15 minutes responding to the questionnaires at baseline, 6 months and 12 months (45 minutes in total).

You will be involved in the interview, which is no longer than 2 hours at baseline, 6 months and 12 months (6 hours in total).

*For the time spent on the project, compensation is given.*

- *Patients that have the technology (PC and internet access) will receive a compensation of £450 for their involvement. The money will be paid in 3 instalments baseline (£150), mid-point (£150) and final (£150)*
- *Patients with no access to technology will receive an Ipad with internet access and accessories (keyboard and stylus pen), which they will keep at the end of the project. For travel you a £50 will be given.*

#### **What benefit or risk is there to me if I participate in the research?**

Taking part in the research may not be of direct benefit for you, but using the SMH may hopefully provide you with the information that helps you manage your illness. IT training on how to use the tools will also be provided, which may help you gain better understanding of how to manage internet technologies. Moreover, it will generate evidence to develop a strategy to provide information and enhance communication and networking, useful to patients in a similar condition.

There are no risks directly associated with this study. Your participation is voluntary and non-participation will not affect treatment or you in any way

**What if I agree to participate then want to withdraw?**

If you decide at a later date that you do not want to be involved in the study and have provided us with an email address, then contact Cristina Vasilica [C.M.Vasilica1@edu.salford.ac.uk](mailto:C.M.Vasilica1@edu.salford.ac.uk), at any time and ask for your data and email to be removed from the study list, and you will not be contacted further.

**How will you use the information I provide and keep it confidential so no-one can recognise it was from me?**

All the information you provide will be used for this study only, your responses and email address will be stored safely and confidentially on a password protected devices, accessed only by the researcher and supervisor. The responses of patients with Chronic Kidney Disease (CKD) will be analyzed to better understand and describe their experiences of using social media to get access to information communicate and network with patients in a similar condition, and the impact on behavior and illness management.

After the study is completed your information will be stored anonymously and your email erased.

**How will the study findings be published?**

The study reports and other publications will be written in a way that protects the identity and confidentiality of the people who participate. If you provide an email address all study participants will be sent an electronic summary of the research study or a URL link of where to access the final study full report. In addition study findings will be communicated through KPA network, on the SMH website, the radio, other appropriate social media groups and journal articles. Anonymous data from the study may be used for teaching purposes

**What if I want to complain about how the research is being conducted?**

If you have any complaints regarding any aspect of how this research is being conducted then please contact: Cristina Vasilica ([C.M.Vasilica1@edu.salford.ac.uk](mailto:C.M.Vasilica1@edu.salford.ac.uk), Phone: 07809406743)

**Research Project Contact Information:**

PhD Student: Cristina Vasilica, [C.M.Vasilica1@edu.salford.ac.uk](mailto:C.M.Vasilica1@edu.salford.ac.uk), Phone 07809406743

Supervisor: Professor Paula Ormandy: [P.Ormandy@salford.ac.uk](mailto:P.Ormandy@salford.ac.uk)

If you are unhappy with the way the research is conducted, please contact

Anish Kurien, Research & Innovation Manager, College of Health and Social Care, Phone No:55276, Email Address:[a.kurien@salford.ac.uk](mailto:a.kurien@salford.ac.uk),

Thank you for your time.

Date .....

(Date: 14/03/13 SMH-A3version2)

## Appendix 8: Patient Invitation Letter

Version: 1: 22.11.12

Date: \_\_\_\_\_

Participant Identification Number \_\_\_\_\_

### Invitation Letter

#### **Study Title: Impact of Social Media for information provision, networking and communication**

Dear participant,

My name is Cristina Vasilica, a Graduate Teaching Assistant and Postgraduate Student at Salford University. I am in the process of conducting research that aims to find out how social media can be used to provide instant information to patients affected by a Chronic Kidney Disease and I take this opportunity to invite you to take part in the study.

Attached is a summary of the study, information on how to take part and the requirements of taking part in the study (Participant Information Sheet).

Please read it carefully and telephone me if you have any questions (see below). If you are happy to be involved please send back the completed slip.

