Complex quests towards calm - A co-produced journey

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Submitted in Partial Fulfilment of the Requirements of the

Degree of Professional Doctorate

2020

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TABLES AND FIGURES

Table of acronyms

Acronym	Full Meaning
AA	Alcoholics Anonymous
AQP	Any Qualified Provider
BCE	Before the Common Era
CASP	Critical Appraisal Skills Programme
CE	in the Common Era
CHD	Chronic Heart Disease
CMHT	Community Mental Health Team
COPD	Chronic Obstructive Pulmonary Disease
DTR	Double Trouble in Recovery
EBE	Expert by Experience
EBP	Expert by Profession
ECHR	European Convention on Human Rights
ECT	Electro Convulsive Therapy
FtF	Family to Family
GP	General Practitioner
HIV/AIDS	Human Immunodeficiency Virus**/**Acquired Immune Deficiency Syndrome
HVN	Hearing Voices Network
IAPT	Improving Access to Psychological Therapies
IPA	Interpretive Phenomenological Analysis
MACA	Mental After Care Association
MIND	National Association for Mental Health
NA	Narcotics Anonymous
NEF	New Economics Foundation
NESTA	National Endowment for Science, Technology and the Arts
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
PICO	Population, Intervention, Comparison, Outcome
PRISMA	Preferred Reporting Items for Systematic reviews and Meta-Analyses
RCT	Randomised Control Trial
SMS	Small Messaging System
UDHR	Universal Declaration of Human Rights
UK	United Kingdom
USA	United States of America
VCS	Voluntary and Community Sector
VCSE	Voluntary Community Social Enterprise sector

Acknowledgements

To the people who have helped me with this piece of work, the collaborators, I have a great debt of gratitude. Without you, it genuinely never would have happened and I guess that makes it yours, just the way I actually wanted it in the first place.

My ‘Prof Doc’ buddies will probably all giggle if I mention a certain type of chocolate fringe or Saturday afternoon epistles about procrastination. You, mostly, kept me sane, especially pints with Jimmy and Greg, and chats in the office with Helen, so thanks for being buddies.

I did not really understand the idea of academic supervision at first, nor for that matter did I have any idea that other people might be having thoughts similar to mine. I was extremely lucky to meet firstly Dr Elizabeth Collier and Dr Shelly Allen and latterly Dr Michaela Rogers. Elizabeth and Shelly seemed to have similar thoughts to me and pointed me in the right direction. It must have seemed like riding a tiger to them sometimes as I had some forthright views and ideas and expressed them in a clumsy way. They have all guided me, cajoled me and occasionally pushed me. They have all helped me to see things differently, given me ideas that I have snapped up and in the latter stages helped me through some personal difficulties. In any event, I am indebted to you all; it has been great fun.

When I first started this ‘Prof Doc’ expedition, I managed to convince my board at work that it would only take five years! I want to thank all of the directors of the host organisation, past and present, for their confidence and support. To my ever-suffering staff and volunteers, finally, I will be in the office more often and give you

the attention you deserve. Thank you all for your support, copy reading and encouragement even when you did not know what I was talking about.

My sons Nick and Mike have suffered when I have been too busy to go out, or have just been plain grumpy. It has meant missed trips, evenings out and general family time.

Finally, it is very difficult for me to express just how important the support and love of my wife Christine has been on this expedition. Through good times and hard, Christine has allowed me to slope off to my office and ‘do college work’ and often she even made me do it. Even now, she has no real idea what I have been up to, so to her I simply say ‘Thanks Robs, I love you’.

Abstract

This study explores the influence of the process of co-production in peer-led, self-help groups on mental health. People working in the mental health realm seem to know what co-production is all about; people receiving treatment in the mental health realm do not. Co-production has become something people and organisations say 'was being done' when it may not actually have been. This study explores the experiences of those people, generating new knowledge and the development of a conceptual framework to support the practice of group focussed co-production. This addresses a gap in existing knowledge of co-production in a group situation.

To enable the study, a new co-production group was established. The volunteers, termed 'collaborators' needed for the co-production group were recruited. The co-production group ran for six months after which a series of unstructured interviews enabled data to be gathered. Interview data was analysed using an adapted narrative/thematic method (Floersch, Longhofer, Kranke, & Townsend, 2010) where the thematic (Braun & Clarke, 2006) element was exchanged for framework analysis (Spencer, Ritchie, & O'Connor, 2003).

Six overarching themes emerged which included: being individuals; mental health; professionalism; bad stuff; being in a group; personal development. The need for, role and training of professionals in co-production will change. Professionals in co-production situations in future will find themselves as facilitators and guides instead of being deliverers of service.

Like-minded people who experience mental health problems were keen to come together to take control over their mental health by co-producing services with peers experiencing similar difficulties.

The study illuminated the limited availability of work on co-production, how literature of co-production is in its infancy. The subjects for future study include how ‘Psy’ professions work in co-produced situations and how the process acts on perceptions of mental health.

Chapter One - Introduction and Context

Introduction

The thesis unfolds in seven chapters accompanied by several appendices. The first chapter provides an introduction and background context to the study. This, includes an attempt to locate myself as the researcher, my philosophical influences, and includes a reflexive commentary. Chapter Two provides a review of the co-production literature in group-related mental health settings and situations. This explores the current research evidence that informs the prevailing study. The study methodology presented in the third chapter exposes the practical aspects of how the study was undertaken. Chapter Three includes my philosophical approach to the topic, the ethical background, aspects of the data collection and analysis. It is particularly important to me to evidence that the work completed is trustworthy, the focus of Chapter Four. Chapter Five presents the findings of the study using a schematic, thematic network with an accompanying description. The discussion of findings and how they fit, or otherwise, with existing theory is found in Chapter Six, including an appraisal of relevant views of other commentators and writers. Chapter Seven, the conclusion, explains my thoughts and ideas about how this study can further develop group-based co-production in mental health settings.

Background

People who experience mental health problems:

> *"…are among the most marginalized, oppressed, devalued and stigmatized populations in our society. They experience a range of societal abuses, including barriers to health care, lack of employment, difficulty accessing and maintaining adequate housing, and discrimination" (Benbow, 2009, p. 1).*

This study investigates the method of co-production as a way to address such difficulties. The aim of this work investigates the influence of co-produced, peer-led, self-help groups on mental health (discussed further in chapter three).

Co-production can be defined in several ways, discussed later in the Chapter, but for this study, the definition used is:

> *"A relationship where professionals and citizens share power to plan and deliver support together, recognising that both have vital contributions to make in order to improve quality of life for people and communities". (National Co-production Critical Friends, 2011; Slay & Stephens, 2013, p. 3).*

To grasp the context of co-production in mental health, it is necessary to understand the place of co-production in history, to get an idea of the thinking and influences that formed the contemporary concept.

Attempting to provide a clear path of thought has proved to be a complex, interesting, convoluted, and rewarding journey of discovery. Within the introduction and background chapter, my aim to provide an overview of the key ideas that inform the concept of co-production in mental health.

This is a complex task as the ideas include concepts such as: human rights, philosophy, the notion of mental health, the mental health service-user movement, peer support, the recovery concept, government policies and legislation, the welfare state, and economics and finance as well as others. The breadth of theory and various disciplines make it impossible to include everything. Therefore, I have attempted to capture the essence of the myriad influences through the ages from a

reflexive perspective (Reason & Bradbury, 2001; Ritchie & Lewis, 2003) with a view to locating myself as the researcher in the study.

Ritchie and Lewis (2003) propose that reflexivity is important as we strive for objectivity and neutrality in our work while at the same time allowing us to acknowledge the bias that our backgrounds and beliefs may introduce. We are encouraged to leave clear tracks of thought and influence so others can follow. I will discuss the structure of mental health services later but first, I want to put into context the organisation where the study was undertaken.

The setting of the research was within a voluntary and community sector (VCS) based organisation in the North West of England that has been in existence since the early 1990s.

The host organisation is a user-led and managed provider of services to people who experience mental health problems, which supports people to gain their rights in a democratic, safe, friendly, and empowering environment. This means that the governing body (all of whom are volunteers) and employees comprise predominately of people who experience mental health problems themselves.

Shortly after its inception, the organisation began to introduce support for people who experience mental health problems. The service-users and carers who were the founding members or volunteers brought about this support. Rather than being told by others what might be helpful the carers and people experiencing mental health problems decided what they needed to help.

The members received training in the various skills and services that they needed to be able to deliver to their peers. There was minimal influence from medical and social care professionals although the experience from these two groups of people could be utilised if needed. The services that the organisation provides fall into four categories: talking therapies, information, advocacy, and self-help groups.

Volunteers provide most of the services and approximately 60% of the volunteers are people who have personal experience of mental health problems. Within the organisation, the meaning of ‘volunteer’ is simply that of a person who has the motivation and ability to take part in the delivery of services.

The ethos of the organisation is that of enabling people to take responsibility for and regain control over their lives. The organisation supports people to cope and manage their experiences and understanding of the world. Largely disregarding psychiatric diagnoses as providing any indication of a basis for support or personal development.

The organisation works with between 250 and 300 different people every week with services running every weekday between 10:00 and 20:00. Local National Health Service (NHS), Local Authority, National and Regional Trusts and Foundations, contracts with private organisations, its own earned income and donations fund the organisation.

The service strives to provide an empowering and enabling environment that essentially respects human rights; the following sections explore my own interpretations of the concept of human rights.

Human rights are moral principles that describe certain standards of human behaviour (Nickel, 2014). The concept of human rights can claim a lineage to the philosophy of natural law among the ancient Greeks (Rommen, 1998, p. 5). Both Plato ('The Republic,' 1987) and Aristotle ('The Rhetoric,' 2007), assert that certain rights or values belong to human nature. These rights and/or values can be universally recognised and agreed upon through a process of reason (Halverson, 1976).

Natural law formed part of the philosophy of Stoicism. Interpreted as the rational order of things discerned by right reason and applied to human life by Zeno (334-264 Before the Common Era [BCE]) credited with the idea (Taitslin, 2011).

The philosophy of Stoicism was concerned with equality and the idea that humans, whatever their status within society, were to be considered equal to one another under the law. For example, Epictetus, a slave, would have had equivalent rights to Marcus Aurelius Antoninus, the emperor of the Roman Empire, Both of these men considered themselves Stoics. Epictetus and Antoninus wrote about their ideas in 'The Enchiridion' (Epictetus, 1750) and 'Meditations' (Antoninus, 1634), the first written appearance of the idea of natural rights.

In the introduction to the 'Meditations' the editor writes:

> *"Marcus sought by-laws to protect the weak, to make the lot of the slaves less hard, to stand in place of father to the fatherless. Charitable foundations were endowed for rearing and educating poor children" (Antoninus, 1634, Introduction).*

and

> *"The soul of man is an emanation from the godhead, into whom it will eventually be re-absorbed" (Antoninus, 1634, Introduction).*

I take the descriptive term "weak" (Antonius, 1634: Introduction) to include people who do not have much bodily strength, are physically ill or infirm, and those who experience mental health problems.

The second quote shows that the emperor believed that all men emanate from the same place and that at the appropriate future time, gathered back into that place, there to be equal among others.

From these two short quotes, I think it is reasonable to assume, that even far back in history, the emperor was thinking about and making plans concerning the situation of others from both a spiritual and physical perspective. His aim infers to level out the disadvantage that some members of society experience by creating more equality. In 21st Century terms, we might consider this creation of equality akin to the idea we have human rights, that they are the same for everyone. Perhaps also we may consider this similar to modern day ideas of equal opportunities but first we need to review how thoughts about equality changed during the Renaissance.

The Renaissance considered the bridge between the middle Ages and the modern Age, a time between 14th and 17th centuries. A time of the development of the 'age of reason' leading to the 'enlightenment' that thinking and society in Western Europe began to change.

Middle Age thinking governed by the (Catholic) Church and theological thinkers, such as Thomas Aquinas and Augustine of Hippo. Classical Hellenistic thought (Socrates, Plato, and Aristotle) had been lost to the East due to the demise of the Western Roman Empire in 476 in the Common Era (CE). Religious authorities kept tight control and dissent actively condemned (Fasolt, 2007; Innes, 1912). The people had no rights outside of those given to them by religious authorities (Fasolt, 2007; Innes, 1912).

During the Renaissance, significant social, academic, political, financial and other developments came about to sow the seeds of change (Innes, 1912). Not least of these changes was the invention of the printing press that enabled learning and knowledge in the form of books to become more widely accessible (Marvin, 1979). Prior to the invention of the printing press, the making and distribution of books had been the preserve of the Church which kept tight control over the accessibility of written texts (de Sola Pool, 1983).

All of the changes during the Renaissance period, social, academic, political and financial gradually eroded the power of the Church making way for the development of critical thinking and emancipation of the individual (Kreis, 2008).

Thomas Hobbes was one such thinker who introduced the idea of a social contract in the Leviathan (Hobbes, 1998). This led to the surrendering of some individual rights (Russell, 1946, p. 572) and the creation of moral obligation among citizens to one another. Even though he was against the idea of democracy, Hobbes held that all men are naturally equal (Russell, 1946, p. 572).

The social contract supports the concept of social action or working together for the collective good rather than against one another in a selfish sense. This has clear links to reciprocity and mutuality, the requirements for co-production (explained later in the chapter).

The Magna Carta of 1215 (British Library, Undated) was principally a proclamation of liberty and freedom against tyrannical power. This document importantly illuminated the control of power, and remains on the statute book of the United Kingdom (UK) today, stating that:

> *"No free man shall be arrested or imprisoned or disseised or outlawed or exiled or in any way victimised, neither will we attack him or send anyone to attack him, except by the lawful judgment of his peers or by the law of the land." (Magna Carta 1215, ~~c~~Clause 39, British Library, Undated).*

It was at this point that ideas about natural rights, as previously described over 1000 years beforehand in the classical, Hellenistic, and Roman periods, began to resurface.

Humanism

The development of Humanism as a philosophical movement began during the Renaissance. The International Humanist and Ethical Union Bylaws define Humanism as:

> *"A democratic and ethical life stance that affirms that human beings have the right and responsibility to give meaning and shape to their own lives. It stands for the building of a more humane society through an ethics based on human and other natural values in a spirit of reason and free inquiry through human capabilities. It is not theistic, and it does not accept supernatural views of reality" (International Humanist and Ethical Union, 2009 point 1.2).*

Humanism based on ideas developed during the Age of Reason within the broad sweep of the Renaissance allowed and promoted more expansive thought (Kallendorf, 2002). There are two proposed ways to think about how and why Humanism came about.

First, it is about the way that people learn, in particular that learners need to be empowered and have control over their learning process. It means that teachers change their role to become facilitators. Paulo Freire (1996) further developed ideas about power in learning during the 20th Century.

Freire advanced the idea that oppressed people must individually play a role in their own liberation. The oppressed must struggle and gain knowledge to regain their humanity, as the teachings through the statutory education system serves a political agenda. Linked to this is what he called the banking concept of education, people viewed as an empty account to be filled by the teacher. Freire (1996) notes that:

> *"It is not our role to speak to the people about our own view of the world, nor attempt to impose that view on them, but rather dialogue with the people about their view and ours. We must realise that their view of the world, manifested variously in their action, reflects their situation in the world" (Freire, 1996, p. 77).*

For me, this links back to Humanism, defined earlier, that people can take control over their own situation to give it meaning, but also for people to be able to take action and learn in a way that is meaningful for them.

The second way to think about Humanism is as a kind of friendly feeling of good will towards all men without distinction (Ferguson, 1957). In the 21st Century, we might also include women, different races, skin colours, mental health problems, sexuality,

with the same way of thought. A philosophical and ethical stance that emphasises the value and agency of human beings, individually and collectively. There is a link back to the co-production concept of personal assets and building on people's skills and attributes. Humanism generally prefers critical thinking and evidence to acceptance of dogma and superstition (Law, 2013).

A split between reason and religion developed (Guiness, 1973) which permitted scholars to read and think as they wished, recognising the Church no longer had the right to tell them what to believe (Toulmin, 1990). This led to further division or fork in the road of thinking. One route led toward a closer examination of the Bible in the light of newly recovered 'old knowledge' rather than its interpretation by the Church; the other led toward a humanistic way of thought and living (Schaeffer, 2005).

All of this change in thinking during the enlightenment period came to advocate freedom from tyrannical power, democracy, and reason as the primary values of society (Toulmin, 1990). For me, this creates a link between the roots of Stoicism and the ideas of equality, natural law and early modern times, when classical ideas were recovered.

Liberalism

Liberalism, a political movement, founded during the enlightenment after Humanism. John Locke, the 17th century philosopher, described as the father of liberalism (Godwin & Kemerer, 2002), contended that:

> *"The state of nature is governed by a law that creates obligations for everyone. And reason, which is that law, teaches anyone who takes the trouble to consult it, that because we are all equal and independent, no-one ought to harm anyone else in his life, health, liberty, or possessions" (Locke, 2008 Chapter 2, Section 6).*

The idea of obligations for all correlates to the idea of the social contract proposed by Hobbes, and a clear connection between this and co-production. Two of the constituent requirements of co-production are ‘reciprocity and mutuality’ and ‘building on people’s existing capabilities’ (explained later).

These ideas introduced the concept that people should be compassionate towards others (Locke, 2008 Chapter 2, Section 6) which is important when it comes to the consideration of stigma and mental health and the underpinnings of co-production.

Thick populism

Thick populism (Dzur & Hendriks 2018), as opposed to thin populism, promotes popular participation through the organising strategies of citizen’s movements. Similar to the social contract described by Thomas Hobbes (1998) they discuss contemporary concepts such as asset-based community development. In this way, they see citizens as active shapers of a shared environment through a process of social organisation and collective action.

The ideas seem remarkably similar to the concepts and processes that we find in co-production. That is to say, thick populism builds strength, person by person, people work together to solve their problems. Thick populism does not resolve problems for people it simply provides a methodology for people to handle the problems in their own way.

Development of Human Rights thinking

John Locke credited (Dewey, 1963) with providing many of the ideas behind the United States declaration of independence (United States, 1776), in particular where the second paragraph which begins:

> *"We hold these truths to be self-evident, that all men are created equal, that they are endowed by their Creator with certain unalienable Rights, that among these are Life, Liberty and the pursuit of Happiness" (United States, 1776 paragraph 2).*

The French Revolution, 1789 to 1799, produced a declaration similar to the United States, '*the declaration of the rights of man and of the citizen'*. This declaration proclaimed similarly that:

> *"Men are born and remain free and equal in rights" (New World Encyclopedia, 2013 Article 1).*
>
> *"Liberty consists in the freedom to do everything which injures no one else; hence the exercise of the natural rights of each man has no limits except those which assure to the other members of the society the enjoyment of the same rights. These limits can only be determined by law" (New World Encyclopedia, 2013 Article 4).*

In 1945, the United Nations said:

> *"…to reaffirm faith in fundamental human rights, in the dignity and worth of the human person, in the equal rights of men and women and of nations large and small," (United Nations, 1945).*

After which, the Universal Declaration of Human Rights (United Nations, 1948) was adopted by the general assembly of the United Nations (10th December 1948). The 30 statements begin with the words:

> *"All human beings are born free and equal in dignity and rights" (United Nations, 1948).*

In the UK, legislation introduced more recently such as the Human Rights Act (HM Government, 1998), the Equality Act (HM Government, 2010a) and Article 14 of the "European Convention on Human Rights", ([ECHR] as Amended 1950). This legislation confirms that the enjoyment of the rights and freedoms set forth in the Convention shall be secured '*without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status'.*

In the second decade of the 21st century, the expression of the desire for systems to change and give people who experience mental health problems power over their treatment have been updated and declarations, philosophies, charters, and speeches have all been made.

Despite, having acquired rights little has changed, people who experience mental health problems do not have the power to make decisions about their treatment.

The Care Quality Commission (CQC, 2016a, p. 17) reported a 10% year-on-year rise to 58,400 in 2014/15, in the number of people being detained using powers under the Mental Health Act (HM Government, 2007). The report of 2015/16 shows a further, slightly smaller percentage rise (9%) in the numbers of people being detained (CQC, 2018). These statistics do not show a reduction in oppression or coercion but the opposite, and that will be at the heart of this research about co-production. Such ongoing oppression has its roots in early understandings of 'madness' discussed next.

Early thoughts about madness

Early humans believed that mental distress was the preserve of the divine, the result of spiritual problems, perhaps having offended a deity in some way or some sort of supernatural phenomenon such as possession by devils (Amundsen, 1982; Ferngren, 1992; Foerschner, 2010).

People considered behaving like beasts, losing their humanity, resulted in them being treated as beasts, in return. Traumatic interventions included people being beaten starved, or restrained. In early Christianity, whose duty was “to care assiduously for the sick in body” (Harnak, 1998, p. 132), required that a medicine of prayer and fasting or anointing and the laying on of hands be undertaken.

Hippocrates (460 – 370 BCE) began a move away from supernatural and demonic causes for mental distress by openly stating that disease was caused naturally and not by gods. However, the fall of the Western Roman Empire (476 CE) plunged western society back into believing the demonological explanation of mental distress, such as, possession and witchcraft. The Renaissance period saw a resurgence of Hippocratic ideas.

During the Middle Ages, it was considered that all illness resided in the body and there was no concept of the mind being different from the body and ‘madness’ was ascribed simply to a bodily malfunction, and not a malfunction of the soul. These beliefs in demonic possession were commonplace in the popular European mind during the middle ages (Roffe & Roffe, 1995).

The use of charms, prayer and relics in the treatment of mental conditions were common. In modern day, non-Western societies, such as, Uganda (Neuner et al., 2012) and Sri Lanka (Hanwella, de Silva, Yoosuf, Karunaratne, & de Silva, 2012) belief in possession remains potent.

People who were experiencing ‘madness’ tended to be locked away and kept out of sight (Cooper & Gosnell, 2015; Thompson, 2007). Perhaps not because of their inherent danger but because talking about them, seeing them, interacting with them, and their behaviour was deeply socially shameful (Hinshaw, 2009).

Society at that time, was controlled strongly by the Church, and deeply conservative. The behaviour and ways of living described, as ‘madness’ were actually distasteful and socially undesirable to many. Once there was a way to eradicate the shame, by blaming it on an ‘illness’, the whole ‘madness’ concept moved into the realm of medicine where it currently remains since the Lunacy Act (HM Government, 1845).

Psychiatry

The medical profession in the UK became responsible for treating and curing ‘madness’ after the Lunacy Act (HM Government, 1845 Section 42). Previously, ‘keepers’ had ensured that sufferers were dealt with usually by keeping people out of sight.

The classification and diagnosis of conditions, since the Renaissance, became based on a biomedical model. At first, as highlighted in the United States census of 1840, categorisation consisted of two items, ‘idiocy’ and ‘insanity’ (Collier, 2008). In the UK, mental distress is defined vaguely by the Mental Health Act (HM Government, 2007

Part 1, Chapter 1, 1, (2)) as: *"any disorder or disability of mind".* This Act, however, does make some specific exclusions: 'learning disabilities' and 'drug and alcohol dependency'.

Definitions and classifications have changed and appear to be more, based in culture and morals. Attempts continue to be made to provide a classification, for example, by the American Psychiatric Association with the production of their 'Diagnostic and Statistical Manual of Mental Disorders: DSM-5' (American Psychiatric Association, 2013) and the World Health Organisation (WHO) in the production of their 'International Classification of Diseases (ICD) – 10' (WHO, 2010).

Modern thinking

During the 1960s and 1970s, some mental health professionals began to develop an opposition to psychiatry (Nasser, 1995; Szasz, 1976). The ideas of these professionals were termed anti-psychiatry (Cooper, 1971) in the sense that they did not agree with the traditional views of psychiatry, in fact, they believed that psychiatry was wicked (Nasser, 1995). Psychiatry was considered coercive, controlling, oppressive, and deprived people of their rights. Not least because it forced dangerous treatment on people such as Electro Convulsive Therapy (ECT), shock therapies, and psychosurgery such as lobotomy (Barney, 1994).

Laing (1990) asserts that madness happens in a context and there is nothing faulty at all, simply that a person's individual response to events may be different to that of someone else's. It was also believed that there was no particular need for controlled medication and that changes could be made to people's lives through therapy, living together, and trying to find meaning in experience rather than trying to correct it

(Laing, 1972). The anti-psychiatry movement was regarded as a ‘thorn in the side’ of mainstream psychiatry, since fallen by the wayside (Nasrallah, 2011; Nasser, 1995).

In recent decades, commentators began to consider mental health in terms, caused by psychological and social factors (Barker & Buchanan-Barker, 2005; Bentall, 2003; Szasz, 1976). These included being isolated, being victims of abuse, divorce, retirement, long-term physical illness, employment stress, and bullying. These ideas were often referred to as critical psychiatry, and the approaches challenged the traditional paternalistic and controlling model (Hopton, 2006; Thomas & Bracken, 2004). Instead suggesting that interpretation and pluralism allows or permits people to bring the meaning of their experience to the foreground, contrary to the traditional medical view of ‘this is what your problem is’.

Users have begun to find themselves as experts and equals as opposed to the passive or grateful recipients they had previously been, asserted by “Equity and excellence: Liberating the NHS” (HM Government, 2010b).

Critical psychiatry, maybe an attempt by psychiatry to respond to the growing, in volume and number, service-user movement. No other branch of medicine has quite the same relationship with its users. The coercive relationship between psychiatry and its service-users means that if a person decides not to accept the proffered treatment, it could be forced upon them (HM Government, 2007). Worse still, their liberty removed and they would find themselves forcibly detained in hospital. No other medical speciality has this type of social management role.

It is well understood by practitioners and the public at large, if not always acknowledged, that psychiatry has a social role as well as a medical one (The Mental Health Foundation, 2015a). Psychiatry has the political power to remove people from society on the basis that they might be a danger, to either themselves or others. There is no need to prove a case in court and no misdemeanour needs to have been committed. How strange, if people with high blood pressure be forced against their will to accept antihypertensive medication, or risk being detained. Modern approaches retain coercive practices (HM Government, 2007) and critical psychiatry takes the view that forced psychiatric treatment should be abolished; alongside campaigns for such an agenda (Double, 2005).

Critical psychiatry considers that psychiatry should be more constructive and develop positive engagements, with the people using services. This would mean the prioritisation of meanings, values and relationships that people come to them with, rather than following the technical, systematised, and diagnostic medicine orthodoxy prescribed (Scull, 2015).

There is a scepticism about the biomedical model and the rather scientific, context-free way that psychiatry presents mental health and its treatment. Practitioners would spend more time trying to understand the context and meaning behind the problems that people describe. Bracken and Thomas (2001) describe the experiences of a woman who presented with psychosis and upon further investigation, it emerged that the behaviour was the result of a complex domestic relationship. Framing the woman's behaviour in this contextual interpretative fashion rather than in a medical way enabled her to more effectively deal with her problems. There is extensive writing concerning the efficacy of psychopharmacology (Bentall, 2003; Bracken &

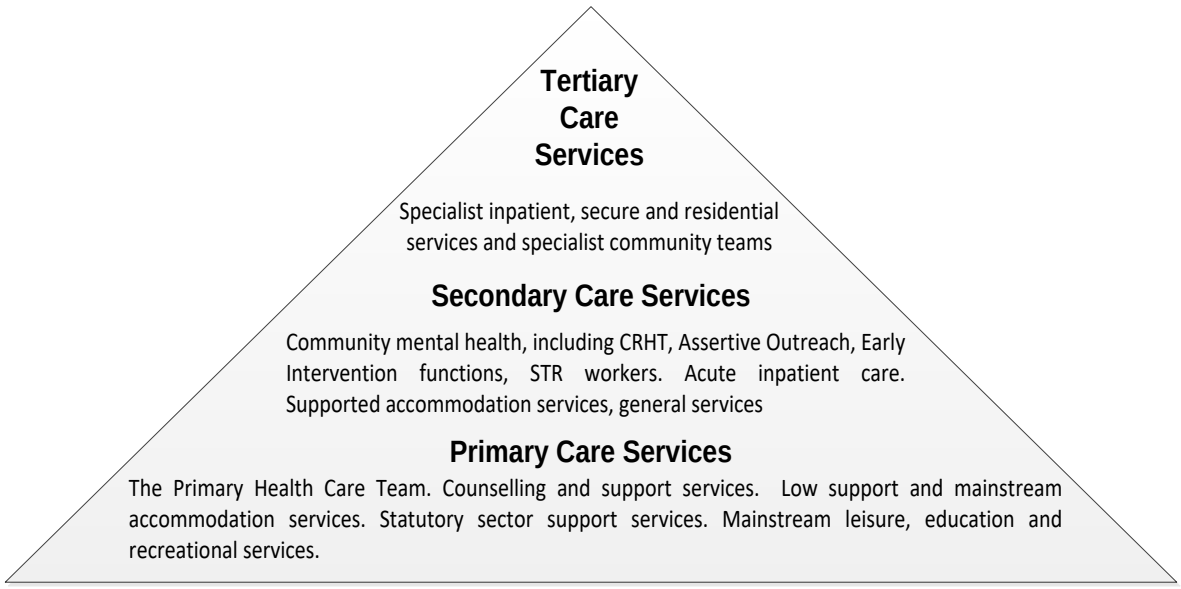
Thomas, 2001; Moncrieff, 2009; Moncrieff, Hopker, & Thomas, 2005) that strongly supports the view of critical psychiatry, that medication is no more effective than placebo.

There remains a real contemporary problem of how modern Western society thinks and talks about mental health despite over 2000 years of history. Controversy concerning the cause and treatment of mental health problems persists (Bentall, 1992, 2003, 2009; Beresford, Perring, Nettle, & Wallcraft, 2016; Double, 2005; Moncrieff, 2009; Szasz, 1976; Whitaker, 2003, 2010).

Modern services

Since the 1990s, in the UK, prior to the National Health Service and Community Care Act (HM Government, 1990), there has been a move towards treating people with mental health problems in the community. Mental health services in England are organised along the lines of intensity of need or severity. Primary, secondary and tertiary services are generally provided, shown in Figure 1.

Figure 1 – Mental health service hierarchy



Primary mental health care services should have a clear holistic focus on prevention, early identification, self-management, and should serve most people with mental health problems (Joint Commissioning Panel for Mental Health, 2012; The Mental Health Foundation, 2015b). Such services delivered by General Practitioner (GP) teams, usually from their surgery base, should offer a choice of psychological and non-psychological interventions. They work collaboratively with other services, provided by the Voluntary and Community Sector (VCS) or, Improving Access to Psychological Therapy (IAPT) delivered by specially trained psychotherapists in the form of time limited, but regular therapy sessions. They also have access to specialist expertise and a range of secondary care services as required (Joint Commissioning Panel for Mental Health, 2012).

Secondary mental health services include inpatient services and Community Mental Health Teams (CMHTs). CMHTs may locally also include: Assertive Outreach Teams, Early Intervention Teams, acute care services (crisis and home treatment, inpatients), rehabilitation, and highly specialist teams working with specific conditions, as well as a range of statutory, non-statutory, and VCS services that support the delivery of care (Joint Commissioning Panel for Mental Health, 2013a). Specialist mental health services are often psychiatrist-led multidisciplinary teams (Gilburt, Peck, Ashton, Edwards, & Naylor, 2014). CMHTs are at the heart of secondary care services.

Tertiary care services surround particular needs and are more specialised than secondary care services, sometimes requiring secure units. They may provide both inpatient and community-based services (Joint Commissioning Panel for Mental Health, 2013b, 2013c). Within tertiary services, therapeutic intervention is more

intensive with far higher levels of support and one-to-one contact time between service-user and service provider. Changes to NHS procurement rules in 2011 (Soteriou, 2012) introduced the concept of 'Any Qualified Provider' (AQP). This resulted in VCS organisations commissioned to provide psychological therapies in addition to a range of other interventions in community settings.

The VCS delivers services mainly for the social and psychological needs of people who experience mental health problems. In contrast to statutory providers, VCS providers are distinctive in that people with personal experience of mental health problems often manage them; described as being user-led such as those of the host organisation.

The sector tends to be mission and values driven as opposed to profit or process driven and is inherently flexible and innovative (Tait & Shah, 2007). The VCS is more able to fill gaps and complement NHS services by enabling access to more difficult to reach groups and providing more meaningful community engagement (Office of the Deputy Prime Minister, 2004). VCS services are themselves very often delivered by professionals who have lived experience of mental health conditions. The provision of these services tends to take place in community settings such as community centres, libraries, and gyms.

VCS services are often non-clinical such as self-help groups, day centres, drop-ins, information, educational groups, befriending and advocacy services. VCS also provides clinical services like counselling, cognitive behavioural therapy and other forms of psychotherapy. Services such as advocacy, befriending and self-help are crosscutting and delivered across all levels of NHS provided services.

As an AQP, the NHS commissions some of the services such as talking therapies, information, advocacy, and self-help groups, that the host organisation now provide. The approach to understanding mental health and the needs of people with mental health problems is often underpinned by democracy, participation, and engagement (National Involvement Partnership & National Survivor User Network, 2015).

NHS services are also expected to engage with users in a similar way (HM Government, 2010a; Patients & Information Directorate, 2013) to remove attitudinal, cultural and inter-professional barriers that exist which sometimes hinder the efforts of staff in their practice (Tait & Shah, 2007). Statutory colleagues often view professionals working in VCS as being unskilled amateurs, the VCS professionals feeling that others do not understand what they do and a feeling of competitiveness between services or their staff (Tait & Shah, 2007)

Service-users themselves may adhere to medical models to explain their problems and a flexible service user-centred approach is much more likely to be a discussion concerning 'what is it like for you?', 'how do you see it?' and so on. Gergen (2013) says that:

> *"the important point is that whenever people define reality … they are speaking from a particular standpoint". (Gergen, 2013, p. 4).*

Co-production enables people to take control of their reality and build it using their own skills, networks and capabilities.

The service-user movement

During the past few decades, there has been the development of a movement of people who experience mental health problems. People have begun to question and criticise what 'is done to them' (Wallcraft & Bryant, 2003).

Service-users now realise that they have been treated in a way that they disagree with, and does not suit them. At the same time, service-users began to form small groups of 'mad' activists and the service-user movement, as we know it, began. In England, this included; Mental After Care Association (MACA), Hearing Voices Network (HVN), MIND (National Association for Mental Health), Rethink (National Schizophrenia Fellowship) and many others. They existed as pressure and campaigning groups.

The organisation which I work with originated by a group of service-users and carers, who came together to try and find solutions for the NHS after it became clear that ' 'Care in the Community' (HM Government, 1990) was not able to deliver what the service-user population required. In a sense, it was at this point that a realisation began that psychiatry did not really deliver. Service-users began to develop activities, therapies and ways of doing things which made sense to them, helped them to make sense of the confusion and distress which they were experiencing, and importantly helped to make it so that they could start to live their lives again.

Service user-led organisations have sprung up to deliver additional or complementary services to those provided by the NHS or their equivalent. In the host organisation, we were commissioned to provide services on behalf of the NHS. Sometimes, this has been National Institute for Health and Care Excellence (NICE) approved services

such as IAPT. At other times, services that the NHS locally cannot or will not deliver such as befriending, self-help and advocacy.

The notion of democratic ideals are all important in that people can be involved in their own treatment, that they have a choice, that they can decide for themselves, that diversity and equality and having a choice are crucial. In very recent years, the UK government has begun to enshrine the idea of ‘choice’, ‘user involvement’, and ‘person-centred care’ in legislation. In particular, recent government reforms are “Equity and excellence: Liberating the NHS” (HM Government, 2010b) known colloquially as ‘No decision about me without me’. This government policy puts service-users ‘front and centre’ and in equal partnership with clinicians. Also “No health without mental health” (HM Government, 2011) introduces the idea that overall health is not possible without mental health and effectivley puts physical health and mental health equal with one another. It lays out the pathway for achievement and includes service-users.

These policies have begun to bring forward the notion of democratic ideals in that people can be involved in their own care, that they have a choice, and can decide in equal partnership with professionals and this includes what some have termed ‘recovery’.

Recovery

Despite some of the methods of statutory services, there has been an attempt to embrace a more positive approach to people who experience mental health problems. There has been a movement away from the traditional notion of clinical cure. This was closely linked to the democratic ideals and possibilities for people

interpreting their own situations (Collier, 2010; O'Hagan, 2009; Shepherd, Boardman, Rinaldi, & Roberts, 2014). People deciding for themselves when they feel well enough to participate in life in the way they feel comfortable. The change in focus meant that for people to recover in a functional sense was very subjective; everyone will be different and they will take control of their situation. It will be through their relationships with others that well-being will be achieved (Gergen, 2013).

For more than a decade, policy and guidance regarding the vision for mental health care and support has focused on the development of services that promote recovery, independence, prevention, and inclusion. Such as 'The Journey to Recovery: the Government's vision for mental health care' (HM Government, 2001), 'No health without mental health' (HM Government, 2011), and 'Closing the gap: priorities for essential change in mental health' (HM Government, 2014b).

The government wants to place patients' needs, wishes, and preferences at the heart of clinical decision-making and has begun to introduce this through 'Equity and excellence: Liberating the NHS' (HM Government, 2010b). This presents the idea of people formally taking more control of their own care and being less passive. A notion supported by the Centre for Mental Health and the Mental Health Network NHS Confederation who have highlighted the shared principles of recovery and personalisation (Alakeson & Perkins, 2012).

It is the recognition of that personal point of view that is most important as it permits a plurality of outlooks, helps to find places for everyone to fit in, and seeks different solutions for all (Davies, Heyman, Godin, Shaw, & Reynolds, 2006). The VCS organisation in which I work uses this more democratic and plural approach and this

underpinning philosophy has informed the development of this study. In England, government policies (HM Government, 2010b; HM Government, 2011) place service-users in equal partnership with clinicians and professionals and emphasise the parity of physical health and mental health. These two key approaches are significant developments informing how work with users of mental health services should move forward.

However, not everybody views recovery in quite the same benign way, indeed two particular issues need consideration. Firstly, McWade, Milton, and Beresford (2015) suggest that activist concepts such as recovery, have been co-opted and politically neutralised by policymakers and service providers. This means that the idea of recovery which held promise for so many people has been used to reduce support to those in need (Beresford & Russo, 2016). Recovery as a personalisation concept and through marketization has seen the number of dispossessed increased and even some deaths occur (McWade et al., 2015; Mills, 2017). Unfortunately, recovery has been linked to both the biomedical model mental health including its medicalised language and the idea that once recovered people can go back to work (Beresford, 2019).

Secondly, recovery defined in such a way makes people responsible for themselves and yet beholden to bio medically focused service providers. This seems at odds to the original thinking behind recovery, which called for collectivist and de-medicalised approaches (McWade, 2016).

The language of mental illness and my reflexive position

Locating the philosophy of the researcher is important in any qualitative work (Altheide & Johnson, 2011) and this reflexivity is revisited later in the thesis.

I do not hold with the idea of mental distress being a medical illness.

Diagnostic manuals promote only a medical model of mental health problems, a position I do not accept in the same sense that maybe Chronic Obstructive Pulmonary Disease (COPD) or Chronic Heart Disease (CHD) might be. However, non-medical alternative language to discuss mental distress has not developed. I prefer words like ‘distress’ and ‘madness’, having been reclaimed by survivor groups (Basset, Faulkner, Repper, & Stamou, 2010; Beresford, Nettle, & Perring, 2010; Beresford et al., 2016).

The group of people who are having difficult emotional and mental experiences, often within mental health services, are commonly referred to as ‘patients’, ‘service-users’, ‘consumers’, ‘survivors’, and a range of other titles. The terms ‘patient’ and ‘service-user’ have been discussed (Simmons, Hawley, Gale, & Sivakumaran, 2010) and to me, on one hand, seem to make them grateful recipients. On the other, people who willingly get involved with the implication of almost being ‘customers’, suggests an implicit power imbalance.

Sometimes, I feel trapped into using a biomedical shorthand because to do otherwise would over-complicate the matter. For example, although I find the notion of a psychiatric diagnosis such as schizophrenia or depression distasteful, to describe it any other way just makes the description more complex. Similarly, to authors in the critical psychiatry movement (Bracken et al., 2012; Moncrieff, 2009), I do not consider such conditions as valid illnesses or these descriptions as useful. Nor do I find other

words such as ‘episode’, ‘remedial’, and ‘treatment’, from a biomedical lexicon easy to digest. These words are for me, so tightly bound with medical discourse, especially when it comes to mental health, that I find they make me feel powerless.

Burstow (2003), a prominent neo anti-psychiatrist, is of the clear opinion that to break the stranglehold of psychiatric language there needs to be an extensive break with biomedical psychiatry and to rigorously de-medicalise. She proports we forget about tinkering in the margins and instead institute a wholesale rethink getting rid of all the medical language, recovery, symptoms and anything to do with diagnosis. Anything less than this will allow psychiatric hegemony and discourse to continue traumatising, stigmatising and depriving people of their personal identities. Many organisations have already explicitly rejected the idea of illness and instead begun to focus on experiences such as voice hearing (Spandler & Cresswell, 2009).

Gadsby (2019, p. 3) of the critical mental health nurse’ network asks “Can a doctor really give a person a clean bill of health when they have no friends, no family, no home, no money, no meaningful roles, no relationships of belonging?”.

These are all things for which we have everyday language already. A language that is not stigmatising, not labelling, definitely not medical and as we shall discover later, most important.

Power

To begin to make sense of how power and control are sometimes thought about, power can be defined as ‘*the ability to control others’* (Collins Concise Dictionary,

1978, p. 587) while control can be defined as '*to exercise authority over; direct; command'* (Collins Concise Dictionary, 1978, p. 166).

Earlier in this chapter, I mentioned the ideas of Freire (1996) concerning how we ought not to impose our view of the world on others. I have related this idea to that of a co-produced mental health peer-led, self-help group as a group of people who experience mental health problems. The oppression of people who experience mental health problems is well documented throughout history (Burstow,1988; Capponi,1992; Chamberlin,1990) and modern approaches retain a controlling and coercive element. Garvin (1985) describes these people as being denied opportunities by virtue of their characteristics such as experiencing mental health problems, by institutions that damage identities and denigrate lifestyles.

People who collaborated in this study take control of the environment to develop it and learn in the way that they want and need rather than that required by the oppressor. In this example, the oppressor could be society at large or mental health services; it is stigmatising and oppressive and in a social sense, portrays people as being members of a despised and disadvantaged sub-class (Abberley, 1987).

These ideas link strongly to the co-production notions of 'facilitating rather than delivering', 'peer support networks', and 'reciprocity and mutuality'. This is in contrast to the scholastic ideas that teachers are the font of all knowledge and that all subject matter be taught in a predefined way. An ongoing criticism of biomedical psychiatry is its connection to compulsion, detention and power (Foucault, 1973; HM Government, 2007; Szasz, 1976) which the CQC suggests is increasing year on year (CQC, 2016b).

Perhaps the most relevant theorist on power within mental health is Foucault due to his examination of madness (Foucault, 1973). For Foucault, however, power is not something that can be held by certain groups or individuals, nor is it exclusive to intentional action.

Power is essentially a positive force that infiltrates all levels of society and people are always simultaneously undergoing and exercising this power. Power, in this sense, is legitimised through knowledge ascertaining to what is considered true. Foucault describes these bodies of knowledge as “discourse” (Foucault, 1977). People are disciplined by discourses that work as normalising structures that guide people to understand the world and their bodies in certain ways (Foucault, 1977). In terms of this work, Foucault’s ideas mean that people are ‘controlled’ by the dominant discourse into behaving and believing what the discourse says about them, which is not necessarily how they would naturally behave or believe.

The struggle against compulsion and control in psychiatry, may be found in the ideas surrounding empowerment, service-user involvement and recovery, which have gained popularity over recent years (Barker & Buchanan-Barker, 2005; Bracken et al., 2012; Double, 2002, 2005; Thomas, Undated; Thomas & Bracken, 2004) and in mental health policy (HM Government, 2011). It is perhaps this struggle that has led to the need for a more egalitarian approach found in the concept of co-production.

Co-production

This thesis locates itself within a democratic approach and co-production is a relatively new method of achieving this. History does provide examples of practice in

mental health that have some similarities in concept to co-production. Two such examples are, the moral treatment idea developed at the York Retreat in 1796 (Bewley, Undated) and more recently, therapeutic communities (Main, 1946).

The York retreat, an inpatient service, initially rejected contemporary medical theories and techniques and tried to create a homely environment where the moral autonomy of people was recognised to give them a sense of contribution, although the environment was paternalistic. Moral therapy was successful but expensive; however, moral treatment was progressively assimilated into medical practice, eventually giving way to large asylums of more recent times (Digby, 1987).

Therapeutic communities are usually run as inpatient units, although day services are common, based on the idea of shared responsibility, citizenship and empowerment (Campling, 2001).

The underlying principles of co-production link to the democratic ideals outlined later, where the power between users and professionals is more balanced. Co-production is the principle that underpins the approach of the VCS organisation I work for. For co-production to work, it is essential that anything is done at the ‘done with’ power level, rather than the more common ‘done to’ or ‘done for’ levels (see figure 2 and table 1 for further clarification). This then encourages service-users to be involved in their own care, promotes and strengthens the service-user movement, and sets users equivalent to professionals.

During the last ten years, the New Economics Foundation (NEF) and the National Endowment for Science, Technology and the Arts (NESTA) have published several

papers (Boyle, Coote, Sherwood, & Slay, 2010; Boyle & Harris, 2009; Boyle, Slay, & Stephens, 2010) relating to the development of co-produced services and implementing them at scale in mainstream statutory services. The UK Government has been promoting co-production of services in mental health for several years (HM Government, 2010a, 2011, 2012) and the NHS has attempted to commission them (Harrington, Neblett, Stephens, & Chambers, 2008). A recent literature review highlights minimal published research concerning co-production of mental health services (Slay & Stephens, 2013).

In a personal email, Julia Slay (who gave permission for this to be reported), key researcher in this area and programme manager of social policy at NEF confirmed that:

> *"Co-production is still a relatively new concept and as such the evidence base is still being built up. It is also a community based intervention, not a medical intervention, and so there has been less funding available for evaluation. Where evidence does exist, it shows promising outcomes for people who are involved in co-producing their mental health support" (J Slay personal email communication: 17th July 2015).*

Co-production is an approach that has been built on peer support and self-help. The latter are concepts that are well represented in the literature (Davidson et al.,1999; Pfeiffer, Heisler, Piette, Rogers, & Valenstein, 2011; Pistrang, Barker, & Humphreys, 2008; Solomon, 2004). This literature supports the effectiveness of peer support and self-help groups and suggests that they are worthwhile in supporting people who experience mental health problems. However, these approaches are not the same as co-production, explored in the next chapter.

This research thesis, therefore, locates itself within a democratic ethos (discussed in chapter three) and will focus on the co-production taking place within a peer-led mental health, self-help group.