With Kind Regards,

Cristina Vasilica,

PhD Student, University of Salford Manchester  
School of Nursing, Midwifery and Social Care  
Tel no: 07809406743

Email: [c.m.vasilica1@edu.salford.ac.uk](mailto:c.m.vasilica1@edu.salford.ac.uk)

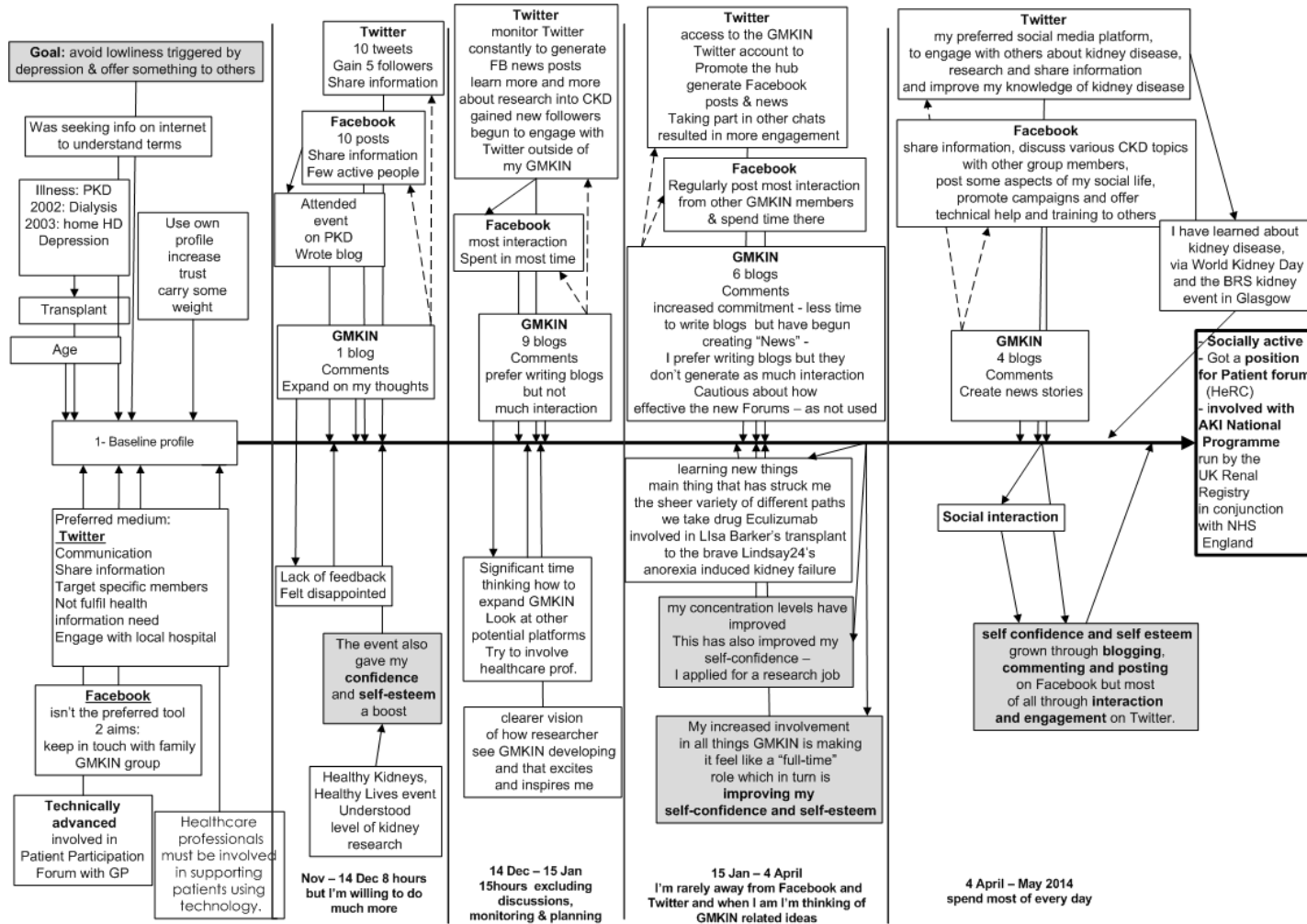
Twitter: @cristinavas

(SMH-version1)