The difficulty with co-production is that it is quite new and popular with lots of individuals, groups, and organisations, who say they are doing it. But it is unclear what exactly they doing (Bradley, 2017). The term co-production is used in many ways, sometimes to express an idea of 'joint working' between departments or organisations and sometimes to express a level of involvement between two or more participants (organisations or individuals). There are several definitions:

> *"A relationship where professionals and citizens share power to plan and deliver support together, recognising that both have vital contributions to make in order to improve quality of life for people and communities" (National Co-production Critical Friends, 2011; Slay & Stephens, 2013, p. 3).*
>
> *"Co-production is not just a word, it's not just a concept, it is a meeting of minds coming together to find a shared solution. In practice, it involves people who use services being consulted, included and working together from the start to the end of any project that affects them" (Think Local Act Personal, 2011).*
>
> *"A way of working whereby citizens and decision makers, or people who use services, family carers and service providers work together to create a decision or service which works for them all. The approach is value driven and built on the principle that those who use a service are best placed to help design it" (National Occupational Standards SFHMH63, Undated).*
>
> *"Co-production is when an individual influences the support and services received, or when groups of people get together to influence the way that services are designed, commissioned and delivered" (H M Government, 2014a, p. 17).*

The definition that I am using is the one provided by the National Co-Production Critical Friends. I have provided three others for comparative purposes. Although they are quite similar in many respects, I do not think that they emphasise the power

element of the relationship sufficiently strongly which could lead to co-production being viewed as simply a new way of describing working together or consultation.

The sharing of power between group members in co-production is important. It is the thing that means: ‘this is a joint endeavour and we all have responsibility to one another’ (National Co-production Critical Friends, 2011; Slay & Stephens, 2013). If power is not shared, then whatever is happening is not co-production.

Pamela Fisher who organised and ran a series of seminars ‘Reimagining professionalism in mental health: towards co-production’ on behalf of the Economic and Social Research Council similarly makes the point very clearly that in her view co-production “involves genuine power-sharing and therefore a fundamental democratising of relationships between professionals and service users in mental health” (Fisher, 2016, p. 345).

To assist with clarifying who I am talking about for the purposes of this study, the membership of the group was made up of research members and non-research members. The distinction is that research members agreed to take part in the research activities and the non-research members did not. Both types of group member were able to take part in all of the normal activities within the group; I term them as ‘group members’. Research group members I term ‘Collaborators’ and they took part in both the normal and research activities of the group.

According to Slay and Stephens (2013), co-production is a process that comprises the following elements:

1. Taking an assets-based approach: transforming the perception of people, so that they are seen not as passive recipients of services and burdens on the system, but as equal partners in designing and delivering services.

2. Building on people's existing capabilities: altering the delivery model of public services from a deficit approach to one that provides opportunities to recognise and grow people's capabilities and actively support them to put these to use at an individual and community level.

3. Reciprocity and mutuality: offering people a range of incentives to work in reciprocal relationships with professionals and with each other, where there are mutual responsibilities and expectations.

4. Peer support networks: engaging peer and personal networks alongside professionals as the best way of transferring knowledge.

5. Blurring distinctions: removing the distinction between professionals and recipients, and between producers and consumers of services, by reconfiguring the way services are developed and delivered.

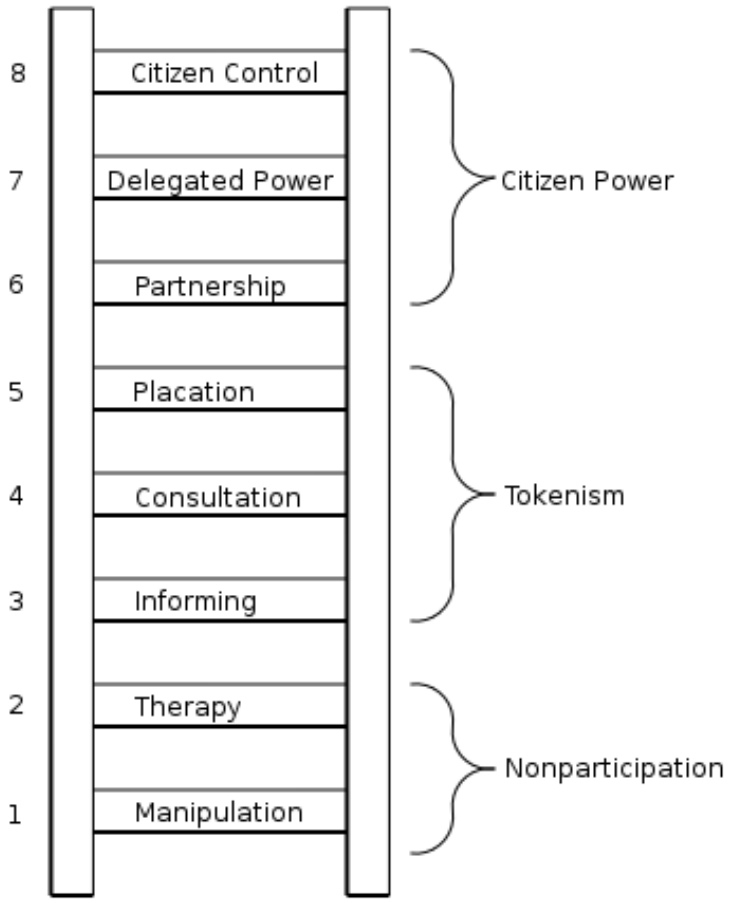
6. Facilitating rather than delivering: enabling public service agencies to become catalysts and facilitators rather than being the main providers themselves.

Co-production is based on the idea of natural equality between the people providing or taking part in their community. The community being considered here is a community of identity including those people who identify with mental health

problems. The process helps to ensure in a positive and active way that people not only take part in community activities but that they are empowered through their own actions in the creation of their own futures. This as an alternative to being passive participants in someone else's power play.

Arnstein's 'ladder of citizen participation' (Arnstein, 1969), not a perfect illustration of power relationships, but co-production is considered (Cahn, 2004; Slay & Stephens, 2013) to be at position 8 - 'Citizen Control' on the original ladder (see figure 2). Arnstein (1969) discusses power relationships and structures in communities where citizens are 'involved'.

Figure 2 - Eight rungs on the ladder of citizen participation



This ladder has been adapted (Slay and Stephens, 2013) to rename the original categories although the original meaning seems to have remained (table 1).

Table 1 – Adapted meanings of citizen participation

Arnstein's ladder	**Slay & Stephens' ladder**	**Interpretation**
Nonparticipation	Doing to	The real objective is to make it appear that citizens have some power when in fact they have no control over what happens. They have no voice and are totally disempowered.
Tokenism	Doing for	Perhaps the most frustrating level where it appears that citizens have power but in reality, there is no control and their power has no bite.
Citizen power	Doing with	The most satisfying level where citizens have real power and are able to take decisions that are implemented. Citizens are able to be assertive, say what they want, and get it.

Chapter summary

This chapter has located the position of the research in a social context and in particular my interpretation, as a researcher.

Across time, there has been the idea that people are born equal to one another and that whatever station they may attain in life or society, they should always be judged

and treated in the same way. This relates back to the concept of natural law and comes forward in time to modern day ideals surrounding democracy and human rights. That is people take responsibility for themselves and their communities, with help if necessary, so that the best outcomes happen for everyone.

We need to consider the idea of the social contract introduced during the Renaissance and how that may balance an individual's concept of her or his rights, against what needs to be surrendered for the overall good of the community. Without that balance, there can only ever be domination leading to one way of doing things that may not be the best way for everyone. The more contemporary concept of thick populism (Dzur & Hendriks 2018) helps to bring those Renaissance political ideas more up to date.

Mental health or 'madness' as I have called it for much of this chapter, continues to provide challenges to us all and how as a society this issue is tackled. There are difficulties with language and the discourse of psychiatry that need to be resolved.

The UK government promotes the idea that co-production is the way forward and that people who use services must be intimately involved in developing, designing, and delivering services. It is important in the whole policy landscape of mental health that the concepts of choice, control, democracy, and involvement, lead the way. As we move from a 'cradle to grave' (Beveridge, 1942; Churchill, 1943) from a state managed welfare system to one where we each begin to take responsibility.

These elements together form the possibility that people who experience mental health problems can develop, create, and implement, their own effective services in

their own context. This study provides the environment in which the various elements described earlier can be brought together to investigate the influence of co-production.

Chapter Two - Literature review

Introduction

The primary aim of any literature review is to put the research in context (Aveyard, 2014; Carnwell & Daly, 2001; Denscombe, 2002). By understanding what has gone on before, it is possible to see trends, theories, and approaches that have already been developed. This chapter details the search strategy used to select relevant literature, provides a critical analysis, and identifies methods and approaches on how best to conduct the research project.

During the last 10 to 15 years (discussed in previous chapter), there has been a comparative explosion of activity in the field of 'doing' co-production in practice (Barker, Needham, Griffiths, Loeffler, & Watt, 2010; Bovaird & Loeffler, 2013; Stephens & Ryan-Collins, Undated). However, there remains limited evaluation evidence of this practice, where people are involved in co-producing their mental health 'it is promising' (J Slay personal email communication: 17th July 2015).

The literature search presented in this chapter illustrates the attempt to locate evidence specifically focused on co-production in mental health services, however there was no dedicated evidence found. As a result, the review focuses on concepts that are precursors to group focussed co-production, namely being peer-led, self-help groups used by people who experience mental health problems.

Appropriate non-medical language is not sufficiently well developed to enable effective literature searching (discussed in chapter one). This meant that the participants in the reviewed studies were professionally diagnosed as opposed to people who self-identified. I can imagine that It would be difficult to find appropriate

studies searching for key words and subject heading such as ‘no friends, no family, no home and no money’. The evidence presented will start to indicate and support a direction for my own research in terms of its structure, scope, and style.

Search strategy

A comprehensive, systematic, and thorough search strategy was developed which included searching for ‘co-production’ as well as ‘self-help’, ‘peer-led’, and ‘mental health’. Despite several reviews and re-searches with limited success, it finally became clear that including the term ‘co-production’ was interfering with the sensitivity of the search. A revised strategy excluded the term ‘co-production’. The new strategy is displayed schematically in appendix 1. Searching the other concepts relating to peer-led, self-help services proved more successful.

To enhance the quality of the search and to ensure a systematic approach, the Population, Intervention, Comparison, Outcome (PICO) framework was utilised. This is a framework that guides rigorous search strategy formation and enables the retrieval of appropriate research (Davies, 2011a). The implementation of PICO was as follows:

- **P**opulation = People who experience mental health problems.
- **I**ntervention or exposure = Community based, peer-led, self-help group.
- **C**omparison = No comparisons.
- **O**utcome = Effect on mental health

This informed the key words and subject headings utilised for the search.

The first step was to establish the likely sources of relevant literature. To do this, all 365 of the available databases offered through the University of Salford SOLAR interface were searched as a scoping exercise. In each case, the database description and subjects that they were concerned with were considered.

In the second step, databases were searched using a simple keyword search term ‘mental health’ to create a shortlist of databases available which offered potential for providing relevant research work more broadly relating to mental health. This route led to identifying a key set of seven relevant databases, which included: MEDLINE, CINAHL, AMED, ASSIA, ProQuest Social Science Journals (PSSJ), ProQuest Sociology (PS), and PsychINFO.

The third step, involved accessing each of the key databases individually to conduct a detailed search using subject headings or MeSH (Medical Subject Headings) (U.S. National Library of Medicine, 2019) where the option was available, or keywords where it was not, to assist in finding relevant information. The decision concerning which search words and phrases to use was complex and frustrating. The language of mental health is complex (highlighted in previous chapter) and when using databases, the categories under which literature is organised uses traditionally accepted medical terminology such as ‘depression’, ‘schizophrenia’, and ‘mental illness’. Subject headings and keyword searches were conducted for the terms shown in table 2 for each database using the Boolean operators ‘OR’ and ‘AND’ as shown (full details are shown in appendix 2).

Table 2 – Subject headings and Keywords

mental health	Self-help	Peer support
mental illness	Support groups	Peer-led support groups
mental disorder	Self-help groups	Peer Group
	Self-care	
	Self-empowerment	
	Mutual support	

The search strategy, implemented on 30th March 2019, across all the key databases located a total of 207 potentially relevant sources as shown in table 3 below, 178 after duplications removed. The 178 potentially relevant sources were then subjected to screening using the defined inclusion and exclusion criteria given below.

Table 3 – Number of potentially relevant sources

Database	**Combined search elements**	**Number relevant sources**
AMED	Mental health AND Self-Help AND Peer-Led	0
ASSIA		1
CINAHL		97
MEDLINE		0
ProQuest Social Science Journals		26
ProQuest Sociology		33
PsychINFO		50

The inclusion criteria included:

- Research reports only.
- Participants in the research must experience mental health problems or be diagnosed with mental health problems and can also be a comorbid issue, for example, cancer, Human Immunodeficiency Virus**/**Acquired Immune Deficiency Syndrome (HIV/AIDS), Motor neurone disease, pregnancy, bullying, physical violence.
- Peer-led, self-help groups as a planned meeting with people who are peers (they are experiencing similar distress or anguish such that they can relate to one another's experiences).
- Peer-led, self-help should only include face-to-face activity.
- Documents written in English and providing an abstract.

The exclusion criteria included:

- No position papers.
- No expert opinion.
- No policy documents.
- No one-to-one meetings.
- No group meetings that solely comprise remote activities such as text, telephone, and online peer groups.

The rationale for the inclusion and exclusion criteria were twofold: to assist in focusing the search of literature, and to make it clear what the review is concerned with (Aveyard, 2014). These criteria helped to ensure that only research literature concerning face-to-face, planned, group meetings was reviewed.

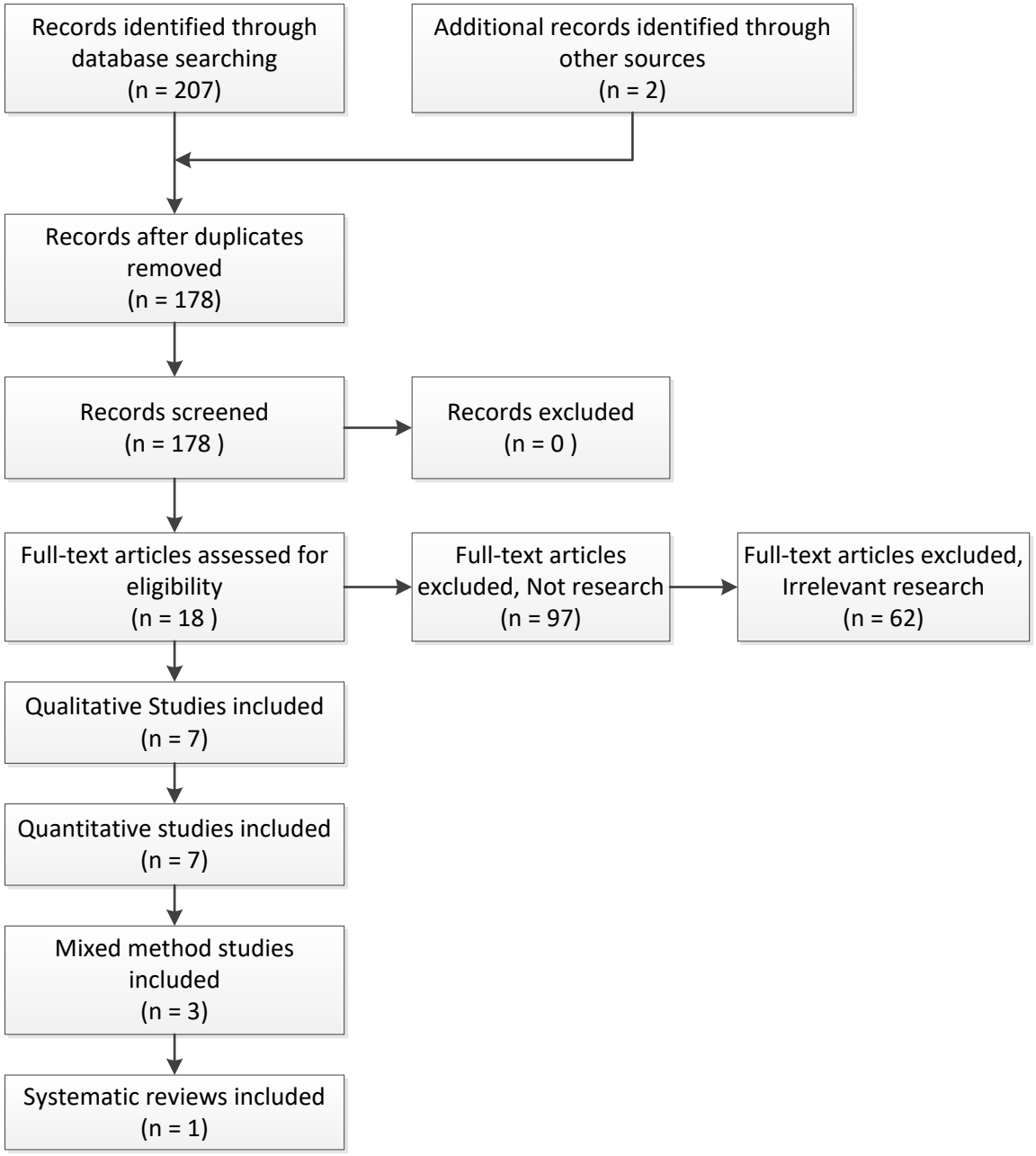
When the inclusion and exclusion criteria were applied, 18 papers remained: seven quantitative research papers, seven qualitative research papers, three mixed methods studies, and one systematic review. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Moher, Liberati, Tetzlaff, & Altman, 2009) procedure was used and the outcome of this procedure (Liberati et al., 2009) can be seen in figure 3.

Results

Of the literature located, ten studies were from North America: nine from the United States of America (USA) (Chinman, Weingarten, Stayner, & Davidson, 2001; Corrigan et al., 2002; Eisen et al., 2012; Laudet, Magura, Vogel, & Knight, 2000; Lucksted, Stewart, & Forbes, 2008; Prevatt, E.M., & Desmarais, 2018; Rowe et al., 2007; Schutt & Rogers, 2009; Simoni, Pantalone, Plummer, & Huang, 2007), one from Canada (Coatsworth-Puspoky, Forchuk, & Ward-Griffin, 2006). The remainder were three from Australia (Dos Santos & Beavan, 2015; Lawn et al., 2007; Lloyd, 2007), two from the Netherlands (Stant et al., 2011; van Gestel-Timmermans, Brouwers, van Assen, & van Nieuwenhuizen, 2012) and one each from Italy (Uccelli, Mohr, Battaglia, Zagami, & Mohr, 2004) and the UK (Boyce, Munn-Giddings, & Secker, 2018).

In addition to these 17 reports, a single systematic review (Pistrang et al., 2008) was located. The 18 papers were read in full and critically evaluated with reference to a critical appraisal tool (CASP, 2010). Data extraction tables provided in appendix 3.

Figure 3 – PRISMA Diagram



Literature Themes

A range of methods exist, used by qualitative researchers, to identify relevant themes from text (Ryan & Bernard, 2003; Ryan & Bernard, Undated). These methods, in particular ‘compare and contrast’, ‘pawing’, and ‘cutting and sorting’, were used to identify five overarching themes that emerged from the literature:

- peer-based, self-help being used by medical professionals
- peer-based, self-help following a predefined, structured programme of activity
- adapted 12 step programmes,
- peer-led organisations, and
- self-help groups being established and led by peers.

Themes are critiqued and considered in sequence, with the systematic review discussed separately.

Peer-based, self-help being used by medical professionals

Simoni et al. (2007) report on the use of peer-based, self-help being used by medical professionals, with the aim of driving up adherence to medication regimes. Peers were recruited in voluntary capacities using a purposive method to undertake the role of supporting others to be more adherent to their medication, and help the medical professionals achieve this. While this shows peer involvement in the activity and it is voluntary, the activity is more concerned with achieving goals that are being determined by the medical professionals and may not be those of the peers in the groups. The perspectives of the peers are unclear.

Participants (n=136) recruited were allocated to peers (current clinic patients who provided the intervention) by research staff based on presumed capability in this randomised control trial (RCT) (Simoni et al., 2007). The participants, were “indigent people living with HIV/AIDS and at risk of depression”, did not seem to have much control over what was happening in the group. Taking part involved a group meeting every other week for three months in addition to receiving phone calls from peers

three times a week. The role of the peers in the group was to facilitate discussion and refocus the discussion when it drifted from medication adherence.

There was a low level of participation in the peer intervention and nearly a quarter (23%) did not take part in the group at all. For those participants who did attend, greater intervention exposure (turning up to the group) was associated with higher self-reported adherence, higher social support, and lower depressive symptomatology at follow-up.

The main weakness of the study concerns its lack of ability to control for social aspects of participants such as them having more pressing problems, for example, attending to where to live and when they could next expect to eat. The authors of the report provided some good ideas about why the intervention had not worked as expected which were related to the group design itself and characteristics of the population. Regarding the design, there were two concerns. Firstly, there was unease that insufficient exposure to the intervention had an impact and it was recognised that even if there had been sufficient exposure, it might not have been enough to overcome other competing barriers to adherence. Secondly, participants may have been slow to develop trust in the intervention and their allocated peers.

With regard to the population under study, there were four further concerns. Firstly, as already alluded to, participants had other pressing problems. Secondly, participants had high levels of substance misuse and chaotic lifestyles. Thirdly, eligibility criteria permitted the inclusion of participants who were satisfied with their current lifestyles and were less inclined to change. Finally, the sample was described

as an experienced HIV/AIDS population and the authors felt that to mean that participants had a history of chronic non-adherence to medical regimens.

Although the researchers report participants giving consent, there was no evidence of ethical permission having been received even though the research was conducted at the Jacobi Medical Center, a public institution, supported by the National Institute of Mental Health.

Peers, who were to deliver the intervention, were trained and assessed at their skill in addressing barriers to adherence and sensitively providing appraisal, spiritual, emotional, and informational, adherence-related, social support. They were also provided with ongoing supervision.

This study highlights that if participants do not appear to have control of their situation and are simply expected to take part in the group, their outcomes are poor.

Peer based self-help following a predefined, structured programme of activity

Three of the six studies in this group (Eisen et al., 2012; Lucksted et al., 2008; Rowe et al., 2007) used a purposive sampling method recruiting 240, 31, and 114 participants respectively. Others (Uccelli et al., 2004; van Gestel-Timmermans et al., 2012) used a snowball method recruiting 44 and 333 participants respectively while Lawn et al. (2007) recruited 35 participants at an appointment with their case manager using a convenience method.

In each case, the people engaging in the intervention did not determine the programme or course of training. Professionals, often with the support and help of

peers, always developed it. The members of the group fall into two categories, those delivering the activity and those receiving the activity. The people doing the delivery could be either professionals or peers trained specially to deliver the intervention. Sometimes, the professionals had a special dispensation to stray from the predetermined course of the programme, which the peers did not have, however, they did not seem to use it.

The goal of Eisen et al. (2012) research, an randomised controlled trial (RCT) to examine the outcomes of a Mental Health Peer Education and Support Group for veterans was to compare the effect of attending peer-led groups against professional-led groups. This was felt to be important because if they are the same or better, it brings into question the need to run professionally-led groups.

The study took place in the USA in two Veterans' Affairs hospitals. The inclusion criteria was that participants must be at least 18 years old, English speakers who had at least one psychiatric diagnosis, had received mental health services over the past 12 months, and had not taken part in the vet-to-vet program. Participants chose to be included after being provided with further information, informed consent was gained from all participants and ethical approval from both sites.

This was a comparative study, an RCT with observations at the beginning and once at three months. The method for the qualitative arm of the study was not reported. The measures were validated and reliable, addressing both professional and user perspectives. There was an intervention of a 12-week peer-led recovery group called 'vet-to-vet' in addition to treatment as usual. This was set in comparison to a 12-week professional-led group in addition to treatment as usual. Finally, people not allocated

to either group were given treatment as usual. The 298 participants were allocated to one of the three groups randomly although it was not clear how many were in each group.

The key findings were: firstly, there were no statistically significant differences between the two types of group; secondly, better group attendance was associated with more improvement. Overall, according to the authors, there was no short-term benefit or harm from peer services.

Lucksted et al. (2008) utilised a constructivist grounded theory approach to investigate the intervention 'Family to Family' (FtF) where friends and family members of people experiencing severe mental health problems participated. FtF was structured in a peer-led, self-help format, a 12 week structured group facilitated by two trained volunteer peer family members meeting for 2 to 3 hour sessions. The study participants were not all from the same cohort of the intervention. The data collected from interviews was processed and this led to the emergence of a single model. Participation in FtF led to new skills being learned, enhanced emotional and practical support, and new ways of understanding information.

A mixed methods US study on peer-support group intervention was undertaken to reduce substance use and criminality among persons with severe mental illness by (Rowe et al., 2007). The study was designed to evaluate the inclusion of peer support and a group intervention, alongside standard clinical treatment. A total of 114 people participated, 41 in the control group, and 73 in the intervention group. The quantitative element comprised a 2 by 3 prospective longitudinal RCT.

The two levels of intervention were a community-oriented group with citizenship training and peer support plus standard clinical treatment (described as 'The Citizens Project') and a jail diversion service. The control comprised standard clinical treatment and a jail diversion service. Recruitment was achieved through posting information at a local social rehabilitation centre and emergency shelter, in social service newsletters and on the information table at a local mental health centre.

The eligibility criteria included adults with severe mental illness who had criminal charges within the two previous years before enrolment. All participants gave informed consent before undertaking the baseline assessment. The group component of intervention consisted of classes and topics relating to social participation, citizenship classes/community integration, followed by supported acquisition of valued social roles.

Classes delivered by a project director twice weekly, include two hour sessions during two different eight week periods. The classes were held in a local church involving six to ten participants. In both tranches of classes, participants were permitted to help define and shape the content of the classes, and provided with a peer mentor. Six peer mentors, people who had been diagnosed in similar ways to participants, completed extensive training. The training covered elements such as confidentiality, client engagement, cultural competence, distinct roles within the criminal justice and mental health systems.

Peer mentors appeared to adopt a role like that of a case manager with lived experience, role model, advocate, and befriender – all in one. Meeting participants on average every week, the peer mentors helped people identify goals and set targets,

shared experiences and coping strategies, encouraged sobriety, provided social support and friendship, and advocated access to services.

Assessment periods took place at baseline, six months, and twelve months, including interviewing participants about drug and alcohol use and reviewing public databases on criminal charges. Ethical approval for the study was obtained from the sponsoring University.

The authors identified five limitations. First, the possibility that the extra assistance that intervention participants received facilitated the outcomes found, independent of the specific elements of that assistance. Second, the design did not allow differentiation between the relative importance of peer mentoring, and classroom-based components. Third, although focus groups and participant observation were conducted, a full-scale qualitative study was not conducted, which might have helped understanding of participant alcohol use. Fourth, the study design did not permit significant qualitative-ethnographic research on the institutional and community contexts that affected participants' prospects of becoming "full citizens". Lastly, the sample was small and so raised concerns regarding this study's statistical and external validities. The key findings were that decreased alcohol consumption was attributable to the experiment and it was also reported that the peer/community-oriented group support may facilitate decreased alcohol consumption over time. The 'valued role' part of the project gave participants the chance to safely challenge their understanding of their capabilities and explore their interests.

Uccelli et al. (2004) reported a prospective study where professionals held the view that peer groups propagated illness. The results showed that support groups

provided inconsistent improvement in quality of life or depression in patients with Multiple Sclerosis. Their suggestion is that people experiencing more severe depression in the study improved, but that people experiencing mild or moderate depression taking part in peer groups remained symptomatic or deteriorated.

The study used self-help facilitator training originating in Canada, translated into Italian. However, the authors offer no critique of the issues raised from translation of this sort that may result in a transcultural conflict in understanding (Meyer, 1991).

Uccelli et al. (2004) recruited to their study using a purposive snowball method, a non-random strategy (Faugier & Sargeant, 1997). This is often used when people who have been purposively recruited, having been told what the required characteristics are, then recruit from among their acquaintances who have the same desired characteristics. The study recruited 44 participants who were asked to attend eight, weekly sessions. The results were limited, however the study suggested that if the duration of the peer support was longer it may have been different. Indeed, they infer a longer or even unlimited exposure to social support, perhaps with learning to cope strategies, could have delivered a more positive result.

Lawn et al. (2007) conducted a mixed methods piece of work into the mental health expert patient. The quantitative element of the work comprised a non-randomised, longitudinal experiment using pre- and post questionnaires but the qualitative aspects were not reported. A series of focus groups were used during and at the end of the project to collect data, but the paper gives no indication about any methodology that may have been used.

Gestel-Timmermans et al. (2012) study aim was to establish the effects of a peer-run course on recovery from serious mental illness using an RCT. It took place at 18 mental health care institutions and patient associations across the Netherlands. The intervention, ‘Recovery is up to you’, consisted of 12, weekly 2 hour sessions.

Two employed trained instructors, with ‘lived experience’, led each session and they had previously successfully completed the course themselves. The trainers received ‘on the job’ training and learned by experience while working with instructors that were more proficient. The study was established as a longitudinal RCT with assessment at enrolment and three months.

A total of 333 people were enrolled; of these 168 were randomly assigned to the experiment, the remainder to control. After the initial 12-week experiment was complete, the control group was permitted to attend the experimental condition but this did not form part of the study. The project was advertised in local free papers, posters in hospitals, psychiatric care services, primary care settings, and by mental health care providers.

Participants were recruited using a snowball method. They had the project explained verbally and in writing before giving written consent. They had to meet two eligibility requirements: self-reported psychosis, personality disorder, affective disorder, anxiety disorder, addiction problems, eating disorders, or other psychiatric problems, and self-report of having experienced disruptive periods in life from which the person was recovering. They were excluded if they were unable to speak Dutch, were illiterate, expressed suicidal ideation, and had florid psychotic symptoms or substance abuse during the course.

The intervention followed a standardised manual, which each participant also used. The manual covered a range of themes including the meaning of recovery, personal experiences of recovery, personal desires for the future, making choices, goal setting, empowerment, and assertiveness. The various themes were discussed in the group where individuals were able to share their experiences and practise their skills. There was also a homework section.

The limitations include having no control group, being unsure exactly which ingredients contributed to the effect of the peer-run course; all of the instruments being self-report, and transcultural applicability were questioned. Key outcomes were that the intervention had a significant and positive effect on empowerment, hope, and self-efficacy beliefs. Data for the intervention that participants indicated was greater recovery at three and six months compared to the control participants. It was considered that the outcomes underline the importance of peer-run services, which add value to recovery-oriented mental health care because they offer participants an opportunity to make an active start on their recovery.

The key findings across the studies in this theme were that there was a positive change in the way that people saw themselves. This new insight led to people responding to challenges in new ways (Lucksted et al., 2008), and there was a significant effect on empowerment and hope (Eisen et al., 2012; van Gestel-Timmermans et al., 2012). Participants took control in their peer support environments (Rowe et al., 2007). Respect for the expertise of each member of the partnership, including the patient, was enhanced (Lawn et al., 2007).

Health professionals reported a surprising shift in their view of the competence and capacity of people experiencing a chronic mental illness to self-manage. They noted that patients felt more empowered to become an equal partner and expert in the management of their health.

Adapted 12 step programmes

This theme brings together two studies (Corrigan et al., 2002; Laudet et al., 2000) based on the adapted 12 step mutual aid-style groups; typically used by organisations such as Alcoholics Anonymous (AA) (Bill, 2001) and Narcotics Anonymous (NA). The 12-step model is peer-led and relies on a process called 'sponsorship', where a more experienced person in recovery guides and supports the newer person through the process. There are no professionals involved in the process. To recover, peers (or members as they are called) must adhere to and try to attain the 12 steps. The AA program takes a spiritual approach to recovery. The process and structure of open and closed meetings ensures a tightknit community. Speaker meetings enable members to share their experiences with alcohol abuse, how they have experienced the programme, and about their recovery through the programme. Both of these studies adopted a purposive recruitment method and recruited 22 and 310 people respectively.

Corrigan et al. (2002) used grounded theory to analyse the narratives provided by 22 users of the programme they were researching. Leaders within the organisation selected the participants, as good examples, from a much larger set of narratives. The study utilised a narrative approach where repeated ideas, concepts, or elements became clear. It was unclear how and in what context the peers were involved other

than as participants or consumers in the programme, which is very briefly described as ‘a 12 step mutual help programme for people with mental illness’.

Laudet et al. (2000) used a cross sectional prospective experiment to enable them to report on addiction services. Dually diagnosed people from the New York City area who were taking part in a programme called ‘Double Trouble in Recovery’ (DTR) were eligible to receive the one-time baseline interview. All of the 310 participants were given a cash incentive to take part as long as they had already been attending DTR for a minimum of one month.

The interview comprised ten elements and took between two and a half and three hours. The ten elements covered; socio-demographics and background, mental health including current status, history, treatment and medication, substance use and status, treatment history, participation in DTR, and the use of other 12 step services.

Key findings of both groups of researchers described that people participating in the community and accepting their own value were essential processes in the programme. The studies reported results that those people who diligently attended the groups were more likely to report higher wellbeing and recovery from mental health disorders and substance use. An important point to note was that to get the most benefit from this type of group, the people in them needed to give of themselves to others in the group. This included turning up regularly and supporting everyone not just themselves.

Peer-led organisations

Examples of peer-led organisations rather than peer-led groups were demonstrated in three studies (Chinman et al., 2001; Coatsworth-Puspoky et al., 2006; Schutt & Rogers, 2009).They showed that multiple, different services and activities that took place in safe, non-judgemental, and friendly environments had positive impacts. The services on offer were sometimes quite simple, such as a place to have a shower, get a meal, and be warm (Schutt & Rogers, 2009). All three studies used the purposive method to recruit participants and recruited 79, 10, and 26 participants respectively.

Schutt and Rogers (2009) in the USA, through a large national study, considered how empowerment and peer support contributed to the effective operation of a user-led organisation in a mental health setting. The study aimed to examine motives for involvement, social processes and consumer orientation, reasons for retention, and processes for participant change. The programme director based recruitment to the study on availability subsequent to referral. The research design was unclear and from a methodological point of view, they claim:

> *"reliance on retrospective self-reports" (Schutt & Rogers, 2009, p. 700).*

and that:

> *"… ongoing ethnographic research …" (Schutt & Rogers, 2009, p. 707)*

would provide clearer outcomes. They report that:

> *"… our analysis reveals only how participants made sense of their experience at the center" (Schutt & Rogers, 2009, p. 707).*

Chinman et al. (2001) considered the utility of peer support in improving 'person – environment' fit, in people who experience mental health problems in establishing

viable footholds in the community. The report suggests that if the environment is appropriate for the person, then mental health will improve and the number and duration of admissions will reduce. This idea moves away from the traditional biomedical model of psychiatry towards a more social model, where the environment is seen as disabling, not the impairment (Beresford et al., 2010; Beresford et al., 2016).

Mutual support (both consumer and professional) groups also have been found to enhance quality of life, improve self-esteem, provide valued roles, and enhance supportive social networks. Although consumer providers are more able to 'empathise' (Chinman et al., 2001). The 'Welcome Basket' programme (Chinman et al., 2001) is based on peer support principles that suggests that those with mental health problems will benefit from coming together to provide aid for each other in the context of a supportive social relationship. However, Chinman et al. (2001) ascribe negative attributes to people such as 'difficult to engage', risking reinforcing a deficit model, not entirely congruent with the principles of the research.

The research reported by Coatsworth-Puspoky et al. (2006) used ethno-nursing as its methodology. Ethno-nursing attempts to combine ideas from ethnography and nursing, and devotes its focus to general or key informants, usually in populations of place, rather than populations of identity (Leininger, 2006). The technique mainly observes and documents how the daily activities of living influence care, health, and nursing care practices (Molloy, Walker, Lakeman, & Skinner, 2015). An ethno-nursing researcher is described as a co-participant to discover how people experience and practise care in their daily lives (McFarland, Mixer, Webhe-Alamah, & Burk, 2012).

It was not clear how the researcher acted as a co-participant, or when and how the observation and documentation occurred. The community or population being reviewed were the two consumer/survivor organisations and what was of interest were the relationships between the peers and their supporters (Coatsworth-Puspoky et al., 2006). The peer support environment was more akin to a service provision organisation of quite a large size. In this research, unpaid peer support workers in more of a structured one-to-one relationship are supporting peers. The authors describe peer support workers as 'consumer / survivor providers' (supporters) and recipients (clients). There appears to be a clear power imbalance between the peers and the peer support workers. Peers were selected to function and operate as being both separate and in another way the same as the peers they worked with.

The results of these three studies fell into two categories. First, Chinman et al. (2001) reported an overall 75% reduction of inpatient days as an indicator of improved mental health. Schutt and Rogers (2009) and Coatsworth-Puspoky et al. (2006) both describe improvements in relationships and how participants learn about meeting the needs of others in similar situations to their own. The key finding is that this environment of experiential knowledge leads to camaraderie - *"they've seen me at my worst and at my best and they're still my friends"* (Coatsworth-Puspoky et al., 2006, p. 496) and a bond with trust.

Self-help groups being established and led by peers

There were five studies in this theme, three of a qualitative nature (Boyce et al., 2018; Dos Santos & Beavan, 2015; Lloyd, 2007), one mixed method (Prevatt et al., 2018) and one quantitative (Stant et al., 2011). They all used a purposive recruitment method and gathered 8, 4, 100, 197 and 106 participants respectively.

Dos Santos and Beavan (2015) investigated the usefulness of peer support in the management of distress in voice hearers. The findings of the study support ideas that peer support is a key component of recovery, of which non-judgemental environments, feeling safe and cared for are vital elements (Mead and Copeland, 2000).

Dos Santos and Beavan (2015) considered the experiences of people who hear voices and use peer support groups. Interpretive Phenomenological Analysis (IPA) (Smith, Flowers, & Larkin, 2009) was used to study the experiences of participants. IPA allows a rigorous explanation of idiographic subjective experiences and social cognition and explores how people ascribe meaning to their experiences in their interactions with the environment (Smith, Jarman, & Osborne, 1999). It also recognises that researchers getting involved with participants' interview transcripts has an interpretive element that through systematic analysis enables them to develop a deeper understanding of the participants' inner world (Biggerstaff & Thompson, 2008).

In the qualitative study eight individuals who self-harm were interviewed about their experiences of using self-help groups (Boyce et al., 2018). Similar to the study by Dos Santos and Beavan (2015), with the most obvious difference being that the people being interviewed heard voices rather than self-harmed.

To contextualise, the research group members were asked about their experiences prior to joining the group. Judgemental attitudes and lack of wider community understanding had led to most group members keeping their self-harming activities

hidden. Members described feeling socially isolated and unsupported by the services that were available to them. Although they described improving understanding and awareness of self-harm in wider society, they nonetheless continued to feel stigmatised, guilty and shameful.

The thematic analysis (Braun & Clarke, 2006) undertaken revealed four themes: a safe space, a different approach, alleviation of isolation and learning from others. Findings indicated that self-help groups offer a unique position, a safe space where people who self-harm can meet peers for support. The individual feelings of isolation and loneliness that group members reported can reduce. The self-help facilitates a sense of normality and likeness among members, alleviating the negative effects of perceived difference. Members gradually realising that they were not alone with their self-harm and that there were others like them in the “same boat”. The groups helped with the development of trusting, supportive relationships and led to a more extensive network of support, in and outside of the group. This occurred through text messages, a feature highly valued in self-harm groups where support is often limited or lacking (Boyce et al., 2018).

Although explained in slightly different terms, these ideas map well to the findings identified by Dos Santos and Beavan (2015). They recognised that participation in self-help led to enhanced coping, more confidence, less tension and frustration, better family communication, deepening acceptance, and more hope.

Boyce et al. (2018) illuminated an idea identified earlier in this chapter from Uccelli et al. (2004), that professionals hold the view that peer groups propagate illness. Boyce et al. (2018) make it clear that notwithstanding the concerns of some professionals

that self-help for self-harm propagates self-harm, the evidence does not support that view. They say that the group “was not about the “mechanics” of self-harm, but more to do with the issues behind it” (Boyce et al., 2018, p. 61).

Lloyd (2007) explored the potential in creating community-based, peer supported, self-help rehabilitation processes; based on a model of community of belonging that he described as an “open urban tribe”. Subjects for the study were selected by public promotion to join a voluntary community of belonging and to pair up with buddies in keeping a fortnightly life journal of feelings and experiences for one year.

Eligibility criteria was simply living with an intellectual disability and/or a psychological challenge, or volunteering to buddy with someone with such a challenge and to be able to approach every participant as an equal. Despite initial awkwardness, participants began to relax and share openly, people began to inspire each other with their stories or just their way of being. Procedures adopted included group discussion, shared exchanges of personal experiences, and reflective deliberative conversations about life with a psychological challenge.

The research revealed that people living with mental illness experienced improved quality of life and self-determining sense of self when they are included in communities of belonging. It exposed that people with mental illness feel better about themselves and express more confidence and independence when they are in a community of belonging, where respectful, equitable relationships of safety, trust and openness, and caring are encouraged. People reported feeling well, showed evidence of finding more energy for life and began pursuing more diverse activities and creativity. This study did not provide any quotes or corroborating evidence and

although there is a clear statement of findings, it is not well supported by the actual evidence provided by the participants.

Lloyd (2007) used a method of collaborative inquiry in participative action research (PAR) (Reason & Bradbury, 2001). The idea of this style of research is that it requires what are traditionally called ‘research subjects’ to behave within the research as collaborators and be active. Its aim is more concerned with the empowerment of marginalised people rather than simply generating knowledge for its own sake (Freire, 1996). Of particular interest is the ‘support’, described as supported collaborative enquiry, which is offered and accepted in the study. In essence, those collaborators with skills, for example, being able to read and write, are actively able to help those people who are less able to keep their journals and take a meaningful part in the study. The study included 100 participants which seems very high for this type of study (Mason, 2010). Much lower numbers are usually considered for such qualitative work, less than 10 and some used only four participants in their work (Mason, 2010; Ritchie, Lewis, & Elam, 2003; Dos Santos & Beavan, 2015).

Prevatt et al. (2018) reported the satisfaction and effectiveness of self-help for postpartum depression, a mixed methods study using community based participatory research methodology (Minkler & Wallerstein, 2008). The program consisted of a free, weekly peer-support group, co-facilitated by two peer-facilitators (former group attendees), trained in group dynamics and maternal health professionals. The duration of the group was about 90 minutes. It was developed to increase social support and destigmatise postpartum mood symptoms and took place in the non-mental health setting of a large obstetrics and gynaecology waiting area. The

meeting size ranged from one to twelve attendees with an estimated typical attendance of eight mothers.

Four study aims included; participant satisfaction, participant perceptions, between participant comparisons and within participant comparisons. All data was collected via questionnaire and analysed using a range of statistical methods. The development of the questionnaire was not clear, such as the origins of descriptor's (supported, understood, informed) to capture participant perceptions of the group, which were measured using a typical five level Likert scale.

This study, similarly to others (Boyce et al., 2018; Dos Santos & Beavan, 2015), reported broadly comparable benefits. There was a reduction in symptoms, feeling more normal and less isolated, shared experiences, normalising thoughts and feelings. A sense of support and understanding among its members were cultivated and a social network established, experiences of acceptance, increased social support, symptom normalisation, and stigma reduction.

No group member reported any ill effect from participating in the group but some of the least helpful characteristics of the intervention were reported, not presented in any of the other studies reviewed. In particular, where there was a large variability in group size, facilitator effectiveness and potential for secondary trauma were noted. Group members reported that a large group sometimes meant that they would not get a chance to speak, something that they did not like. They related this to the variability of facilitator effectiveness at handling larger groups. Comments suggested that women talked over one another, and there was not enough time to talk above providing an introduction. Other group members indicated that hearing "troublesome

stories made me worse" suggesting the idea of 'vicarious trauma' and the likelihood of secondary traumatisation was introduced. Indeed one participant reported she only attended one meeting because of this. With hindsight, Prevatt et al. (2018) felt that facilitators could have implemented a desensitisation protocol before groups started or to encourage participants to practise self-care.

Stant et al. (2011) through 10 participants aimed to understand the economic aspects of minimally guided, closed, peer support groups for people with psychosis. Participants were randomly allocated to the intervention group or 'care as usual'. The session time was 90 minutes on alternate weeks for a duration of 16 sessions. All sessions had the same structure.

Nurses were trained in minimal guidance and intervention techniques to stimulate peer-to-peer interaction. The results of the intervention were not considered to be statistically significant or clinically relevant. However, for people who took part in the group, there was a significant increase in contact with peers outside of the group. There was an improvement in self-esteem and high attenders functioned significantly better than low attenders did, and high attenders made less use of healthcare resources and generated fewer costs than low attenders generated.

Overall, the results indicate that *"psychosocial rehabilitation… happens best in communities of belonging*" (Lloyd (2007, p. 99). Indeed, "positive experiences" were reported by Dos Santos and Beavan (2015) such as a sense of normalisation, shared experiences, and reduced isolation. Peer support for women experiencing postpartum depression provides a potential mechanism for improving mental health

outcomes (Prevatt et al., 2018). Stant et al. (2011) whose primary concern was the cost of the group also reported an increase in social contacts and self-esteem.

Systematic review

The one systematic review located in the search is appraised separately to give fully appreciate and understand the extensive and varied subject matter reviewed.

Pistrang et al. (2008) conducted a review of effectiveness studies examining mutual help groups for mental health problems. A variety of empirical studies concerning the improved psychological and social function of people who experience mental health problems after participating in mutual help groups were interrogated. The review aimed to answer the question: “What is the evidence that participating in a mutual self-help group brings about positive changes for people with mental health problems?” and considers that an effective intervention will lead to improved psycho-social functioning. In addition, the main purpose of the review was to determine if the outcomes of mutual help groups were equivalent to professionally delivered interventions.

The review considers a range of twelve studies of mutual help groups covering three areas of mental health. Briefly, these target ‘problems’ were described as ‘anxiety / depression’, ‘bereavement’, and ‘chronic mental illness’ occurring within adults.

The search strategy which was used was comprehensive and in three stages: firstly, existing reviews of the literature were used; secondly, searches of relevant and appropriate databases such as PsychINFO, CINAHL, MEDLINE, and EMBASE were undertaken; and finally, information was acquired through manual searches, through

reference lists, and on the recommendations of experts. The periods from which articles were selected were made clear, as was the fact that only English language peer reviewed work would be considered.

The types of studies to be considered in the review were identified in the protocol. This resulted in the selection of four RCTs and eight quasi-experimental studies (which involved pre-existing groups), where either a comparison group was available or a longitudinal design made it possible for comparisons to be made at two or more time points. Studies needed to satisfy further selection criteria of certain group characteristics, target problem, outcome measures used, and research design.

Concern was raised that the definition of a mutual aid group be clarified. If this had not been the case, the selection of applicable work would have been more complex due to authors placing a wide variety of meanings to this phrase. Following the robust and systematic assessment and inclusion criteria, the most relevant and important studies appear to have been identified and included.

The results of the twelve studies were combined and an overall result derived. Strong evidence by two RCTs supported that outcomes of mutual help groups were equivalent to professionally delivered interventions. A further five studies were considered indicative but with no particular strength.

The search strategy was thorough and clear with the exception that they agreed they would accept an outcome measure of social functioning and a search of the ASSIA (Applied Social Sciences Indexes and Abstracts) database was omitted. This may have revealed other important evidence. The review could have provided details of

how many articles were retrieved from each database searched. This information presented in a chart or flow diagram would have clearly indicated the numbers of studies at each stage from each database. Indeed further examples of the studies not included in the review would have illuminated how the inclusion and exclusion criteria had been applied, and a deeper understanding of the review scope gathered.