## Appendix 9: Updated Matrix

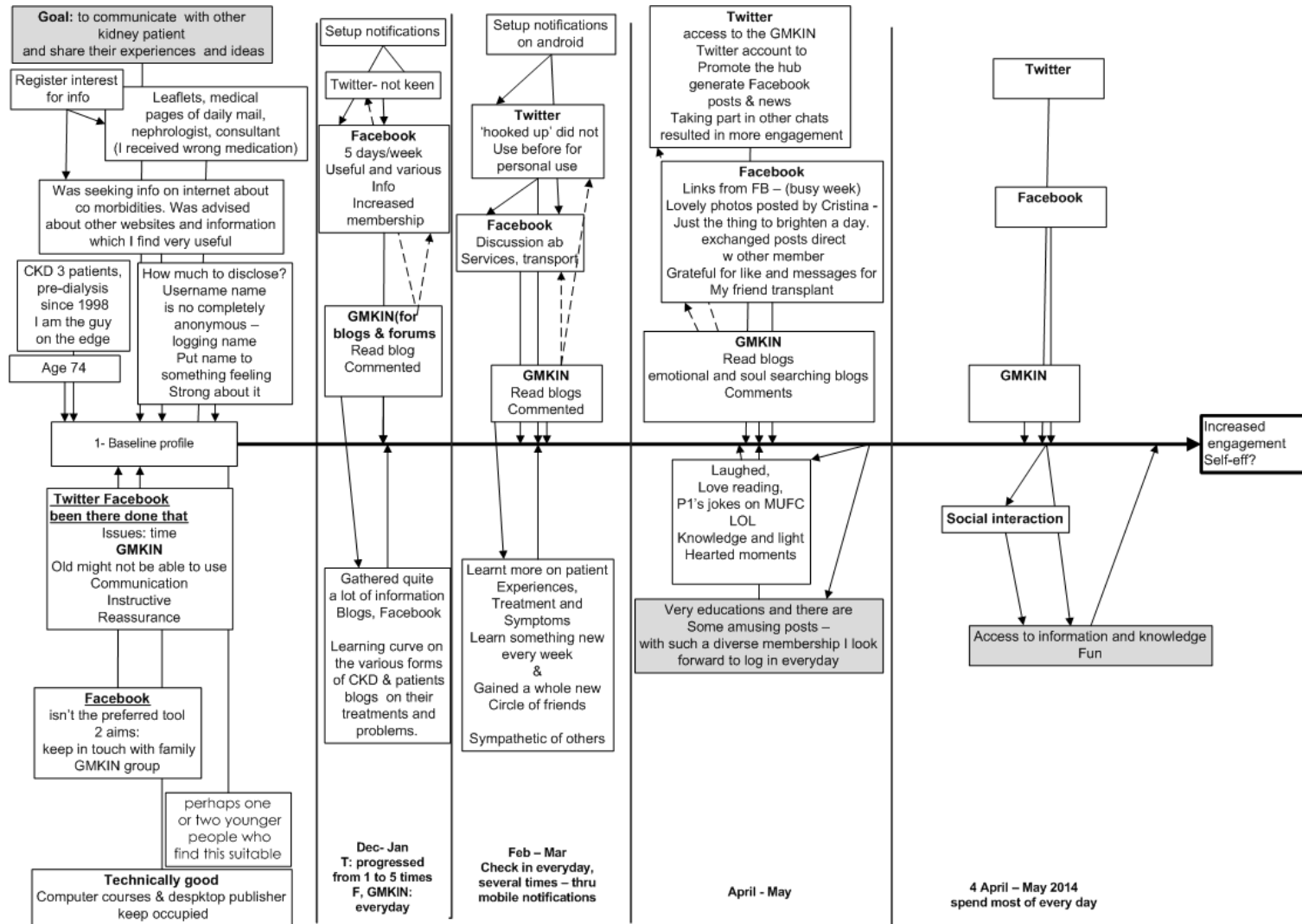
|  |   |
|--|---|
|  | Overarching Themes                                  |
| Contextual factors   | Patient health profile (whom)                       |
|  | Patient online profile (whom)                       |
|  | Partnership with healthcare professionals           |
|  | Local group   |
|  | Goals   |
| Mechanisms   | Patient activity                                    |
|  | Engagement  |
|  | Process of engagement                               |
|  | Voluntary activity                                  |
|  | Negativity / positivity                             |
|  | Passing phases (step out, return to GMKIN)          |
|  | Technical issues                                    |
|  | Health issues                                       |
|  | Literacy  |
|  | Confidentiality                                     |
| Quality of information   |   |
| Fun  |   |
| Commenting (Feedback)  |   |
| Friendship outside GMKIN   |   |
| Role of Ipad (patients who received the Ipad)                                    |   |
| Most used (favourite) Social media tool: Facebook, Twitter, blogs, forum) (why?) |   |
| Information generated  |   |
| Outcomes   | Satisfaction of information need                    |
|  | Self-efficacy                                       |
|  | Patient perception of the difference GMKIN has made |
|  | Psychological benefits                              |