The review emphasised the authors pluralist position and they considered multiple sources of data to be important. Although the richness of personal experience is excluded in favour of objective data, at odds with a pluralist stance. They also adopted a view that people will only want to engage in mutual help if it is able to demonstrate that there is an evidence base for it. This of course largely depends upon what users want and not what professionals or researchers say is good. There is a growing body of evidence to suggest that traditional psychiatry only provides a partial solution at best and that it is a part of the problem (Barker & Buchanan-Barker, 2005; Bentall, 2003, 2009; Bentall, Jackson, & Pilgrim, 1988; Moncrieff, 2009; Whitaker, 2003, 2010).

The analysis pivots on quantifiable data. The review provides a single idea proffering how qualitative data could have been included, then discounts it on the grounds of being ‘less convincing evidence’ suggesting a lack of confidence in qualitative analysis. Disappointingly, this review has failed capture any of the richness that may have been expected from a mixed methods approach.

The quantitative data demonstrates a partial essence of what is really happening in the groups. Conceivably, using qualitative data may have shown a different image and this data was available in some studies, so it may have been possible to

extrapolate. Their proposals preclude the idea that mutual help might be effective in its own right. There is a statement that clearly proposes researching combined professional and mutual aid interventions, matching the reality that people often find themselves in. Although this proposal provides an opportunity for not moving away from, and continuing to deliver, only professionally governed interventions.

The authors of the review recognised that methodologically RCT, although the gold standard for experimental design, was a poor choice for gauging mutual help groups. They identified that RCTs are rare in the mutual help literature, also suggesting that they are not a good choice of method to research this topic.

It is unclear if using a short term, time-bound RCT provides a true representation of what really happens in mutual help groups. The fact that group members know that they are participating in a trial that has been set up to measure its effectiveness may have an impact on the results. Similarly, it is difficult to imagine how facilitators, professionals, researchers, and participants, could be blinded in a true mutual help group.

Given that the people participating in mutual aid groups only have some similar characteristics, it is no great surprise that there is a lack of homogeneity. Of course, four of the groups considered were established specifically to undertake the research as RCT. It is possible that participants in these groups were more homogenous because of the selection procedures used in each case. It was from two of these four groups that the strongest evidence for the effectiveness of mutual aid groups came. This brings into question whether or not service-user established groups (the remaining eight), with their natural heterogeneity, inbuilt confounding elements, and

general lack of experimental control, do make a significant and real contribution to the results.

There is merit in this review, it draws together, in a systematic way, twelve studies that might not otherwise have been compared and points to some useful conclusions. It has attempted to consider a naturally 'messy' area of life in a controlled and systematic way. Conclusions identify that mutual help groups are effective in comparison to professionally delivered interventions, with no negative effects upon participants. This is important because it starts to recognise and at least illuminate some of the complexities of competing discourse and philosophy. Although adopting a positivistic philosophical viewpoint some evidence that self-help can be an effective intervention was gleaned. The authors considered the idea of psychological and social functioning in the sense that it can be interpreted or constructed rather than just measured.

Chapter summary

This review has focused on peer-led and self-help literature in the absence of any research on co-produced self-help groups. Although there is a range of types of research, the majority of papers selected used purposive sampling, considered most appropriate for this client group. Much of the literature discussed appears to remain connected to underpinning philosophies related to paternalistic medical culture and language. Those studies that appeared more democratic in approach showed that when participants sensed that they belonged to the group, they became more hopeful and confident, and were empowered to take control of the group. Participants accepted that they had personal value and learned how to use that by supporting others in similar situations leading to trusting, open relationships.

The deficit focussed biomedical models and ideas indicated by a number of studies conflict with the ideas of co-production that is concerned with promoting the assets of people as discussed in the previous chapter. The main ideas that I take from the literature that will inform the development of this study fall in to three categories: sampling, participant characteristics, and professional/service-user relationships.

The literature has helped to identify several useful outcomes:

- People who experience mental health problems recover better when they are part of a community of belonging to a self-help group or organisation, where they feel safe and respected.
- For people who experience mental health problems, it is important to be in control of their situation; lack of control can lead to poor outcomes.
- There is a realisation that everyone has something to give as well as something to get from the group, although they may not always realise or anticipate that.
- Outcomes are better if people turn up regularly, take part, and be altruistic. Participants ought not to expect to receive if they are not willing to give.
- Improvements in relationships between group members are important and can lead to fellowship and trust. In turn, there can be a development in confidence and resilience.
- Professional involvement can have both positive and negative impacts upon outcomes.
- The outcomes of self-help groups can be equivalent to those of substantially more costly professional interventions and no evidence of negative effects.

Overall, it seems clear that there is evidence to support the idea that peer-led, self-help may be effective in influencing recovery outcomes, but many critical points relating to underpinning philosophy and negative findings suggest the need for further evidence.

There was no specific research on co-produced, self-help groups despite the UK policy having embraced it, thus study focused on this topic is justified. Building on the literature reviewed here, it is important to explore from the point of view of people who use VCS based mental health services, what is the influence of co-producing, peer-led, self-help groups on mental health. The methodology of such a study, is discussed in the next chapter and the approach critiqued.

Chapter Three - Methodology

Introduction

This chapter builds on discoveries from the literature review and brings together the work that was carried out as part of the research. It has been difficult for me to make choices or decisions about how to proceed and I have regularly felt trapped. When I have done so, I have (metaphorically) trodden on a philosophical, methodological or practical land mine creating a frustrating life.

This chapter draws through important elements from previous chapters and learnings to influence decisions surrounding sampling methods, characteristics of participants and the relationships between professionals and people taking part. These are reflected in the philosophical and methodological underpinnings, what actually happened from methodological, analytical, and practical points of view. The research challenges and problems encountered which influenced changes to the methodological plan are discussed. Data analysis methods are explained but decisions resulted, in the trustworthiness of the study and findings being presented in subsequent chapters, before moving on to discuss and conclude the study.

Power imbalance

I hold a senior position in the host organisation and recognise, this may be perceived by other collaborators in this study as being extremely powerful. A strong culture of equality was instilled at the beginning by the founders and has been developed over many years. There is no escaping that this research was my idea in the context of an academic programme, and I have been the driving force behind it.

In practical terms, every time I have met with collaborators, I have over emphasised to them to forget what my day job is. I have reiterated that my role is simply about the research, that I am a student, that I can be held to account by the University and the host organisation, if I do not follow the rules. I am tall, physically large and have a loud voice. In my manner and actions, I have tried to make myself as small and insignificant as possible. The way that I try to achieve this is to use a soft voice, and stoop or sit, to make the height differential less obvious. I hope that this stance enables a more equal relationship which is what I want but at this stage I do not know for sure how I am perceived.

In an attempt to equalise the research relationship (Aldridge, 2015) I have considered initially, prioritisation of voice. There is a division in conventional research between who is doing the original storytelling (conventionally, the research participant, subject, or object) and who is responsible for, and takes ownership of, the data and the final research narrative (conventionally, the academic researcher).

This is not something I wish to do, it is important that the voice of collaborators are not shut down, minimised or devalued in anyway (Baldwin, 2013, p. 106). A fundamental principle and intention in participatory and emancipatory research is to achieve the ‘fluidity’ (Plummer, 2001), and to give the collaborators opportunities to be actively involved in research. It is equally important to allow collaborators time to examine, consider, and reflect on the data they produce.

I plan to draw on four reflexive research strategies used in qualitative studies (Pillow, 2003, p. 181): reflexivity as recognition of self, reflexivity as recognition of other, reflexivity as truth, and reflexivity as transcendence. These strategies are

interdependent and offer the researcher opportunities to resolve some of the difficulties they face.

In particular, I believe that reflexivity in my writing helps to evidence that I am doing my best to return power to collaborators, in fact not to take power from the collaborators, so that collaborators take precedence in the work.

The research setting

The context and setting for this study is within VCS based organisation in the Northwest of England. It serves the mental health needs of a local population and the governing body (all of whom are volunteers) and employees comprise predominately of people who experience mental health problems. This structure ensures that services are designed around the needs and wants of the people who use them. It aims to be collaborative and consensual in its activities. The services, which the organisation provides, fall into four broad categories: talking therapies, information, advocacy, and self-help groups. Volunteers (the majority) work alongside professionals in enabling people to take responsibility for and regain control over their lives.

In the role I hold, my reflexive position is an important part of the construction of the research. Ken Wilber's (1996) ideas of everything being connected to everything else and being part of everything else appealed to my spiritual senses. Prominent psychiatrists and psychologists often quote Wilber (Anthony, 2005; Grof, 1998; Rowan, 1993). In considering the transpersonal, a connection was made for me, which has informed my way of thinking and being over recent years. For me, this points to individuals working towards and attaining their own psychological fulfilment

or ‘self-actualisation’ as Rogers (1961, pp. 350-351) termed it. Undertaking the professional doctorate relates to my need to show just how important people’s experiences are in their own mental health.

The environment in which I work is strongly influenced by a biomedical discourse. I have previously mentioned that I find it oppressive and that it makes me feel powerless. I wanted to try to find a research topic that returned power to the people subjected to that oppressive influence. Knowing that people in the mental health realm often have things done to them I wanted to find a way of working that gave as much power as possible to the collaborators. I noticed at work that we did not need to provide specialist or professional support for everything we do. I like the idea that people are all connected to each other and because of this; we can all help each other. I like the concept of ‘you help me and I’ll help you’ in a non-competitive sense. This seemed to me to be the way to go and that pointed me at co-production. In essence, the research question arose because I wondered why the government was promoting co-production so hard with no apparent evidence that it worked as a process. It seems strange to me that a process gets in to policy with nothing to back it up.

My first thoughts at the start of this investigation process were: “I wonder what research is?” The dictionary (Collins Concise Dictionary, 1978, p. 638) defines research as *“systematic investigation in a field of knowledge, to discover or establish facts or principles*”. Others such as Redman and Mory (1932, p. 10) provide a similar definition: “*systematized effort to gain new knowledge”.* In this, there seems to be an emphasis on the systematic element of the definition, because of that, it should be supported by an infrastructure, as well as being able to discover and learn. Using this

method, researchers are able to explain how they arrived at their answers, using a checklist type of approach is advocated as being the appropriate infrastructure to use (Denscombe, 2003; Kumar, 2011).

Research aim and objectives

According to Denscombe (2003) a question, or aim, is needed and the eventual answer to that question needs to be either filling a knowledge gap or solving a problem. The principle aim of this work was to investigate the influence of co-produced, peer-led, self-help groups on mental health. The research questions to consider included:

- How was the mental health of collaborators, from their personal point of view, influenced by being part of the co-produced group?
- How ready collaborators were to engage in a process, which required collaboration rather than simple attendance?
- Were collaborators able to create the environment which nurtured collaboration?
- Did collaborators experience any harm from engaging in the process of co-production?

A paradigm

The research paradigm most relevant to answering the question helps us to understand our point of view in relation to the question (Guba,1990; Lincoln, Lynham, & Guba, 2011). It helps us to consider the assumptions which we made, how we see the world, our grasp of how knowledge is made and understood, our place within the research, what good evidence might look like, and how we should go about conducting all of the associated research activities. In particular, Guba (1990)

espoused the idea that research paradigms can be characterised through their ontology, epistemology, and methodology. Kuhn (1970) brought the term paradigm to the academic community and gave it a particular meaning that characterized a paradigm as a world view that embodied the beliefs of scientists. When undertaking a research project, good practice suggests that the basis for claiming to 'know what we know' is outlined and it is the research paradigm that does this for us (Reason & Bradbury, 2001).

Crotty (1998, p. 3), on the other hand, takes a different view suggesting that the terminology used in research literature is confusing with epistemologies, theoretical perspectives, methodologies and methods:

> *"thrown together in grab-bag style as if they were all comparable terms" (Crotty, 1998, p. 3).*

Rather than establishing a paradigm first, a researcher initially adopts a particular stance towards the nature of knowledge, for example, objectivism or subjectivism (Crotty 1998). This stance then underpins the whole work and directs the particular theoretical worldview selected, such as interpretivism. Some researchers, and I'm one of them, have begun this work without confirming my research paradigm, although I felt that I knew what I wanted to do. It has only since I have been engaged in the work that I have been able to illustrate my paradigm effectively.

Ontological positions do not matter so long as you have a clear epistemological position (Crotty, 1998). In other words, if all knowledge is subjectively constructed, then the "true" nature of reality does not matter, because we can never get outside our socially based constructions. He says:

"to talk about the construction of meaning [epistemology] is to talk of the construction of a meaningful reality" (Crotty, 1998, p. 10).

However, to enable me to gain a clearer understanding of my philosophical stance in relation to this work, I preferred the checklist approach (Denscombe, 2003; Kumar, 2011). As such, I created a simple map that outlines my research paradigm, table 4.

Table 4 – Paradigm Map

(adapted from O'Gorman & MacIntosh, 2015 and Lincoln et al., 2011).

Paradigm elements	**What it means**	**My stance**
Theme	World view	Interpretivist
Ontology	What is reality? Is there one truth or many?	Relativist – Social constructionist
Epistemology	How do you know something? What counts as knowledge?	Subjectivist - Constructivist
Methodology	How do you go about finding it out? What sort of data will you look for?	Qualitative. Stories, comments, themes.
Methods	What tools are used to understand the data	Interviews
Analysis	The tools or processes used to make sense of the data and turn it in to information	Narrative Framework analysis

Ontology

Ontology is defined as '*the study of being'* (Crotty 1998, p. 10). Ontology concerns itself with subjects such as the type of world we are examining, the nature of

existence, and the structure of reality. Guba and Lincoln (1989, p. 83) state that the ontological assumptions are those that respond to the question '*what is there that can be known?*' or *'what is the nature of reality"*?

The ideas of Foucault and Freire influence my thinking. What is clear is that the powerful can privilege and propagate their own version of the truth (Hui & Stickley, 2007). As Foucault (1973) suggested, once a powerful position has been achieved, this dominant position can be exploited through the repetition of certain language and actions. This often results in embedded change and a broad acceptance of the supremacy of the 'knowledge' subscribed to by this dominant group. Thus 'the truth' is socially constructed.

Socially constructed reality assumes that reality as we know it is constructed intersubjectively through the meanings and understandings developed socially and experientially. According to Kölbel (2011), global relativism is self-refuting, but locally relativism is not. This means that relativism works on a local scale but not globally.

Other social scientists, under the influence of Karl Marx, Max Weber, and Wilhelm Dilthey, have given credence to the idea that human beliefs and actions could be understood and evaluated only relative to their social and economic background and context. Carol Rovane (2013) suggests that relativism is driven by the existence of truths that cannot be held together, not because they contradict and hence disagree with each other but because they are not universal truths.

The sociological view that beliefs are context-dependent, in the sense that their context helps explain why people have the beliefs they do, has also been used to

support what is sometimes called “social” or “sociological relativism”. This is the view that truth or correctness is relative to social contexts because we can both understand and judge beliefs and values only relative to the context out of which they arise.

Bracken and Thomas (2010) present a view that some supporters of critical psychiatry (they claim vociferously not to represent the movement) hold the view about the nature of reality that it is less binary and more nuanced and plural. Critical psychiatry considers that psychiatry should be more constructive and develop more positive engagements with the people who use its service (Thomas & Bracken, 2004). This means the prioritisation of meanings, values, and relationships, and that people come to them rather than following the technical, systematised, and diagnostic medicine that orthodoxy prescribes (Scull, 2015).

There is a scepticism about the biomedical model and the rather context-free way in which biomedical psychiatry presents mental health and its treatment (Bracken et al., 2012; Double, 2005; Horwitz, 2002).

Critical psychiatry practitioners spend more time trying to understand the context and meaning behind the problems that people describe. The success of any treatment approach depends upon how those recipients interact with it, value it, and respond to it. The success of the treatment would depend upon the context in which those recipients receive treatment, who those recipients receive treatment from, and what the involvement of those recipients has been in making or constructing the treatment. The success of the treatment would depend upon the places in the world and society

of those recipients, what those recipients' connections are, and how those recipients feel about the treatment.

It is this deep, personal, instinctive understanding of their problems that is known by recipients and communicated to practitioners. Heron and Reason (1997) make the point that:

> *"knowers can only be knowers when known by other knowers: knowing presupposes mutual participative awareness." (Heron & Reason, 1997, p. 5).*

Ontologically, therefore, this study will be conducted in the belief that reality, with its objects, entities, properties and categories, is not simply "out there" to be discovered only by empirical investigation or observation. Rather, it is constructed through a variety of norm-governed socially sanctioned cognitive activities such as interpretation, description, and manipulation of data. Constructionism insists that there are indeed no facts except for socially constructed ones, created and modified at particular times and places dependent on prevailing theoretical and conceptual frameworks.

Epistemology

I, like Guba in Lincoln and Guba (1994), previously occupied a position within a different epistemological tradition. A definition of epistemology that I adopt is:

> *"epistemology is a theory of what gets to count as knowledge". (Gunzenhauser & Gerstl-Pepin, 2006, p. 332).*

My formative years were spent learning and working in the chemical industry. I dealt with objective information that I could prove by experiment and from first principles

what would happen in any given reaction. I knew that others could perform the same reaction and always get the same answer as me. My view at the time was that I could prove how and why things happened in the laboratory and in the factory. It would always be the same and only the same one answer would result. It is only in later years that I have come to realise and accept that my beliefs about knowledge have been so strongly influenced by my place in society.

As a younger person, I often found myself at odds with prevailing thought and occasionally did not understand how ideas could fit together. I have realised that this was because I was taking a positivist worldview. The idea that there was a single reality, a positivist philosophy, seemed to make sense in the environment I inhabited.

As I have grown older and my life has changed and developed, I have become much more interested in the complexities of life and knowledge. I have moved from the chemical industry to a role in mental health and have begun to realise that there does not have to be a single truth about things. Listening to competing football fans, for example, clarifies that to understand which team is best does not necessarily depend upon who scores the most goals or who is highest in the league table – objective things which can be measured or counted – but can also include a shared social history with other fans and families, their relationship to players, where fans stand or sit in the ground, and how they feel about their club – subjective things which need teasing out, understanding, clarifying, and confirming.

Eventually, using this inductive process, provides an interpretation of what has been going on (Owen, 1992). So it depends on what the question is and how it is framed whether we want to fill a knowledge gap or solve a problem. I intend to approach this

study by filling a knowledge gap and creating understanding of the situation, by using a subjective method. The reality of the situation can exist only in the individual minds of the collaborators and using a subjective interaction seems to be the way to access them (Guba, 1990). This is in contrast to the mental health system that currently exists as previously discussed.

Constructivist and Constructionist (both subjective) paradigms move away from the positivist idea that the world is objectively knowable, and move towards the idea that there is no one true reality, but that 'reality' can be considered as being plural and having more than one dimension. The constructivist paradigm views reality as being constructed by the individual, while the constructionist paradigm views reality as being constructed through interaction, through language. A social constructionist perspective, as opposed to a constructivist perspective:

> "locates meaning in an understanding of how ideas and attitudes are developed over time within a social, community context" (Dickerson & Zimmerman, 1996, p. 80).

In essence, social constructionism is the claim and viewpoint that the content of our consciousness, and the mode of relating we have to others, is taught by our culture and society. All the metaphysical quantities we take for granted are learned from others around us (Owen, 1992, p. 386). From a social constructionist perspective, language is more than just a way of connecting people. People 'exist' in language. Consequently, the focus is not on the individual person but rather on the social interaction, in which language is generated, sustained, and abandoned (Gergen & Gergen, 1991). People socially construct reality by their use of agreed and shared meaning communicated through language (Berger & Luckmann,1966). From the

social constructionist perspective there are no ‘real’ external entities that can be accurately mapped or apprehended (Anderson & Goolishian, 1988).

Social constructionists prefer stories based on a person’s lived experience rather than on expert knowledge. All knowledge evolves in the space between people, in the realm of the ‘common world’ or the ‘common dance’ (Hoffmann, 1991, p. 5). Only through the ongoing conversation with intimates does the individual develop a sense of identity or an inner voice. Social constructionism considers the creation of constructs and understanding between people and within societies. We thus build our internal models in a pseudo-shared way in response to our perceptions of perceived constructs we receive from others. Construction can thus be seen as a social process whereby constructs (and hence 'reality') emerge from ongoing conversations and interactions. With co-production being an interactive, participative activity, it makes sense to me that in view of this, the epistemological stance of this work ought to be social constructionism.

Methodology

The research method is a strategy of enquiry (Myers, 2009); the most common classifications of methodology are either qualitative or quantitative, shown in the paradigm map (table 4), this research is qualitative in nature.

Qualitative research attempts to study the everyday life of different groups of people in their natural settings, it is intended to help researchers understand people and the social constructs through which they live (Myers, 2009). Within this methodology, complexities and differences can be explored. An obvious distinction between the two worlds of quantitative and qualitative methodologies is the form of the data,

analysis and presentation used. Qualitative research is predominantly conducted through interviews or observation and quantitative research is undertaken through the use of questionnaires, surveys or experiments. Through this process of diverse methodologies, different claims can be made in relation to what is ‘true’, based on the philosophical paradigms adopted.

There are three primary reasons for utilising qualitative methodology, all linked to the research question and purpose of this particular study. These are exploratory, descriptive and, explanatory. Exploratory research is the process of conducting research in an area that has been under researched (Hesse-Biber & Leavy, 2011). Descriptive research seeks to describe a certain aspect of life richly. Finally, explanatory research seeks to explain social phenomena and the relationships between different components of a topic.

It is the exploratory approach where this thesis will be aligned, focusing on the descriptions about the self-reported mental health of the collaborators. As discussed previously, there has been no previous research into the subject of co-produced peer-led self-help groups in the mental health arena.

Ethical Considerations Methods

From the outset, I have been striving to develop research that uncovers evidence that people who experience poor mental health are able, competent, effective, and valuable members of society. It is an attempt to mitigate the view that some professionals still hold, that people with ‘mental illness’ ought not to be used as research ‘subjects’. Of course, informed consent is one of the most important aspects

of ethics in human research and aims to make sure that people “knowingly, voluntarily and intelligently and in a clear and manifest way, give consent” according to Armiger (1997, p. 334). There is an interpretation that because of the apparent reduced capacity of people with ‘mental illness’ they are in some way unable to effectively consent to take part. Therefore, research involving people who experience poor mental may be unethical on the grounds that those people are vulnerable and unable to protect their own rights and welfare. There is further worry that people who experience mental health problems have enhanced needs for sensitivity and protection from researchers.

In this research I show that people who experience poor mental health do not always need to have recourse to these blanket protections. There is also a concern about the use of deficit focussed language (mental illness), terminology (research subject) and ways of thinking that I am deliberately trying to move away from. In some circumstances when people are ‘acutely, floridly unwell’ (as medical practitioners might say) I agree that safeguarding procedures may more easily circumvented. In this research there was nobody having those experiences, however there were several safeguards in place to limit and prevent any harms that might have been done had there been. Those safeguards included:

- Collaborator information sheets - which described what was expected from me as the researcher and from collaborators.
- Consent forms – highlighted what collaborators were signing up for, withdrawal clauses and methods.

- Private and Group discussions – meetings which enabled everyone to voice their concerns (either there and then or at a later stage) about how their involvement might affect them.
- Information about an independent person to contact at the university if people were unhappy with the way things were going.
- External mental health focussed services that could be accessed in the case of distress.
- University of Salford ethics committee approval.
- Host organisation approval.
- Access to a free, non-statutory mental health advocacy service if required to support complaints and offer advice.
- Risk analysis of the intervention.
- The collaborative style of research.

Consent

Written informed consent was obtained from each collaborator at the beginning of the study. This was achieved by providing an information sheet and invitation letter (appendices 5 and 6), and requiring at least participation in either a group information session or a private information session. This consent encompassed collaboration in interviews and focus groups throughout the duration of the study and there were different forms provided for both. It was made clear to collaborators during information sessions that as the study unfolds, their further consent may be necessary. The idea was to ensure mutual trust, so that collaborators were aware that their information, contributions, and confidentiality were of importance and would be held securely. For example, it may have been that one or more of the collaborators said they want to be involved in the dissemination process. At that point

it would have been necessary for them to confirm in writing their consent to disclosure of the fact of their collaboration in the research. Consent forms are provided as appendices 7 and 8.

Ethical approval

This research revolves around the experiences of collaborators in a peer-led, self-help group established and operated by its group members with the support of professionals as required. There was no professional (or other) body with oversight, regulation, or governance over the activities of self-help groups. In view of this, I have been guided by the Research Councils of the UK policy and guidelines on governance of good research conduct (Research Councils of the United Kingdom, 2013). Although not a formal ethical code, it enabled me to consider concerns such as data storage and access, anonymity and confidentiality, and informed consent in a more flexible way.

The University of Salford Ethics Committee under whose guidance the research has taken place approved the study (appendix 9). The host organisation also provided approval for the study to take place (appendix 10).

Data protection

Data was processed according to the requirements of the Data Protection Act (HM Government, 2018) and followed the requirements of the University of Salford data protection policy, information and records management policy, information security policy, and guidance on the retention of research information (University of Salford, 2013a, 2013b, 2013c, Undated).

The University of Salford information security policy (University of Salford, 2013c) describes research information as confidential and therefore “should be locked away”. In terms of electronically held information, this means that it was secured on password-protected University of Salford approved systems. Hardcopy information was locked away in an appropriate filing cabinet, to which only I have access. Audio recordings were held on password secured servers at the host organisation and University of Salford file store and were destroyed following transcription and analysis of the project was complete.

Confidentiality/Anonymity

It needs to be considered that because this study involved a group of people meeting regularly, they inevitably got to know one another and developed relationships. As collaborators, they knew who was taking part. I recognised that some collaborators wished to remain anonymous and others to be identified. In such situations as mentioned previously, anonymity and confidentiality were negotiated individually and on a situation-by-situation basis. The data (recordings and transcripts) were anonymised once collected. This enabled security of collaborators and allowed for the protection of identities in any future publications. Recordings were transcribed confidentially by a professional transcription service ‘Outsec’.

The group nature of this co-production made it difficult to guarantee anonymity and confidentiality during the process. It is normal in these situations to negotiate with group members, as a group, how this is dealt with. Collaborators were made aware of the research context and of the potential sharing of personally attributable information and ultimately it was their choice to take part or influence how the group as a whole handled this subject.

Recruitment process

Purposive sampling (discussed in previous chapter) is a strategy which qualitative researchers tend to use when there is a specific group of people that are of interest to them (Aveyard, 2014). Given that the studies reviewed were only interested in populations with certain characteristics, this approach appears to be appropriate. This sampling method will give those people who are interested, the opportunity to volunteer to join in. In addition, in terms of the number of people needed to take part in the study, it could justifiably be as low as four (Dos Santos & Beavan, 2015).

Within the literature it was noted that the people being studied did not only have characteristics of mental or other illness, they were also be described in other ways such as; by their gender, race, age, where they live, heritage, their education, and housing status. The illness characteristics of the people taking part need not be very tightly controlled. In fact for this study, given thoughts from the first chapter about how language exerts power over us it is important to include people with no formal diagnosis at all. Although the people participating in the reviewed studies did not all have a diagnosed mental health problem, they all had very personal experiences of the impacts of such difficulties, however they were described. In some studies, where diagnostic information was not provided, the symptoms or difficulties people experienced were noted or alluded to. There included for example, being socially isolated, being irrational, being in poverty, experiencing anxiety, feeling frightened, hurting others, feeling stigmatised, feeling vulnerable, and lacking insight.

The recruitment plan was to promote the idea of taking part in this project through the display of posters at appropriate organisations and venues in the locality that the

organisation serves. The poster described the criteria required to take part, what collaborators would be required to do, the point of the research, and consent to collaborate (appendix 4). However, within a few hours of advertising the project, people put themselves forward. At the host organisation, the usual process is for people to volunteer to take part in activities that are being provided or suggest new things. There was not even time to put up posters in most of the planned places.

People were very delighted to be involved and they all signed the consent forms. To enable potential collaborators to get to the point where they wanted to take part in the research, there were several opportunities offered over a period of six weeks. Private and group meetings were held to discuss expectations, what they were willing to take part in and how they could influence the development of the research. Eight people eventually signed up to take part in the research element (as collaborators) although there were several more in the actual group. Some of the group members, including collaborators, already knew one another. A ‘getting to know you’ start up meeting was held with the objective of introducing the collaborators, describing the research and to begin the process of consensus-building so that the project could begin.

The group began and met every Friday afternoon for two hours. All research activity was planned to be undertaken outside the normal group meeting times. Originally the plan had been that collaborators alone would record a debrief session prior to the beginning of each group session, with the objective of collecting and reporting more data. They decided that this was not something they wanted to do and they actually preferred to meet as a whole group. The group was planned to operate as a research group for six weeks. Instead, due to pressure of work, the group was active for about six months, much longer than planned.

The inclusion criteria to take part in the project consisted of adults who experience mental health problems (diagnosed or not), who lived in the locality, and who wanted to take part.

The activity and involvement in the research was voluntary. The action of collaborators was at their own discretion, however, the plan behind the study was explained to them in advance and they all confirmed their understanding. The activity of the collaborators who opted to take part comprised the establishment of a new self-help group specifically for the purpose of the research. It was agreed that the group might continue after the planned six weeks was complete at the discretion of the group members, which it did.

The literature on self-help offers no insight into appropriate numbers for a group, a minimum of four could be acceptable for research purposes (Dos Santos & Beavan, 2015). Group therapy suggests numbers between six and sixteen as being appropriate (Bernard et al., 2008; Yalom, 1995). The experience of the host organisation is that the number of people who will usually participate in self-help groups will be between four and twelve. Therefore, twelve was accepted to be the maximum number to be recruited including collaborators. The number limit was mainly concerned with the resources open to the group such as the available space and the number of facilitators. From the point of view of group facilitators being able to engage with people sitting in a circle, people need to be close enough to be able to look at one another without much movement, but equally be far enough apart to not be cramping one another.

Data collection and analysis

The interview as a data collection tool was chosen as it gives the information that cannot be obtained by direct observation, such as how someone feel, their thoughts or intentions. There are many definitions of an interview offered in the literature, one example defines it as:

> *"deliberate initiated conversation wherein two persons engage in verbal and nonverbal communication towards the end of gathering information which will help one or more parties reach a better goal " (Matarazzo, 1978, p. 47).*

Patton (1990) identifies three types of qualitative interviews, each different in their structure and format relating to their questions, and each with advantages and disadvantages. These are classified as being the informal conversation, the general interview guide approach and the open-ended interview. However, more commonly, interview styles are referred to as the unstructured, semi-structured and the structured (Minichiello, Aroni, Timewell, & Alexander, 1990).

The idea of a structured interview gave limited flexibility to handle the likely responses from the collaborators. My objective was not to compare but rather to discover collaborators' experiences without the restrictions imposed by structured questionnaires or interviews.

Unstructured interviews are to be used when the researcher knows little about the subject (Morse and Field, 1996), to allow the investigation of more complex issues, and a more comfortable research atmosphere. Unstructured interviews have the potential to generate the richest of data in comparison to other types of interviews (Fontana & Frey, 2000). The initial meaning of the unstructured interview is that the researcher wishes to explore a very broad area or aspect of experience, with very

few specific questions or topic areas defined in advance (Parahoo, 2006). However, the term 'unstructured' may be misleading. The interview is only unstructured in the sense that there are no specific questions or direction. Clearly, the practical aspects of the interview such as consent, venue and attendance are structured. It was for these reasons that I used face-to-face unstructured interviews to collect my data.

Collaborators were asked to keep personal notes and reflections to submit as part of the process that they did not do, nor did they take part in the planned weekly debrief recording which was intended.

When it came time to do interviews, I was unable to make appointments with two collaborators to complete the interviews. When contact was made after three attempts, one person described themselves as being extremely anxious and could not leave the house. The other person seemed evasive, which I interpreted as a signal to ‘leave me alone’, which I then did.

The interviews went ahead as planned and were digitally recorded. The six interviews completed ranged in duration between 45 minutes and 75 minutes. They took place at the host organisation in one of the consulting rooms. I did make a mistake in one interview where I did not activate the recorder. Fortunately, the collaborator concerned was happy to come back later in the week for a second attempt. That was fortuitous because, although broadly similar, the second interview brought out some things that did not occur in the first.

I used an unstructured style of interview with interview starter questions (appendix 11). Interviewing was interesting and instructive but I found it hard to maintain my

focus. I have subsequently discovered that I have a specific learning disability, one aspect of which means that I am unable to make contemporaneous, meaningful notes. Hence, although I tried, I do not have any useful memos or field notes regarding non-verbal or other activity relating to the interviews taken during each one. However, it is suggested that memos and diagrams can be meaningfully developed to assist in understanding after the event (Corbin & Strauss, 2008). To overcome this deficit, I used a thematic network map (Attride-Stirling, 2001) which helped collect and organise additional information (conceptual framework appendix 13). In each case, the interview wound down to a close where collaborators seemed to have said all that they wanted to contribute.

This report of events is my own view of what I have understood and my construction of what I think happened in the time and space when it did, with the people involved (O'Gorman & MacIntosh, 2015).

I was keen to keep the voice of the collaborators in focus rather than trying to summarise, collapse and box in what they have said, to deliver a co-produced interpretive process. I realised that I could achieve this by using a combined narrative/thematic analysis approach (Floersch et al., 2010; Shukla, Wilson, & Boddy, 2014; Braun & Clarke, 2006) and adapting further to include framework analysis (Spencer, Ritchie, Lewis, & Dillon, 2003; Spencer, Ritchie, & O'Connor, 2003).

Transparency and Trustworthiness

This work needs to be transparent and trustworthy while being congruent with the concept of co-production. It was also important to consider how to organise and present this thesis in a way that fits with the principals of co-production. To help with

this idea, I thought that I could use the concept of member checking. Exactly what happened and how it was used is discussed in chapter four.

Analysis

It took me a long time to get to the stage where I was immersed in the data. At the beginning, I felt as if I was just skating over the tops of the words (there are just so many), skidding around and not being able to grasp any meaning or hold on to them. This lack of a grip made me feel anxious and panicky. I struggled to find a way to get a foothold. I thrashed about trying this and that method in a frantic attempt to deal with such overwhelming feelings. Slowly, over time, I calmed down and found structures, frameworks and methods that helped me to gain more command over the data. Eventually it began to make sense.

Struggling with the idea that by selecting one or other analytical method of the narrative, say content over form, means that choices for me and the voice of collaborators may be lost. In my normal life, I like to keep options open and do both things, if possible, so although it is slightly anxiety provoking, this is how I see the world and how I was going to make sense of it in this analysis and interpretation.

It was important to understand what these stories tell me about how co-production influenced the collaborators' mental health. By excluding or emphasising certain parts of their stories because of the constraints of the analytical framework chosen, I was anxious that this aim may not be possible to achieve.

Often when a researcher is more interested in the meaning of the data collected, they interpret and look for themes within it, some of which may not be directly expressed

in the data, but emerge upon intensive analysis. The focus of this thesis is exploration, '*to look into closely or investigate'* (Collins Concise Dictionary, 1978, p. 265). Qualitative data is about meaning, intention, belief, and can lead to consequences (Miles & Huberman, 1994). Data occurs in a context either historical, social, or some other form, where a thick description (discussed further in chapter four) is required. The process of moving through exploring language as communication in social situations leads to a system of cultural knowledge (Tesch, 1990). Language can be explored from the point of view of its structure or from the what it communicates, it can be considered as an art form, as information, and interpretation (Miles & Huberman, 1994).

The research interest for me in this thesis is in the comprehension of the meaning of the narrative of the interviews and transcripts.

I considered that I might try to present a single chapter or section per collaborator. To try to understand what they had said individually and therefore, collectively when compared, would have been useful. It certainly seemed useful to investigate the individual and collective narrative to see if there were any repeated stories within. This led me towards the idea of an adapted narrative thematic analysis emerging. Researchers have used a combinations of thematic analysis, narrative analysis and grounded theory (Floersch et al., 2010; Shukla et al., 2014) so adaptation to the needs of the project seemed to be the best way forward.

Framework analysis

Framework analysis, a variation of thematic analysis, maintains a clear link to the source data, which was important to this study but also I recognised the need to

reduce data for analytical purposes. This meant that collaborators and readers were be able to move easily between the narrative of the interviews and any concepts developed from the discourse.

The process of creating a framework comprises seven steps (Gale, Heath, Cameron, Rashid, & Redwood. 2013a; Ritchie & Spencer,1994), some of which are similar to thematic analysis which often comprises six phases and requires the researcher to follow them stepwise (Braun & Clarke, 2006).

The seven steps of Framework analysis begin by transcribing the recorded material. A professional transcription may be appropriate to enable the better use of resources (Ritchie & Spencer, 1994). The second step was to gain familiarity with the data and in particular to read and re-read the transcript and listen to the recording at the same time. Whilst doing this, notes were made in the margin of the transcript. The next step was coding and it is at this point where there was a departure from thematic analysis. Coding was undertaken line-by-line, aiming to classify all of the data so that it can be compared systematically with other parts of the transcript. Importantly, researchers code initially but then collaborators can also be productively involved to offer alternative viewpoints ensuring that one particular perspective does not dominate (Gale, Heath, Cameron, Rashid, & Redwood, 2013b). Coding can be completed using either manual methods such as writing on post-it notes and charts or within this study using a software tool (NviVo 11) that has framework tool embedded. The fourth step was to create a preliminary framework, achieved by grouping together all of the codes generated, using a tree diagram, and including a code for ‘other’ to avoid ignoring outliers and things which did not fit well. The framework was then applied to subsequent transcripts using the existing codes and categories (fifth step). Charting

data into the framework (step six) involved summarizing the data by category from each transcript. Good charting required an ability to strike a balance between reducing the data on the one hand and retaining the original meanings and ‘feel’ of the collaborators ’words’ on the other. The final stage was to interpret the data. Gradually, through familiarity with the framework, characteristics of and differences between the data were identified, enabling the exploration of relationships and/or causality.

Coding

The first thing to do when beginning a coding exercise is to understand what codes are and where they come from. A definition of a code is:

> *'A code in qualitative inquiry is most often a word or short phrase that symbolically assigns a summative, salient, essence-capturing, and/or evocative attribute for a portion of language-based or visual data' (Saldaña, 2009, p. 4).*

According to Saldaña (2013) coding is not just labelling, it is linking - from the data to the idea and back to other data. This idea resonated with me because I wanted to try and show the voice of the collaborators throughout the work.

I developed codes 'on the fly' as I read transcripts. I had some initial ideas or preconceptions about the sorts of things that might be codes but I waited to see if they came out in the description. In some cases they did. I noticed the more transcripts I reviewed, the more codes I saw as being important. By asking myself the question, ‘What are collaborators really trying to describe?’ when considering sections of the data and using collaborators’ own words, whenever possible, assisted in ensuring that labelling reflected collaborators’ accounts (Smith & Firth, 2011).

Codes are about collaborators, collaborators' views about others, and about my views as the investigator, but it is also about *'making sense of what things mean'* (Krathwohl, 2009, p. 316).

There is a range of ideas about how coding should be developed or at least the labels of the codes. I am keen to keep as much of the collaborators' voices in the coding and analysis, therefore, I tried to use an in-vivo method. I used collaborators' words to label codes. Using the words of collaborators, I took a few words or a sentence to convert that in to a code. There could so easily have been hundreds of codes. Friese (2012) recommends 120 to 300 codes, others such as Lichtman (2010) suggests 20 to 100, while Creswell (2013) starts with 5 to 6 provisional codes.

I found that as I was reading transcripts, there might be inconsistency in how I coded elements of the text. I realised that if I had a definition of what each code meant, things might be easier, more consistent, and less stressful. I created explanatory descriptions of the codes meaning and examples of what ideas or elements might be summarised under that code. Those explanations of each individual code provided at least some consistency of coding. Creating such a definition or description has helped with the trustworthiness of the coding, as others will be able to follow my thinking more accurately. A table showing the codebook was created (appendix 12).

Difficulties with coding

I struggled with the coding and theme development at the first attempt reading through all the transcripts. I used NviVo to help me keep track of the coding that was helpful. In addition, a big post-it note on the side of my computer monitor with a growing list of codes acted as an aide-memoir. Each line of the transcript was read

including anything I said and I tried to understand if there was anything in that piece of text which either had words or meaning in it (as interpreted by me) which correlated with the codes I already had, or if a new code was needed.

I found it difficult, sometimes, to keep enough in my mind to be able to do this process. It was as if I was trying to compute all of the possible combinations of words and meanings to try and make sense of the transcript and then code it. As mentioned earlier I had spent my formative years working in the chemical industry. In this environment objective analysis is key and it is important to get analysis accurate, there is no scope for interpretation. I found coding anxiety provoking because I was keen to get it right and give my own interpretation of what the collaborators meant by what they said.

In trying to decide what was important enough to code, I used a list of six elements (Taylor & Gibbs, 2010):

- It was repeated in several places. I found that the same idea or phrase repeated in several different places in the transcript.
- It was surprising. What the collaborator said I found a surprise and I was not expecting it.
- The collaborator said it was important.
- It reminded me of a theory or concept.
- I have read about something before.
- I just thought it was relevant.

Quite often, I found myself confused and overwhelmed in trying to read and understand the tumble of the words that collaborators had said. I found that the

words did not always make sense, but there was a meaning. Trying to pick out the nuggets of what might help answer the question I posed from amongst all of the other things that were said was difficult. I wondered if the language collaborators used was important as it seemed to present them in certain ways. One person was very contemplative, another quite aggressive, another apologetic and so on.

It was almost as if people used the language in the interview to deflect from their own feelings about how things had influenced them that often related to how others behaved, their needs, and how they responded in the group.

Narrative analysis

Narrative analysis can be applied through four different models (Riessman, 1993).

- structural analysis where the emphasis is on the way the story is related.
- interactional analysis where the emphasis is on the dialogue between the teller of the story and the listener.
- performative analysis where the emphasis is on narrative as a performance that explores the use of words and gestures to get across a story.
- thematic analysis that permits a focus on what is said rather than how it is said.

I spent many days and hours pondering how best to analyse the data using a narrative method. I considered the ideas of Riessman (1993, 2007), Polkinghorne (1995), and Bruner (1986, 1991). I researched the practicalities of the analytical process using techniques such as conversation analysis and discourse analysis. Finally, I decided that I can represent the individual voices of the collaborators in this research sufficiently well simply by using a framework approach. It will allow me to

consider the narrative of each individual collaborator, case by case. This would seem as if it were individual narrative analysis of each interview transcript. Indeed, it was but analysed in a framework rather than in a textual interpretation. The framework allowed me to review and interpret the combined narrative of all collaborators. For example, I was able to simply gather all the narrative excerpts relating to one issue and from that provide an interpretation.

Narrative Framework Analysis

Both thematic and narrative approaches lend themselves to constructionist paradigms that view experiences, meanings and social structures as mutually constitutive (although they can be used with other epistemological frames, particularly realist/experiential ones). They are particularly (although not exclusively) associated with the analysis of textual material (Shukla et al., 2014). Braun and Clarke (2006) suggest that thematic analysis is flexible because it is independent of any particular theory or epistemology and there are a range of possible thematic analyses.

Despite the features the methods share, the different features of the approaches mean that thematic analysis was better suited than narrative analysis to providing broad overview of a dataset, while narrative approaches allowed an extended focus on particularities, including particular cases.

Chapter summary

In this chapter, I illuminated my own way of thinking about the philosophy, methodology and more practical aspects of how I planned and conducted the

research activity, including how I dealt with the power imbalance between collaborators and myself.

I used a systematic approach to the work, a paradigm was developed consisting of ontology, epistemology and methodology, guiding me how to handle the subjects of data collection and analysis. The analytical aspect consisted of developing an adapted narrative thematic approach, swapping the thematic element for framework.

Finally, I have used this methodological infrastructure to support the interpretation of the data to develop findings of the work. Throughout the research it was so important for me to give clear voice to the collaborators because in most mental health focussed situations they are disempowered. The language that I have tried to use is different from the dominant discourse; I have used more everyday language. The words have not been medical and I have avoided medical terminology where I can. Collaborators described in most mental health focused situations (other than this co-produced group) their voices were downgraded, ignored and sometimes even ridiculed. I have been in the position of having my voice taken away by professionals and I did not like it, so for me it was important that I had not got control of the language. A trustworthiness chapter, which follows, has been constructed in an attempt to maintain the links to co-production and evidence and recognise as far as possible, the study has been true to those principles.

Chapter Four - Trustworthiness

Introduction

By identifying quite specifically what it was that I wanted to study I came to the realisation that my methodology would be interpretive. An interpretive stance meant that I would need to address other concerns such as my power in relation to collaborators, how things are connected to one another not just how I would collect, code and analyse data.

I have spent some of my life living and working in a more objective world, so even now many years later, aware of the value of interpretive work, I still have the urge to 'prove' its credibility. I want this thesis to be true as far as possible to the concept of co-production but also to what the collaborators have said.

Before moving on, I want to make comment about reflexivity in relation to this study, particularly this chapter. I understand reflexivity as a continuing process of 'reflecting on' and then doing something maybe other than what had originally been planned rather than simply 'reflecting'. Reflexivity has not necessarily been an insular activity, for me it has included the challenges of academic supervisors, theory, discourse, work colleagues, and the people who use the services the host organisation provides. Reflexivity is an active and ongoing process that I am involved with. Through being reflexive, I have gained a deeper insight into various aspects of the study. In no way does it mean, that by way of reflexivity I overcome bias, or made the work perfect, simply that I have tried to make it obvious that my work is tainted by my own lived experience.

Considering reflexivity as truth (Pillow, 2003), for me has meant examining and selecting carefully the method of analysis of the data collected. The separate trustworthiness chapter emerged as a result of the reflexive process. What I mean is that originally I had not planned to include it. As I began to write I started to feel that even using the framework method (and all of the benefits that brings) I still did not feel that I was doing justice to what collaborators had said returning their voices to them. It felt as if their voices were missing and I wanted to find a more overt way to try and place them at the forefront as well as central to the framework. The biographical snippets that appear in this chapter are my attempt at trying to relinquish control of the process in regaining the truth that collaborators spoke and to get it right.

In an attempt to support this idea and battle my feelings, I discuss the trustworthiness of my research as an important element of the findings of the study. Ensuring credibility is one of the most important factors in establishing trustworthiness (Lincoln & Guba, 1985). To achieve this goal requires the discussion of and evidencing of four main considerations inextricably linked: credibility, transferability, dependability and confirmability (Guba,1981).

Credibility

Establishing the credibility of the research firstly requires that the findings fit in with the culture of the organisation in which it is being undertaken (Shenton, 2004) and how well the findings fit in to that reality. The organisation is based in the Northwest of England and is led by people who have personal experience of poor mental health. There is a focus on thinking about and providing support based on individual and group needs in terms of dealing with symptoms and problems. This gives people the

opportunity to help themselves and each other rather than being reliant upon [professional] others. The themes identified in chapter five concern how individuals act in their social environment as individuals and as a group.

Credibility, in part at least, relies on the sampling method used (Patton, 1999). The purposive sampling method used in this study (discussed in chapter three) helps in establishing trustworthiness. Although it holds less strength than a random method (Stake, 1978), from a methodological point of view it was appropriate (Marshall, 1996).

Collaboration is important in establishing trustworthiness (Creswell & Miller, 2000) and it means that collaborators are involved in the study not just as participants or interviewees. The subject of what research participants would be called in this study was discussed in chapter three. They have a more active role that might be helping with dissemination or as in this case, checking over their transcripts adding further credibility to their accounts.