# Appendix 10: Inleuencer (Activity Diagram)

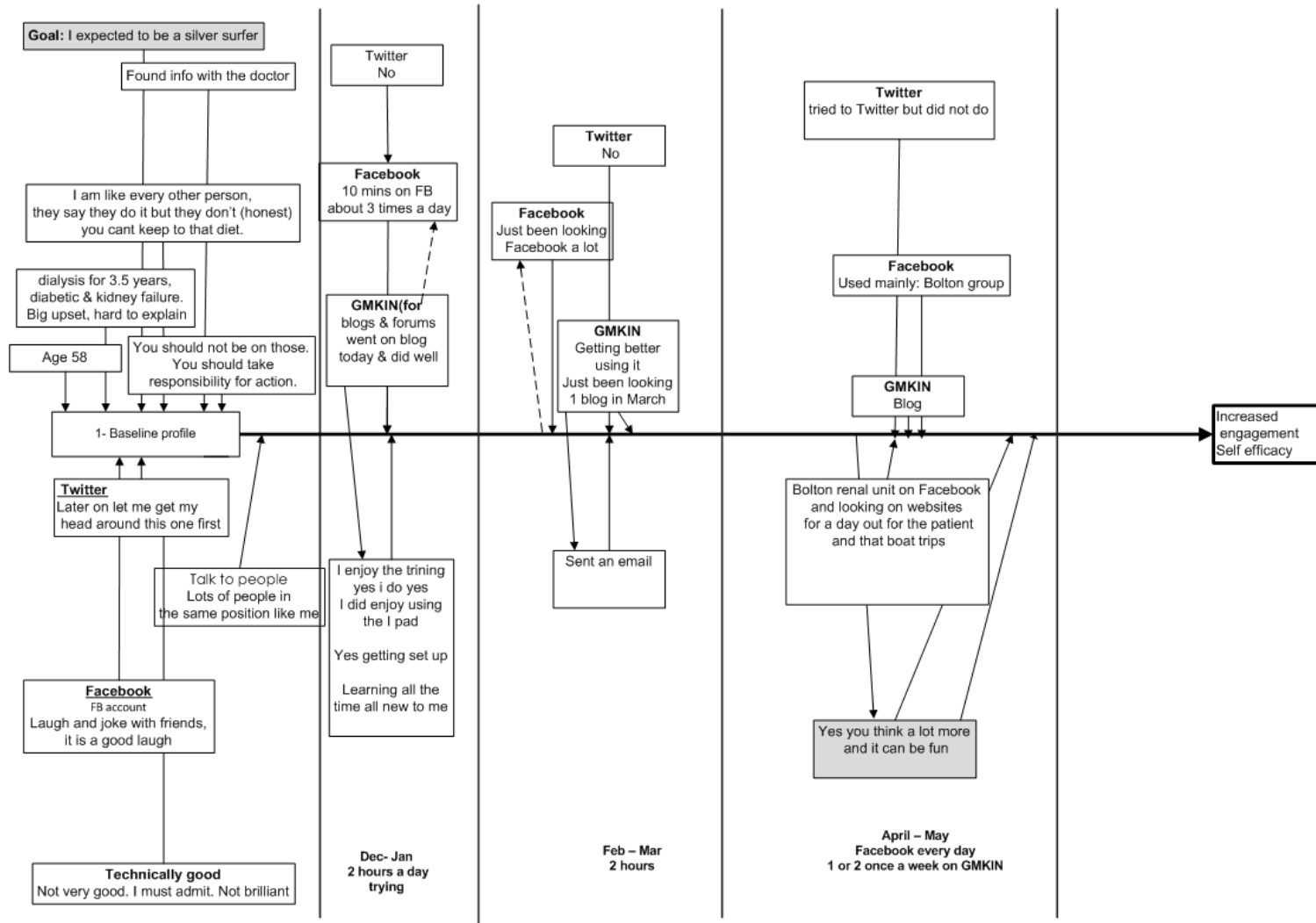




## Appendix 11: Conversationalist (Activity Diagram)



## Appendix 12: Browsing



## Appendix 13: First Level Of Analysis

Excerpt from matrix

|          | P1  | P2  | P3   | P4   | P5  | P6  | P7  | P8   | P9  |
|----------|---|---|--|--|---|---|---|--|---|
| Activity | <p>I engage in conversations, I post, I post a lot, I am posting more in terms of my social activities, in terms what I do outside of my day to day dealing with the condition and hopefully that helps other people as well so I also blogging but not so frequent as I was because I am spending much more time working on GMKIN as a whole still feel I need to mentally prepare for a blog, sometimes the process is quite quick but other times I have to go through the process in my head for few days before hand before I commit anything to a blog</p> <p>I still post thinks that interest me like politics, music and things like that specially on twitter</p> | <p><b>Reading bit is brilliant.</b></p> <p>If I do know about something and I am 100% sure that I am right I will say something down, but I have to be 100% sure.</p> <p>I put them events, Bolton trips in, different things in general people came back said hello</p> <p>If I am on Facebook and it is a bit quiet I pop into that and see who is coming on , because not a lot of people are on all the time there are good things coming on and I do read, I read everything that goes on.</p> | <p><b>Obviously I got more and more involved in it since its form,</b> I mean it was [name] that guided me ...find out that [name] went to the same school as me..</p> <p>Well, I don't boder much with anything apart from GMKIN. I mean occasionally I went to twitter and got couple of nephews and nieces and not spoken who them for a while and contacted them and one or 2 other people, I used to drop off particular groups you know ...I sent a message but other than that is gmkin.</p> <p><b>I put comments and chatter and keeping in touch with people to join the laughs, they inevitable the lighter side you know and taking</b></p> | <p><b>I comment as well, I sometime post as well, I read most of the blogs</b></p> <p>regarding different situations what is happening I means I read a lot of blogs every time</p> <p>I use the FB in the morning when I finish with my mother I use to read if there is any posting on the group, any attachment there I read there and that means 3 or 4 times a day means I cannot tell you the exact times, it van be 10 – 15 minutes</p> | <p><b>I read the blogs and all the events they have in different places</b></p> <p>At the moment I am so engrossed in this Gaza I am a big campaigner now I wasn't, I did not know where it ll came but watching the biased news, they comparing few rockets with bombs ....so I look for trues news and put it on FB, it is a good thing I love it</p> <p>you remind me I tend to forget about it and I am going on main Facebook, I think I am a bit confused I think that if I am just putting on FB is going to go everywhere this is what I have been thinking and then you remind me 'can you please put it on there as well' then I realised that is not</p> | <p><b>I would not say I have used it as I should have done. Because sometime I don't know I don't use social media in general</b></p> <p><b>I posted probably 3 things</b> on there and I go on and read it but when it comes to post I am lost for words and some people stories are intrigue and interesting</p> <p>sometime I just dotn know what to put reply back</p> <p>The last think I posted in there was about we all should meet up. Everyone should meet up and I did not really get any replays to it.</p> <p><b>I don't know what to type. I don't know what to out on.</b></p> | <p>A lot of it has been but only because I had problems with computers and <b>being ill it has been mainly the FB at the moment but I did go on the blog the other day and looking at what people have written on the blog.</b></p> <p>Might be once or twice a week I go on the actual computer.</p> <p>[phone] Laziness I suppose. Because I am out a lot thru the day because I will not stay in while is nice so obviously if something pops up on the phone I can look at it and still keep in touch with people that way.</p> <p>every time night</p> | <p>I will go on 7 days a week. Let's be honest the computer takes over your life. O do this [mobile] but I hate this more that I hate the computers. I don't hate the computers really it is a life line when you are not working</p> <p><b>Few comments that I am saying on GMKIN I left like saying 'you need shacking up, get a grip what you saying is all wrong'. There are some stupid comments, common!</b></p> | <p><b>It depends how I am feeling. It has been times this year ...I have not looked on FB</b> because not really been interested on what people have put thru because I have been circumvented of how I am dealing with things and also, I know it sound very terrible but went on Facebook and people said my life is so wonderful and I so happy and you know you are not happy and you think I don't want to hear about it so it is kind of depended on how I have been feeling but I'd say on average once a week, where I will just have a scan and see what people are up to.</p> <p>In terms of updating not as much as that because it take a bit of time to write down all my blogs have been quite long and when I have been doing it I have been like I must not miss anything so when I done them it has taken me couple of hours at least to</p> |