The collaborators have had the opportunity to influence how their contribution was reported. Burnard (1994) suggests that returning transcripts to collaborators to ask them to read for accuracy and to note any main points that they want to convey is a helpful activity.

I have used a member checking process (Creswell & Miller, 2000; Kornbluh, 2015) to aid me in achieving this goal. The most common meanings for member checks refer to interview respondents being sent for review, comment, and/or correction of a transcript of their own interview:

> *"the member check is the most crucial technique for establishing credibility" (Lincoln & Guba, 1985, p. 314).*

They also state:

> *"The investigator who has received the agreement of the respondent groups on the credibility of his or her work has established a strong beachhead toward convincing readers and critics of the authenticity of the work" (Lincoln & Guba, 1985, p. 315).*

Research guides and texts discussing quality, validity, and credibility in qualitative research often recommend member checks. This includes sending respondents their transcript for review, to confirm or enhance credibility in qualitative research (Kornbluh, 2015; Lo, 2014).

> *"Within a constructionist epistemology it* [member checking] *can be used as a way of enabling participants* [collaborators] *to reconstruct their narrative through deleting extracts they feel no longer represent their experience, or that they feel presents them in a negative way." (Birt, Scott, Cavers, Campbell, & Walter, 2016, p. 1803).* [My alterations in square brackets].

Often such collaboration is assumed to facilitate reciprocity and equalisation of power relationships between researchers and participants, and facilitate empowerment of participants (Fossey, Harvey, McDermott, & Davidson, 2002; Goldblatt, Karnieli-Miller, & Neumannc, 2010; Kornbluh, 2015; Tracy, 2010). These ideas link back to the concept of co-production.

I had one transcript returned containing no comments or alterations; the other five collaborators did not return their transcripts. I have taken that as a sign that the five were no less engaged, simply that they did not feel the need to do anything more. The member checking activity has not been about validation or correcting the transcript. Rather, member checking is concerned with the idea of collaboration in the

research and getting collaborators more involved. In participatory or collaborative research strategies, selective use of member checks may be justified (Thomas, 2017), and active involvement of collaborators in qualitative work adds further credibility to that work (Creswell & Miller, 2000).

In this study, collaborators were made aware that they would have the opportunity to be as involved in the research as they wished.

Although this is only a small opportunity to work collaboratively (but with potentially massive gains for the individuals in terms of confidence and self-esteem), it is nonetheless just that. The idea fits well with the concept of co-production and whilst it may have limited impact on the quality of the research, collaborators will have had the opportunity to collaborate in the development of the study as a whole.

It is important to deal with the analysis using a holistic approach, to examine the differences and similarities between people and an understanding of what unites them. I have begun to consider that to gain a valuable view of the data, both holistic and thematic elements need consideration, from an individual and group perspective. That involves examining a whole transcript against the framework of themes, then triangulating and exploring new and additional themes with next transcript, and so on.

Triangulation in qualitative research, a term borrowed from the land surveying field (Patton, 1999), is the final element in establishing the credibility of the research. It enables the identification of multiple metaphorical landmarks against which it is possible to deduce one's location. In this case, being able to decide if the

collaborators report similar experiences even though their actual experience may be somewhat different, or as Van Maanen (1979) says:

> *"to check out bits of information across informants" (Van Maanen, 1979, p. 548).*

Triangulation involves the use of different methods and types (Denzin, 1978; Patton, 1999) including individual interviews which form the data collection strategy for this study. Triangulation of sources examines the consistency of what collaborators say about their experiences of the same thing (Patton, 1999).

The way that I have handled this is to provide narrative biographical snippets. Each concerns one of the collaborators and their experiences during the research process. Collectively, these narratives provide a consistent view of what they collaborated in, demonstrating trustworthiness. The names used are not the real names of the people concerned but are consistent with the names used in chapter five.

Camila

Camila was retired; her grandson had been subjected to an assault which reminded her of how badly bullied she had been at work. It was the bullying that made her mental health get worse in the first place. She wanted to show that she understood how her grandson might be feeling and spent time with him. She reported that she told him:

> *… nothing was his fault … nobody did that to me.*

Attending the co-production group and being;

> *… a mother hen really,*

Other group members gave her the opportunity to reconstruct her confidence and self-esteem so badly damaged by the bullying. She had a role and was able to share her experiences to help others. The group built up Camila's confidence by recognising she has more knowledge and encouraging her to share it:

> *… It's given me an awful lot of confidence and she was able to help others in the group … I'm trying to help him [another group member] recover from that.*

The learning and sharing in the group helped Camila begin to get an understanding of how her mental health fluctuated. With the help of the group members, she learned about her early warning signs and what to do as anxiety started to reappear in her life.

She got such a big boost from the group that she said that in future she wanted to take up a more formal role as a facilitator, commenting about the group:

> *… I just think it rescued me.*

Claire

Claire was out of work and had no work colleagues she could share with, nor did she have any friends she could confide in. Claire was unsure initially of her role in the group. She found the process helpful in addressing her mental health needs and planned to go on to support other group activities within the host organisation. Claire described a level of dependency on the group. She felt that without the group, she would have been unable to express herself in the way that she wanted and that would have been detrimental to her mental health.

Claire discussed how over time, the activity had helped her to become less isolated. Claire felt isolated when she first came to the group. She quickly realised that she was not isolated anymore. She was surprised to find that the other people in the group were able to evidence that they were having the same sort of feelings, even if they might have arrived at them in a different way to her.

The group has changed for her from being something she depended on to her feeling that she is part of something that is important in her life and something that has helped her to overcome her isolation:

> *It's like you're just not isolated anymore because you're sat in that group with these people.*

Claire had poor mental health when she first got involved in the co-production group and was taking prescribed psychoactive drugs. At the beginning, she said she was:

> *…just all over the place … a bit of a mess … my depression and anxiety… wasn't very well managed.*

Many weeks after beginning at the group, Claire had managed to regain some control over her mental health and it had improved. She worried about what might happen to her if she left the group. She struggled with the idea that she might leave and began to wonder if she should stay or go. Her concern was what would happen if she did not go to the group meetings and as a result, her mental health becoming worse.

Her regular attendance at the group was very important as she could talk in a safe, friendly and confidential space. She felt dependent on the group and being able to

take part and contribute to the activity of the group helped her to feel good; she felt 'rubbish' when she could not attend:

> *… I could come and talk to people in the group, if for some reason I couldn't do it, it was a bit rubbish because…I couldn't, you know what I mean.*

People she had made friends with formed an important part of the activity of the group. Coming to see friends helped her to develop her peer and social network. This in turn allowed her to learn from the experience of others and for her to share her experiences in a way that she felt was useful to others:

> *…it is not as difficult now because I know I can share with the people in the group and I can talk about it now. Whereas, even just talking about it before was difficult.*

Tom

The reason that Tom joined the group was that about a year before, he had tried to end his own life. His social worker referred him to the organisation and he joined the group. He says that the group:

> *… stopped me killing myself, stopped me wanting to kill myself.*

Before developing poor mental health, Tom worked in the restaurant and bar industry in a local big city; he was a bouncer and club manager. He was known as a hard man, not to be crossed, sometimes carrying a weapon. He came home one day and was being burgled. He says that he:

> *… got beat up basically and that's the… it was the shame.*

That ‘shameful’ experience triggered the deterioration in Tom’s mental health. He became a recluse, did not wash himself or clean his home; he stopped eating, and alienated himself from family and friends. It was only after an emergency admission for pneumonia that he got any help.

Tom’s self-confidence had been totally shattered by the experience and it has taken him a long time to begin to regain it. He says:

… the main thing coming here, built my confidence back, self-esteem.

Tom has begun learning to become a facilitator; he has undertaken the course and has a certificate to show for his dedication and work. It has helped him to feel better about himself in situations where he has felt powerless.

He says he is a funny man, the comedian in the group. The jokes that he cracks make the others laugh. It makes him feel useful and valuable in the group:

… making people laugh makes you feel confident.

Robert

Robert held the role of lead facilitator in the group. He had previously held similar roles and was experienced. He got a lot of satisfaction out of the role and enjoyed the communication aspects of it. Robert felt that he was a good communicator, having been told so, by a lecturer, many years previously at university. He was told that he:

… kept things simple,

and that people got a lot out of the work he did. The role sometimes made him feel frustrated that group members did not always engage in the way that he wanted. He wanted their mental health to improve and he felt they were not exactly helping themselves:

… and they might end up no better.

Robert said that when the group first began, he used to get really anxious, have panic attacks and so on:

… but now I don't.

He feels that his mental health has improved greatly and in particular, it has made him more patient with others.

However, Robert says that he lacks confidence. He likes to think of himself as an important and knowledgeable person. His role in the group helps him to maintain that position. Some of the group members:

… put him on a bit of a pedestal,

which he recognises as a potential difficulty, even though it feels quite nice and massages his ego a bit. One of the outcomes that he has noticed is that as time has gone by, group members have become friends and he is included in that. Robert compares himself to professionals such as lecturers and when people say things like:

… that was great today Robert,

it boosts his confidence.

His role in the group has helped Robert to realise that he needs more than just the group; he thinks that what he has learned is:

… in my personal life I need more.

Dawn

Dawn joined the group because she wanted to feel better. She had gathered the courage to come to the group but she was frightened to expose herself to the other group members. She was able to make the first move with other members at the coffee break. She was simply able to say:

…Hi, I'm Dawn, who are you?

This was not something she had been able to do for a long time.
Dawn was concerned that she would not have anything in common with the other members. She was anxious and wondered to herself:

… is it going to make me feel better? Am I going to get better?

Frustration with other group members was a feature of Dawn's membership. She felt that she was a demanding member and felt bad about that. She was brought up not to put herself first or be demanding. On the other hand, she wanted others to make suggestions for doing things*:*

… to kind of move themselves forward…

and not just go with what the rest of the group did. She wanted to make progress and she wanted the others to make progress as well.

Dawn sometimes found the group difficult because she knew that there would be elements where she would need to do things that would make her feel nauseous. She knew those obstacles would be difficult to overcome but other people in the group would help. In fact, they would help each other to overcome them. When the group has come up with strategies to help, she states:

… they've been the most helpful for me, outside in the real world.

David

David had previously been working with the church to support homeless people in various parts of the country. He says the role he found in the group was like:

… an unofficial counsellor.

He liked to bring support and reassurance to others in the group. This made him feel stronger and more comfortable with his own life. He enjoyed the feeling of knowing that he had helped others and that they were happier and more content with their own lives. It helped him develop his self-awareness.

In David's earlier life, he says he had often behaved in a tense fashion so that he would:

…react there and then

This found him storming out of the room:

…instead of hitting people.

The group helped him to gain a deeper understanding of his mood and he learned that if he was in a positive mood, he was more likely to respond to events in a helpful way. That helped David to feel less disappointed in himself and build his confidence.

David felt that he was an important part of the group. He helped in lots of different ways, such as supporting group members who were upset or struggling in the group, establishing a social media group for everyone to use. He felt that he gained real friendship from the other group members. Some of those friendships flourished and grew, others were just for the day, but equally important. David felt that people were actually happy to see him:

> *…it felt like I belonged… a lot of people here call this, the [organisation] family and it kind of felt like that.*

Summary

In this short summary, I draw together elements of the collaborators snippets to illuminate how they link to the themes developed in the findings chapter, five.

In terms of the theme of personal development, all of the collaborators said that their personal confidence had been boosted, rebuilt or grown. This showed that everyone was focussing on the same sort of issues, in this case confidence. As for being individuals, Claire made a point of highlighting that taking part had helped her to feel less socially isolated. David said it had helped to develop his self-awareness. Camila, her past experiences of being bullied had helped her to help others. Everyone talked about their own mental health. In every case, it was something positive, such as learning how to identify early warning signs, reduced panic attacks, or gaining control over it. Robert felt that collaborating in the group had enabled him to feel more

professional. Being in a group was an activity that everyone gained from. Collaborators all made comments such as I belonged, I felt important, I had a role, I wanted to be supportive, I learned about the power of the group.

As discussed earlier, it can be read in the snippets that collaborators were experiencing and talking about similar feelings, thoughts and behaviours. This showed a high level of consistency (triangulation) among the collaborators.

Transferability

Transferability is how a qualitative researcher shows that the study's findings are applicable to other contexts (Lincoln & Guba, 1985). This could include similar situations, populations, and phenomena. One of the ways in which qualitative researchers can evidence transferability is to use thick description (discussed in more detail later in this chapter) to show that the research study's findings were applicable to other contexts, circumstances, and situations (Ponterotto, 2006). Transferability does not involve broad claims, but invites readers of research to make connections between elements of a study and their own experience.

Transferability is synonymous with generalisability, or external validity, in quantitative research (Lincoln and Guba, 1985). They discuss 'naturalistic generalisation' a concept introduced by Stake (1978):

> *What becomes useful understanding is a full and thorough knowledge of the particular, recognising it also in new and foreign contexts. That knowledge is a form of generalisation, arrived at by recognising the similarities of objects and issues in and out of context and by sensing the natural co-variations of happenings. (Stake, 1978, p. 6).*

This is a more instinctual and realistic form of generalisation based on the researcher's own experience and feelings, rather than one that is based on statistics. The findings of this qualitative project are specific to a small number of individuals acting in particular environments, therefore it is impossible to demonstrate that the conclusions are applicable to other situations and populations.

Despite the widespread use of the term thick description in qualitative research, there appears to be confusion over precisely what the concept means (Ponterotto, 2006). The root of the concept can be found in *Concept of the Mind* (Ryle, 2009) where he discusses in great detail:

> *"the description of intellectual work" (Ryle, 2009, p. 279).*

The "thick" description interprets the behaviour within the context and ascribes thinking and intentionality to the observed behaviour. It involves understanding and absorbing the context of the situation or behaviour (Ryle, 2009), and ascribing present and future intentionality to the behaviour.

Denzin points out:

> *"A thick description . does more than record what a person is doing. It goes beyond mere fact and surface appearances. It presents detail, context, emotion, and the webs of social relationships that join persons to one another. Thick description evokes emotionality and self-feelings. It inserts history into experience. It establishes the significance of an experience, or the sequence of events, for the person or persons in question. In thick description, the voices, feelings, actions, and meanings of interacting individuals are heard." (Denzin, 1989, p. 83).*

When thick description is contrasted with thin description superficial account that does not explore underlying meanings is becomes clearer (Holloway, 1997). A thin

description simply reports facts, independent of intentions or the circumstances that surround an action (Denzin, 1989), so thick description facilitates a deeper understanding and honesty.

Dependability

Dependability concerns the extent to which a study could be repeated by other researchers and that the findings would be consistent. A qualitative researcher can use inquiry audit in order to establish dependability, which requires an outside person to review and examine the research process and the data analysis in order to ensure that the findings are consistent and could be repeated.

Dependability in qualitative research can be defined as '*the stability of data over time and over conditions'* (Bitsch, 2005, p. 86). Dependability can be compared to reliability in quantitative studies. Dependability answers the question: if someone else did the same study following the same procedures would similar results be obtained?' Lincoln and Guba (1985) stress the close ties between credibility and dependability, arguing that, in practice, a demonstration of the former goes some way to ensuring the latter. Dependability is established using an audit trail, a code-recode strategy, stepwise replication, triangulation and peer examination or interrater comparisons (Anney,2014). Each of these elements are considered in turn.

An audit trail, is one of the criteria for dependability that relates to the consistency of findings (Guba, 1981). However, as many qualitative methods are developed to match specific research questions and situations, there are no methodological shorthand descriptions, like interrater reliability, such as might be used in quantitative studies. The exact methods of data gathering, analysis, and interpretation in

qualitative research must therefore be described. Sandelowski (1993, p. 2) used the term ‘auditable’ to describe how other researchers could clearly follow the processes and decisions made by the originator of the study. In this thesis, these auditable elements are found throughout, but largely due to space constraints, in the appendices. They show the detailed workings of how and why I arrived in this place.

Guba (1981) also suggested that a stepwise replication technique be built into the design of a qualitative study to enhance dependability. The idea of this technique is that two or more researchers analyse the same data separately and compare their results. If the results are similar then dependability is said to have been achieved (Bitsch, 2005). In this study, there is only one researcher so it is impossible to adopt this technique.

Another method that can be used to improve the dependability of the study is to conduct a code-recode procedure on the data during the analysis phase of the study (Krefting, 1991). After initially coding the data, a period of at least two weeks should be allowed to elapse, after which the researcher can return to recode the same data and compare the results. In this study, a similar activity was undertaken where after initial coding was completed, a period of many weeks elapsed after which the titles of each code were renamed and redefined as part of the code book exercise discussed in chapter three. This created a catalogue of what codes were originally called and what they ended up being called prior to the next stage of the analysis.

The final method proposed to enhance dependability is peer examination. Peer examination is no different to member checking (Bitsch, 2005; Krefting, 1991) but can also include research of peers or other neutral colleagues. The idea here is that peer

examination helps to keep researchers honest (Bitsch, 2005; Krefting, 1991) and as a consequence, the research more dependable. Member checking process was used in this research.

Confirmability

Confirmability concerns the degree to which the results of an inquiry could be confirmed or corroborated by other researchers (Baxter & Eyles, 1997). The concept of confirmability is equivalent in the qualitative researcher's mind to objectivity in the quantitative realm. Patton (2002) associates objectivity in science with the use of instruments that are not dependent on human skill and perception. He recognises, however, the difficulty of ensuring real objectivity, since, as even tests and questionnaires are designed by humans, the intrusion of the researcher's bias is inevitable (Patton, 2002). Miles and Huberman (1994) consider that a key criterion for confirmability is the extent to which the researcher admits his or her own predispositions. Confirmability is:

> *"concerned with establishing that data and interpretations of the findings are not figments of the inquirer's imagination, but are clearly derived from the data" (Tobin & Begley, 2004, p. 392).*

Studies suggest that confirmability of qualitative research is achieved through an audit trail, reflexive journal and triangulation (Bowen, 2009; Lincoln & Guba, 1985). According to Bowen (2009):

> *an "audit trail offers visible evidence — from process and product — that the researcher did not simply find what he or she set out to find" (p. 307).*

Guba (1981) viewed neutrality not as researcher objectivity but as data and interpretational confirmability and described the audit strategy as the major technique

for establishing confirmability. This strategy involves an external auditor attempting to follow through the natural history or progression of events in a project to try to understand how and why decisions were made. In addition, auditability suggests that another researcher could arrive at comparable conclusions given the same data and research context. The auditor considers the process of research as well as the product, data, findings, interpretations, and recommendations (Lincoln & Guba, 1985).

Lincoln and Guba (1985) identified six categories of records that can be included in an audit. These comprise: raw data (field notes, video and audio recordings); data reduction and analysis products (quantitative summaries, condensed notes, working hypotheses); data reconstruction and synthesis products (thematic categories, interpretations, inferences); process notes (procedures and design strategies, trustworthiness notes); materials related to intentions and dispositions (study proposal, field journal); and instrument development information (pilot forms, survey format, schedules). Evidence and audit trail of al these types if records can be found, throughout this thesis (either in the main body text or appendices 14, 15, 16 and 17).

Triangulation of multiple methods, data sources, and theoretical perspectives test the strength of the researcher's ideas. Documentation, should be provided for every interpretation, from at least two sources, to evidence that the data supports the researcher's analysis of the findings (Guba, 1981). Another way that neutrality can be enhanced is to use a team of researchers familiar with qualitative methods rather than a single researcher. This method was discussed earlier in this chapter; however, it focussed on the biographical snippets rather than the assessments of a team of researchers.

Reflexive analysis is also useful to ensure researcher awareness of their influence on the data. There is an assumption among researchers that bias or skewedness in a research study is undesirable. As Malterud (2001) writes:

> *"Preconceptions are not the same as bias, unless the researcher fails to mention them" (p. 484).*

Confirmability also can be established using a reflexive journal (Wallendorf & Belk, 1989):

> *“reflexive documents kept by the researcher in order to reflect on, tentatively interpret, and plan data collection” (para 77).*

The researcher was required to keep a reflexive journal, which should include all events that happened in the field, personal reflections in relation to the study. Personally, I found keeping such a journal extremely hard and gave up early in the process. As mentioned previously, I meet the diagnostic criteria for a specific learning difficulty, Dyslexia, one of the characteristics of which is that I have a very poor short-term memory. What that means for me is that as I try to write the words down, they just trickle away from my mind like water through my fingers under the tap leaving me with a couple of unconnected words, if I am lucky. If I were to go through the process again, I would use a voice recorder for processing later, all of the time so that I could capture in sound, what others are able to write down. According to Krefting (1991):

> *“reflexivity is an “assessment of the influence of the investigator's own background, perceptions and interests on the qualitative research process” (p. 218).*

Pillow (2003) makes it clear that the principal characteristic of reflexivity is concerned with a recognition of self; she calls it ‘researcher know thyself’. A researcher’s background influences the way their study is organised and findings analysed (Krefting, 1991). I took this to mean that researchers ought to strive to find and become aware of the various elements of their personalities and ways of thinking. Doing this would have an influence on their choices, decisions, interpretations, values, experiences, biases and prejudices. For me this meant becoming aware of some of the effects of my past life and experiences and understanding how they influence me and how that knowledge affects the study. I became aware that I have characteristics in common with collaborators and in some ways, I relate to them. I have also began to recognise more clearly some of my deeply held values, which I have discussed often; for example believing that we are all born equal, that we all have responsibilities to ourselves and others, and that we all have different experiences and views.

To this end, beliefs underpinning decisions made and methods adopted should be acknowledged within the research report; the reasons for favouring one approach when others could have been taken should be explained and their weaknesses admitted. In terms of results, preliminary theories that ultimately were not borne out by the data should also be discussed. Much of the content in relation to these areas may be derived from the ongoing "reflective commentary". It is by now clear, I hope, that I provide a reflective commentary as I write so it is evident what my own biases, stereotypes and preconceptions are.

Chapter summary

Trustworthiness of qualitative research is made up of four elements: credibility, transferability, confirmability and dependability (Shenton, 2004). This idea of trustworthiness requires that other members of the research team, or suitably qualified peers, crosscheck every element. In bringing together this chapter, it has become clear to me that although not perfect, good efforts have been made to ensure the trustworthiness of the work. Doctoral qualifications such as this, to my knowledge, are solitary undertakings so any activity that requires a team approach is impossible. I have tried here to show those elements of trustworthiness that have been achieved; also to explain why other elements of trustworthiness have not been achieved.

Credibility comprises elements of organisational culture, sampling method, collaboration and member checking, and triangulation. In chapters one and three, the culture of the host organisation was discussed. The fact that the trustees were happy to permit the work to go ahead and the fact that collaborators were recruited indicates that the culture of the organisation was supportive of this type of work. Member checking and collaboration, has been attempted. Everyone who took part in the research has been involved in a member checking process and they have all been given the opportunity to collaborate in the research. Biographical snippets from each of the collaborators assists triangulation. The short summaries highlighted that all collaborators talk about the same things, just in different ways, supporting the themes developed in chapter five. Sampling, discussed in chapter three, even in qualitative research should be random to avoid charges of selection bias (Shenton, 2004). Clearly random sampling in this study would have been meaningless, so it was not possible or even an intention, to meet this requirement of credibility.

Transferability is the qualitative equivalent of quantitative generalisability or external validity (Lincoln & Guba, 1985). To achieve transferability, researchers show how findings are applicable in other settings, achieved in this study through a process of thick description (Ryle, 2009). Thick description does not pertain to single pieces of this thesis but the whole of it. Having read the thesis, a reader might reasonably be able to envisage how the same could apply in a context they were thinking about. In this instance, it would be the reader who decides if the writer has provided enough contextual information to enable them to make such a transfer. As a lone researcher, it is impossible to make an informed decision about transferability, but those people who have read this far, have been able to imagine how this work might fit into different contexts.