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|  |  |  | <p><b>the serious stuff</b> I mean P1 he is doing nothing else sitting there 24 hours in the screen some of the stuff you look on FB is there ..he is all over the show</p> <p>No, I will be promoting gmkin at Fairfield hospital.</p> | <p>per time and I use.</p> | <p>going everywhere. Because when you put it on he main FB it goes on yr timeline so I thought is going on everyone.</p> <p><b>I always [post] even if it is good luck and I hope you well I have to do that,</b> they might just started the group or you don't even know them is just a name because they made the effort to put something on you just read that saying good luck I hope you well.</p> <p>Comments and blogs . I have put a lot of pictures and you know videos on, stories on. I do a lot of that. On my wall and other people's wall.</p> | <p><b>I don't care. I am not fussed about it</b> I don't know what to put on social media like I'd say if I have to speak with someone I will ring, I will text and all. I don't even like texting. I am liar. U don't text people back. Someone texting I don't text. I might just ring someone and speak to them. I don't text. It is just much easier.</p> <p>I would say I have been inconsistent with the way I read it, I haven't read it all the time from start. ...I have been consistently inconsistent if that makes sense. I have been on and off.</p> | <p>time comes in only just put the computer on some days. If I go on the computer 9 times out of 10 is when I get up because I have that bit more energy</p> <p>no really it is just a <b>matter of being on it and have a look.</b> A lot of time I am being on it believe or not like I say when I am in bed or when I am sat downstairs and I just looking thru it and <b>I always end up going to the gmkin section for some reason but I can't tell you any other way of why I am doing it.</b></p> <p><u>that way you learning more by people actually speaking out right to you and saying what is going on</u></p> | <p>Oh yes I don't, is an open post so <b>I follow everything I listen to everything I look at everything but I choose not to make comments,</b> that is all it is. I mean if he said something really stupid then I will say something but then will be a private message I will go on his personal site and send a private message I will not do it on open forum.</p> <p>I use Twitter and LinkedIn but these are from a business point of view, from the website.</p> | <p>write each one so needs energy to sit down and I feel better, whenever I do I feel always better and I am glad I have done it but I am just so suffering from tiredness having the motivation but on average once a week I go and have a look and not quite as often for updating</p> <p>I will carry on the way I am doing, <b>keep doing the blog, I have got the notifications [...]</b> because that reminds me of people are doing so just makes it easier to access the information and keep updating my blog every so often for people to know where I am up too, having a scan of the website but that is it really.</p> <p><b>I think someone posted about mentoring and commented back</b> that I want to be part of it.</p> |
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## Appendix 14: Second Level Of Analysis

### Excerpt from matrix (P1)

| For whom  | Baseline   | What works   | Why  | Difference   |
|---|--|--|--|--|
| <p>P1<br/>58</p> <p>10 year transplanted patient with PKD, I don't think I am depressed now but I will go to see a councillor to try and talk about mindfulness</p> <p>I don't think I am depressed now but I will go to see a councillor to try and talk about mindfulness</p> | <p>Goal</p> <p>Involved with Patient participation group at GP surgery and I end up stepping down, partially because of health problems ... partially because I was struggling to pursue people that technology was a good way to go, the committee was made of retirees who will not agree</p> <p>Use of Twitter and FB. Prefer Twitter</p> <p>I think I may have something to offer...</p> <p>I really thought I have something to offer</p> | <p>Activity</p> <p>I engage in conversations, I post, I post a lot, I am posting more in terms of my social activities</p> <p>I still post things that interest me like politics, music and things like that..specially on twitter</p> |  | <p>I applied for one research position I didn't get that one, it did not stop me doing applying for another one and I have got that one. I feel as tho I have some purpose now whereas I did not have purpose before</p> <p>It has given me purpose, it has given me fore focus, I have not allowed things like fatigue or lack of concentration to stop me. It has given me a motivation that was missing before that motivation is primarily to help others.</p> <p>the structure of my day has changed one of the side effects of getting involved my concentrations levels have improved I can actually stay with gmkin much longer than anything else I have done in the past</p>   |
|   |  | <p>Twitter</p>   | <p>I had to lose the website and FB probably I would not share a tear but really I would not like to use Twitter and I wasn't really getting twitter until I got involved with gmkin and it has opened my eyes to the parallels and the immediacy of it is ..I can't imagine life without it</p> <p>still prefer twitter as a medium it tends to be more immediate and I think I like that immediacy and tends to be broader in range of things you want to #ff. I could not imagine ever try to do on FB what I do on twitter I don't know whether that is my perception of FB or just a different medium to actually working I find twitter much easier medium to working</p> <p>Twitter is in the sense understandable and unusual medium[...].I had fantastic conversations so beyond the kidney side [...] means that to my mind has overcoming a barrier I feel so I gone managed to get the contact from someone which is about essentially kidney related problem but they</p> | <p>So the first 2 I definitely think being involved has helped me there, the 3rd one that is quite significant that one, that is part due to me understanding A)that I am not alone, B)that I am have to say that others want to hear and C) I think I have become more honest with myself about my condition , have a greater self-awareness and understanding who I am , how it has affected me and learning to live with that now.</p> <p>I don't think I would have engaged with her before gmkin I would not have felt confident enough in my self to be able to hold my own in a conversation with someone who clearly knows a lot about not just programme management but also renal problems and that is given me enormous satisfaction but again added to the</p> |

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|  |          |  | <p>have then linked it to other things I think more people within our gmkin community can use twitter in the way and see those sorts of connections being made. I think they can benefit from it.</p> <p>I think Twitter if you let it take over your life but I think I am getting better at managing now.</p> <p>I think this goes back whiteness of FB I think I just enjoy working within the twitter environment I just find it much more .. focused and I do really find it more rewarding than FB because The FB group is closed I think limits it whereas we twitter as I said early on I go beyond just my focus on kidney disease and I talk politics and all sort of things</p> | <p>boost in self-confidence [aki]</p> <p>The implications are growth in self-confidence, self-esteem, feeling of self-worth that I seriously doubt it that I would get and I think that in time has led into entertaining, this is a realistic thought, entertaining the idea of getting some proper employment again and that would be an achievement I never thought</p> <p>I still think there is an awful lot to learn now I still feel I am not quite making the connections I need to make I don't think I am particularly good at promoting things and I think that is reflection of my character and sometimes I miss opportunities that you see in instance that I don't like we have a question son FB about a specific subject and you automatically think of referring that back with what we done on the website and you suggest posting things to a blog</p> |
|  | Facebook | <p>I think less about that I am saying I don't worry now if people disagree and I think done that couple of times now.</p> <p>I think I am more tolerant of what people are posting on FB I don't always agree with it - I don't really enjoy some of the detail people are going to write down in social life.</p> <p>it is so rewarding little things like someone click a like on a comment on FB . if someone posts a comment on a blog that I do that in my mind carries so much weight and emphasis I appreciate that side of it more then someone hitting the like button because I think people click the like button to acknowledge that they seen it rather than drawing anything from it whereas as if someone takes the time to comment there is an interaction there</p> <p>on the FB group a number of people are opening asking for not only advice but comfort.</p> <p>I am pleased it is growing the way it is.</p> |  |  |
|  | Blogging | <p>blogging but not so frequent as I was because I am spending much more time working on gmkin as a whole.</p> <p>still feel I need to mentally prepare for a blog, sometimes the process is quite quick but other times I have to go through the process in my head for few days before hand before I commit anything to a blog.</p> <p>So that is why part of my motivation behind</p>   |  |  |

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|  |   |                          | <p>blogging where the inspiration come from is partially do to the shared experience but partly is something someone will say or I make connection in my head [...]sometimes I just have to get something out of my chest [...].</p> <p>I don't think I quite have the confidence yet to be totally confrontational in my blogging but I do want to try and take challenging view.</p> <p>One the other stimulus for doing them is I really get this buzz out of getting some feedback from it It is an indication of my perceived growth and self confidence that if I committed something like that which is part of me something that in the past probably kept to my self or just close friends within.</p> <p>FB des not lend itself to in journalism the call I long stories, and I think you can do so much more with a blog than you can with a FB conversations, you can focus, you can put your ides out there and if they do generates comments</p> |  |
|  |   | Commenting               | <p>I try not to hit the like button unless there is no need for any further interaction but I think ... I always try to make a comment so even when it forces me to thinking what was my experience of that and something I commented on [...] I do try to make my interaction with Facebook conversational rather than hitting the like button and more and more that is happening.</p> <p>if someone posts a comment on a blog that I do that in my mind carries so much weight.</p>   |  |
|  |   | Facebook, GMKIN, Twitter | <p>[News] I think it is pretty good I just using it partially to drive traffic to the website because I had this debate with you about the facebook group being closed and support the reasons behind closing but I still think there are parts that could be shared and creating a news story I can then feed that in FB also make that public. So that s helped enormously and that I tend to link them all together twitter, facebook, and news stories and the blogs.</p>  |  |
|  | I do, I look around, especially if I come across a term I have not experienced before I try to find | Information seeking      |  |  |

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|  | <p>I struggle to cope with and I was looking around the other day for depression with kidney patients</p> | <p>Information need</p> | <p>past experiences/illness<br/> how you are going to cope with the changes, the specific events, the surgery, a lot of it don't encounter until we first get diagnosed with kidney disease.<br/> the depressions one I suppose was one that I been bubbling under my mind for a while, in one stage I would not have even admitted to very close friends that I had counselling for depression because that is still associated with stigma , other people associate stigma with it but I felt I had to as part of my own process I had to be open about it in the hub that do inspire others to not do what I did initially ignore the reality of the situation I was in.<br/> the sheer variety of routes people take into kidney disease<br/> I have seen people there who developed as a result of cancer, people picking up viruses and getting kidney failure, the genetic condition that I have and so many roots into it and so many paths to it so it is open my eyes a lot but in terms of breath of people experiences but also that so many of them no matter what he root still resignate with me because we all still overcoming some of these what appear to be extremely difficult hurdles.<br/> I blogged on one of the things I like to see a road map routes to ckd and that is always enjoyed doing made reference that I always loved maps and I find that an easy way of understanding things<br/> experience and our perception but I think they do act as street light on that journey<br/> I used a reference in one of my blog this all having little bits of information which we don't attach any value to because it is based on our experience and our perception but I think they do act as street light on that journey. If you can say something to someone else actually it wasn't that bad, it didn't turn this way, or I got around the problem like this I think that actually helps and I think that is being one of my primary motivations for staying involved and wanting</p> | <p>I think I just needed that reassurance that I wasn't alone, I really drew an awful lot from that<br/> Scientific advance<br/> in terms of generally understanding the condition the development in research areas, I have been motivated to go looking for things like that because of gmkin partly for my own benefit but partly because I want other people to see what is happening. And there are developments which made me think that other who follow me would not have to go thru , scientific advance.<br/> Patients stories<br/> I think this shared experience, the things I gone thru other people who already been thru, and hopefully we are helping other people that have to go through understand them better so that has been primary</p> |
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|  |  |  | <p>to share the light because it is a dark journey, it is a dark journey it remains a dark journey despite all the quality improvement programmes or the efforts of patients involvement</p> <p>on care.data</p> <p>one I did on care.data is one that have been bugging me for weeks and I don't know why I did it on that day I think I knew that things coming on later that day that if I have written after event would be influenced by other things so wanted to get that out on the day so was a true expression of the things concerns me rather than me picking influences from other people</p> <p>medication</p> <p>I did a little blog on it about changes to prescription processes again that was much a personal thing I would love I'd be able to share other people experience as well</p> |  |
|--|--|--|--|--|

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