Dependability requires that an audit trail be provided so that other researchers may follow and if it were repeated using the same participants, in the same context with the same methods, similar results would be obtained. The audit trail includes the research design and its implementation (discussed earlier in chapter three). Evidence of the audit trail provided in appendices (14, 15, 16 and 17) are extracts from the interviews of Camila, Tom, David and an extract from the framework.

Confirmability is achieved through an audit trail, reflexive journal and triangulation, discussed previously. With the majority of the requirements for trustworthiness having been introduced and applied to the study, it seems reasonable to say that the work is trustworthy, which provide a secure foundation from which to move on to the next stage of this thesis, the discussion of findings.

Chapter Five - Findings

Introduction

The findings of the research are presented in this chapter, underpinned with the evidence and demonstration of trustworthiness from the previous chapter. Incorporating the trustworthiness knowledge garnered previously with my personal insights gleaned from years in my work position a process of inference began. Through this inference process (Morse, 2006), I was able to draw together the different perspectives of the collaborators. At his point it is important to remember some of the key messages from chapter two:

- people recover better when they are part of a community of belonging where they feel safe and respected,
- It is important for people to be in control of their situation,
- everyone has something to give as well as something to get, turn up regularly, take part, and be altruistic ,
- relationships are important and can lead to fellowship and trust.

For reference, there was one research aim, which was posed: to investigate the influence of co-produced, peer-led, self-help groups on mental health. Within this chapter this aim is achieved through the description and interpretative findings of the qualitative data, derived from an approach using an adapted framework analysis (Spencer, Ritchie, Lewis, et al., 2003; Spencer, Ritchie, & O'Connor, 2003).

Qualitative Findings

The analysis process generated a conceptual framework of six overarching, or main themes. These were: 1), Being individuals 2), Mental health 3), Professionalism 4), Bad stuff 5), Being in a group and 6), Personal development. A diagrammatic representation of the conceptual framework is shown in appendix 13.

What follows is a description of each theme, with illustrative quotes embedded throughout the text. It is important to note that the quotes used within the presentation of findings are of particular importance or of most relevance to the theme being presented. Themes were created using the data gathered and presented in the framework and by making associations between participant contributions and codes in the codebook (see appendix 12) (Gale, Heath, Cameron, Rashid & Redwood, 2013a). Quotes used are verbatim with no corrections; hence, there is colloquial language, language that is not grammatically correct, some that might be considered 'foul' and some that is untidy as collaborators try to express themselves.

For transparency everyone is included, the findings are presented using contributions from all collaborators. All the contributions are anonymised and are referenced with a name that is not the real name of the collaborator. Each of the main themes is presented as a main heading with a high-level label, e.g. 1. Main themes are then divided in to sub-themes (shown with a lower level marker, e.g. 1.1), and constituent themes (which contain the actual contributions) are categorised with the lowest level of label, for example 1.1.1.

I found myself being lured by the nagging feeling that numbers and solid objective data was important in this work, not that they actually are. So much so that I thought it important to show how many of each comment had been made by collaborators. This led to analysis being further divided by coloured headings to show those contributions to which all collaborators contributed (green), those contributions to which only one collaborator contributed (pale blue) and those contributions to which some but not all collaborators contributed (yellow). This can also be tracked in the diagrammatic representation of the conceptual framework (appendix 13).

1 - Being individuals

Each collaborator is an individual within the group with which they are engaged. They all have different motivations, stories to tell, experiences of life, abilities, fears, and a multitude of other personal characteristics.

This main theme of 'being individuals' is divided into six sub-themes: relationships, responsibilities, role, frustration, power and confidence. Each sub theme comprises one or more constituent themes.

1.1 - Relationships

From what the collaborators have said that strong and meaningful relationships have been formed in the group and that they are important to the collaborators. These relationships mimic real life and people feel safe to be in them, in the provided environment. Sometimes when those relationships get a bit hard to manage, perhaps a conflict starts to develop, then people start to get anxious, start to be petulant, become demanding, aggressive and walk out. It is at that point that the safety and process of the group and the holding organisation becomes important.

The relationships formed in peer-led, self-help groups have a multiplicity of facets. Sometimes, it might be a tentatively supportive relationship, like a mother watching her offspring trying something new for the first time:

> *"you see that person operating against that person, you want to say something but you've got to bite your tongue and not – because everybody is able to fight their own battle" – 'David'.*

Other times it is much more about being practical and supportive:

> *"like on the ground encouragement to help that person feel comfortable by making them feel wanted" – 'David'.*

The feedback from those overt relationship interactions highlight how important they are and help to reinforce them:

> *"the good things are that people probably see me as a friend and there's one or two of them very quick to say that was a great day today" – 'Robert'.*

And that helps to build tolerance, which in other situations may not actually be there:

> *"It has made me more tolerant of having to put up with all sorts of people here. So. Not judging them, just all sorts of people aren't they" – 'Robert'.*

Ultimately, these things help to make relationships important and continue beyond their original small remit to something larger, more encompassing and long lasting:

> *"And then some relationships would flourish from that and continue outside and some would just be inside, you know?" – 'David'.*

1.1.1 - Opening up

The idea of opening up emotionally and sharing their experiences, physical, emotional, spiritual and otherwise, led collaborators to:

> *"just put it out there, didn't really give a toss" – 'David'*

There was more than one reason for opening up. One said:

> *"the response I got back [from the other group members] was overwhelming, you know, it was really good at the time. And that give me hope, it give me encouragement, it give me strength to come away and think well, I am going to do that again". – 'David'.*

As if there was some sort of cathartic cleansing going on or maybe an acceptance by the others that it is okay. Another said:

> *"I just kind of desperately wanted to feel better, so I knew I needed to do something but hid there, thinking, don't make me talk and just…yeah, eventually, I came out of myself in [the] group I think because everyone was so engaged and made it kind of fun" – 'Dawn.*

Showing that even though it might be hard to do, and emotionally painful, opening up does get some benefits.

1.1.2 - Like-minded people

The members in the group and collaborators were not especially involved in it because they were like-minded. Some collaborators thought that being like-minded was important and it is possible that like-minded people decided that they wanted to be involved:

> *"And that made a lot – it felt like I felt belonged, felt like I was part of" – 'David'.*

There was a clear link between sharing and like-mindedness:

> *"There has been a lot of understanding, sharing of other people's problems, where they have been where I have been" – 'David'.*

This reinforces the idea that like-mindedness, although not a prerequisite for involvement, is tacitly at least, a determinant of whether or not to join and become involved. Of course comments like the following show very clearly that being surrounded by like-minded people is extremely important:

> *"I have a one-to-one with a psychologist, that didn't help as much as actually being in a situation where there's like-minded people." – 'Tom'.*

1.1.3 - Trust

The collaborators found that trusting relationships were a necessity to make the process work. One collaborator said:

> *"gaining of the trust of the people who were taking the group was the problem. It was like you couldn't trust the people." – 'David'.*

Going on to highlight why it was important:

> *"personally, it meant I couldn't open up as much, you know, around particular people." – 'David'.*

The reason that opening up is important is that it enables collaborators to share, learn, and truly engage and get something out of the process.

1.1.4 - Not being isolated

As individuals, each collaborator took the decision to engage in the process. They all enjoyed the feeling of not being isolated as individuals and found ways that helped

them to feel 'like' the others. Of course, this meant that they formed relationships with others. One collaborator put it like this:

> *"It's like you're just not isolated anymore because you're sat in that group with these people who all have…although they're all more different and they might have all different problems, but they're all in some way or another, have had the same feelings. Or the same problem, in a different situation or whatever, but it's in the same way." – 'Claire'.*

And then:

> *"So then I kept coming back every week" – 'Claire'.*

Finally:

> *"And it's like you're not on your own anymore." – 'Claire'.*

1.2 – Responsibilities

1.2.1 - Responsibilities

Responsibility in the activity feels important but care needs to be taken to ensure that collaborators do not feel overwhelmed. It needs to be enough but not too much:

> *"You feel part of the group and there's a bit of responsibility as well without pushing too much responsibility on them." – 'Robert'.*

1.3 – Role

1.3.1 - Feel welcome

Helping people to feel welcome in the group was extremely important both for the new/joining individual and for the more experienced collaborator. This role was

double-edged. Firstly making people feel welcome provided a useful role for the collaborators. It helped them to feel good when in the wider world they usually did not. Secondly, being made to feel welcome as either a newcomer or existing member boosted feelings of wellbeing and personal value. Collaborator 'Camila' eloquently describes this idea:

> *"But you've got to make people feel welcome in a group because if they feel welcome they will come back. If a person just comes in and they sit there and nobody responds to that person they're going to think, well, that was a complete and utter waste of time. So you have to have…I mean this is me, you know, I mean if I was doing the group, I would make the person feel as much welcome without feeling out of place." – 'Camila'.*

Other group members spending time with you helps in feeling valued, included and welcome. Collaborator 'David' comments about the way the facilitator sometimes spent his time:

> *"he would quite happily spend time with you after the meeting, or in the break, and discuss things and discuss ways of being able to cope." – 'David'.*

1.3.2 - Everyone tries to help

The roles that the collaborators took were very important in the process; everyone tries to help in the process. The taking of roles is important because it instils a level of ownership, a level of self-esteem and a level of satisfaction at their own progress and ability to help others. All of the collaborators took an active role in the process, often more than one. They all took roles within the group. One had a role of facilitator from the start but another also took the role of a co-facilitator:

> *"I felt like I had to take control a bit, because a lot of time I wouldn't think that some of the facilitators were, well," – 'David'.*

"And I've been helping facilitation…" – 'Tom'

One took the role of black sheep:

"we already discussed this didn't we and the black sheep role" – 'Dawn'.

This was important as a character on which to dump all of the group's bad feelings and general waywardness.

One described her role as mother hen taking a protective mothering role:

"Yeah, I'm a mother hen really. I'm a mother hen, if you like." – 'Camila'.

One described their role as informal counsellor. Considered as a superior role where the collaborator felt they had something special to contribute:

"I felt like I was unofficially like a counsellor or something on that role." – 'David'.

One took the role of comedian or joker. This collaborator was able to use his skill and experience as a joker to help people feel better, in particular laugh, a rare commodity amongst this group of people. It also helped to raise his own level of confidence and his ability to communicate effectively with his fellows:

"And I think being a joker I think all comedians, I think a lot of comedians are a bit shy and a bit introvert because telling jokes and making people laugh makes you feel confident. Because you might not be able to assess…I might go in the group and say 'I'm [collaborator] and I did this when I were depressed I did this and I did that' but they might think you're talking a load of crap but if you tell a joke and they laugh, you know you've got through in a sense." – 'Tom'.

All of the collaborators took much less formal roles as listeners, supporters, encouragers, and welcomers. The roles which they adopted were quite fluid and could change from that of being a provider to that of being a receiver. This change could happen in either direction several times within one meeting. The roles were blurred but that did not seem to matter:

> *"I try and make them feel welcome and involved. And give them the time to say what they want to say, if they want to say anything. But like when I first started coming, that didn't even enter my mind. You know, if somebody new came that was sort of like not my job, if you know what I mean." - 'Claire'.*

Taking of roles was not just a 'one each' affair. There were multiple people operating in the same role at the same time:

> *"if somebody new comes, we will try and make them feel welcome and things like that, I'm not the only one. There are a few. There are a few of us that do the same thing." - 'Claire'.*

In the roles, both formal and informal, people like to be able to share their experience, skills and knowledge:

> *"as we go around, I like to be able to pass what I learn onto somebody in the group like, as an example, everybody can have anxiety in the world, everybody" - 'Camila'.*

1.4 - Frustration

1.4.1 - Frustration

Frustration with and between the group members and collaborators was often voiced. It shows that they are all taking care of one another and want each other's lives to improve; also that their efforts to help do not go in vain:

"I get frustrated with people forever not doing work." – 'Robert'.

And:

"I think it's made me aware I had a responsibility to try and, to try and get them to help themselves which the downside is it's very frustrating sometimes." – 'Robert'

Finally:

"I worry that they'll never get better." – 'Robert'.

On the other hand, collaborators have realised that they are frustrating their own efforts and they know it:

"I'm probably highlighting what I know about being impatient and things like that but then I get annoyed at myself but I hide it; it's not something…if you went and asked people in there whether I was impatient, I'm pretty sure none of them would say…[facilitator] might say yes." – 'Dawn'.

1.5 - Power

The facilitator described how he tried as hard as possible to give the power to the other collaborators. The collaborators did not say that they felt powerful, they thought that sounded a bit big headed, but that influential was more how they felt. They described how they could influence the process and direction of the group.

1.5.1 - Influential

Collaborators felt influential in two ways. Firstly, that they had influence over the operation of the group. Deciding whether to take part in the group activity:

"just to have the opportunity to say, no I will pass this week" – 'Claire'.

Stating what their expectations are and what they want:

> *"I said, 'That's not what I come to the group for. I come to this group for anxiety.' I said, 'And that is why I come to the group." – 'Camila'.*

Helping to move the activity in a direction for the benefit of others as they saw fit:

> *"Steer it to comfort others and to be able to make them interject into getting involved, because otherwise they would just sit there like a nervous wreck and not speak. In a way it is like on the ground encouragement to help that person feel comfortable by making them feel wanted and, I don't know, show a bit of compassion" - 'David'.*

And:

> *"It's like, without being like bossy or I'm the boss-type thing yeah. That if there's any issues come up with people talking then I feel like I can help them and that gives me great pleasure in directing them in the right direction." - 'Tom'.*

Collaborators deciding to wrest control if they felt it was going wrong for themselves or others:

> *"I felt like I had to take control a bit" - 'David'.*

But others felt that things were more egalitarian:

> *"I think that with most people, power is fairly evenly distributed" - 'Dawn'.*

Secondly, that they felt that they had a better influence over their mental health:

> *"I've got a bit more control over like my depression and my anxiety." - 'Claire'.*

Another said that he had gained better control over his behaviour:

> *"I tend to storm out instead of hitting people, which I think is better, you know" - 'David'.*

Knowing what is good for them and getting on with it if they can also seems to help:

> *"I know that there's things I absolutely hate and they make me physically sick and it's like, well they're not going anywhere. I need to do them and we have talked about this in the group about practising on things that we all struggle with because they're all going to be different, buddying up and helping each other work on a specific obstacle." - 'Dawn'.*

1.5.2 - Vulnerable

There are differing views about vulnerability of the group members. One collaborator thought that being vulnerable was valuable in helping to get better:

> *"well, yes, I liked the feeling of people being open, people being truthful – making myself vulnerable to get better. So like lying all the cards on the table and saying, well, this is me. Basically by opening yourself wide, I felt like it is the only way I am going to get better." – 'David'.*

On the other hand, others felt the exact opposite, even though they deliberately put themselves in vulnerable situations, describing feelings of discomfort:

> *"it was all so negative that you felt like all you were doing was going in and giving them your raw stuff that you don't want to show people and nothing else, just absolutely nothing else, other than that. Yeah and you think that's not how anybody wants to portray themselves, even if that's the truth and your whole truth at that time; that's not all you want to show people and I just found it really uncomfortable. Yeah, but it wasn't helpful that, in any way, for me." – 'Dawn'.*

Another view is that people ought not to be made to feel uncomfortable or vulnerable, even though they have not voiced this idea directly, otherwise they might leave and get nothing out of the whole venture:

> *"I think the intention though is not to make people feel awkward and more to try and avoid making people feel they have to say something and engage but I think, yeah, you need to make them feel they don't have to say anything they're uncomfortable with but you definitely want them to engage, otherwise, they are going to leave and they're not going to get anything from it and they're not going to feel part of it and even if it is hard" - 'Dawn'.*

1.5.3 - View about others

Collaborators expressed views about others in the group. In particular, they link this to frustration about others not making the sort of progress they want them to:

> *"I noticed some people wasn't progressing on within their lifestyles and their problems and their issues" - 'David'.*
>
> *"they never voice their wants" - 'Dawn'.*
>
> *"why people are not getting out of it what I want…there's all sorts of level of education and intelligence, there's levels of impact from medication as well. Where people are not quite with it sometimes and so on" – 'Robert'.*

1.5.4 - Just one of the group

There was a clear distaste for taking the label or thinking about being 'powerful'. Collaborators, all took part in helping the smooth running of the group; one of them said 'I'm just one of the group':

> *"I'm just one of the group, really. But people do come to me and people have come to me in the past and said, 'Can I talk to you?'" – 'Camila'.*

There was a feeling that although power was present and around it was not concentrated in one person or group. Even that it was denied so that other group members did not feel threatened by it and the group put in jeopardy:

"I think that with most people, power is fairly evenly distributed. [Facilitator] doesn't make a big thing of being in charge; he consciously goes out of his way to not be: I'm in charge, do it my way, sometimes, maybe too much everybody's friend and I don't know how it would work if he didn't do that." – 'Dawn'.

Using power for the good of the group and getting a little bit extra back from it as a by-product:

"I think it all comes down to your own motivation doesn't it. If you're doing it for an ego trip then, but I'm not, I'm doing it to try and help people. It does massage my ego a little bit, 'cos it's bound to if it makes you feel better. But it's a by-product you know." – 'Robert'.

1.6 – Confidence

1.6.1 - Confidence

Everyone talked about confidence. They sometimes used different words such as confidence and self-belief. This seemed to be an outcome of the process that had not been anticipated but everyone saw it as positive and contributed to improved mental health. Confidence was built by simply mixing with other people:

"I think because it's a group as well, I think it's another confidence build…because you're mixing with people." - 'Camila'.

"Again what I've got from here is self-confidence mainly." - 'Tom'.

One collaborator thought that the point of the group was not to do with confidence but nonetheless had gained it:

"I don't think the main purpose of that was confidence. But just by going to the group it gave you confidence." - 'Claire'.

Other collaborators felt stronger, more content and proud:

> *"It made me, kind of, feel a bit stronger and a bit more content with my own life" - 'David'.*

> *"But you know I, I'm quite proud of myself" - 'Robert'.*

1.6.2 - Communication

Learning the skills of communication and then using them have very clear benefits in making people feel better. One collaborator described how social media had been used at which point a message felt to be supportive was received, boosting feelings of wellbeing:

> *"put on Facebook I've had enough of everything, and WhatsApp and one of my daughter's friends who I've not seen for 20 years said 'cheer up [collaborator]' she said 'you made the best mashed potatoes in [place]'." – 'Tom'.*

Others simply described their findings:

> *"So I found out I'm a very good communicator." – 'Robert'.*

> *"But I find very, very straightforward ways to communicate but only if they are effective" – 'Robert'.*

2 - Mental Health

The main theme of 'mental health' contains no sub-themes. The main theme comprises six constituent themes: I feel good, feel nervous, feel human, a sense of calmness, recovery and worry about slipping back.

2.1.1 - I feel good

Feeling good or better were phrases used as expressions on improving mental health, often related to something that happened in the group:

> *"but we'd find something to laugh at and we'd have a laugh and we'd leave and you'd generally feel better about everything, you know, that you can…even though things are horrible, you can still smile and laugh and you know, sometimes that'll be the only time I'll have laughed for a week," – 'Dawn'.*

Even as a personal aspiration or a hope for others:

> *"you can leave feeling better and you know whether people are feeling better, if one leaves with a smile, you think, they didn't come in with a smile and they've left with a smile. The problems haven't disappeared but you can feel better briefly, at least you know it's possible." – 'Dawn'.*

When others feel good or better so can you:

> *"It helps when somebody else tells their story. You feel that you can empathise with them" – 'Robert'.*

2.1.2 - Feel nervous

The collaborators talked about feeling nervous and that the process of the group helped to calm them. Just being there among the others helped to make the nervous feelings go away:

> *"So when I first started coming to the groups, I didn't know anybody and I was feeling nervous. The first group I came to, and I sat down and people were talking and I thought it was nervous. And the more I sat there and listened the nerves just go." - 'Claire'.*

People described how they needed to be in a more positive place to do something:

"I get pumped up to do it. I can't just do it off the spur of the moment. And I used to do it better when I was in a positive mood than a negative." - 'David'.

2.1.3 - Feel human

Feeling human is needed. People like to feel normal or ordinary or not an outsider or not different, just normal, just human, with all the quirks and peculiarities of being a member of that species. Feeling human makes us realise and get in touch with who we really are and create a deep understanding of what our needs are:

"you think oh my god, I feel a bit human; I feel almost like a normal person and it is that safety when you're feeling that bad to be around other people and if you don't talk, you don't if you do, you do" – 'Dawn'.

Of course normal is personal; it relates to individuals not groups of people. Feeling human is the same; it relates to how we each feel, not some higher overarching group feeling that we should adhere to. Understanding that feeling human or normal for you might not be the same as it is for me enables a greater empathy between people:

"You can see the confusion in their face; it's like…and you kind of feel like, they don't trust me or they don't believe me because it's that dichotomy in how you're behaving because that's your normal and not theirs." – 'Dawn'.

2.1.4 - A sense of calmness

Collaborators talked about a feeling of calmness, rather than improving mental health. The process of co-production seems to have a generally positive influence on the mental health of collaborators. Interestingly, although all of the collaborators had formal diagnoses only one of them mentioned that their anxiety had improved. One collaborator in particular talks about how he no longer felt that suicide is the only answer:

"Stopped me killing myself, stopped me wanting to kill myself." - 'Tom'.

Another collaborator reported feeling stronger and more content:

"It made me, kind of, feel a bit stronger and a bit more content with my own life," – 'David'.

Yet another saying: *'greatly improved, more patient, more thoughtful'*.

"It's greatly improved it yeah. Greatly, yeah. It's made me more patient with people. And being more thoughtful with people which is a good thing." – 'Robert'.

No panic attacks and no anxiety:

"Well I used to regularly get really anxious and get panic attacks and so on. And for the first six, eight, ten weeks I used to sit there having a panic attack. But now I don't." – 'Robert'.

The collaborators concept of mental health is clearly rooted in the social aspects of their lives. There is no mention of things influencing their mental health that were outside of their control. They found ways to take control and develop calmness individually and as a group:

"the more I sat there and listened the nerves just go … so the fact that I could do that, you know, made me feel better." - 'Claire'.

"my sister said to me, 'Why do you go?' I said, 'I go for me because I feel as though I'm getting something out of it.' I really do. For years I suffered and suffered, I never really knew what was sort of wrong with me really. But now I do know, I know what's wrong with me. I know if I go on a downer or whatever but it's not as much as I used to be coming to the group. So I get support from that group as well." - 'Camila'.

"It could be just tidying up or going for a walk or making a friend or making a phone call or visiting someone." - 'David'.

"the group's definitely helped me move along and knowing it's there, even if you don't always go, no it definitely helps. I think even just knowing how other people are getting along." - 'Dawn'.

2.1.5 - Recovery

The collaborators have a notion of recovery contributing to their improved mental health. They thought about it in different ways. One talked about not being cured:

"I'm not saying that you're cured of everything or anything like that. But when you go to a group you can come away feeling as though your self-esteem has been risen. That's what I feel from it anyway. That's what I feel." - 'Camila'.

One talks about sharing of experiences:

"I would say sharing of experiences, of life experiences and what got me, more than anything, and I think what helped me on the road to recovery, was listening to other people." – 'David'.

And another, about still needing to work things through:

"I think the only thing that is difficult now, now at this point where I am, because I have…I started and I feel like I have gone through the difficult bit where I had things that I needed to work through and I have done that. And there are probably still going to be hard things that I do still need to work through but it is not as difficult now because I know I can share with the people in the group and I can talk about it now. Whereas even just talking about it before was difficult." - 'Claire'.

Yet another does not know what it is, but it is working:

"whether it's a cry for help or whatever I don't know I don't know what it is, but now Friday…Saturday, Sunday, Monday I want to kill myself but I don't want to kill myself, it's in a Robin William's speech, I don't want to die." - 'Tom'.

2.1.6 - Worry about slipping back

There was a concern that mental health would deteriorate unless strict control was kept:

"And now I have noticed that they have started to do sort of strange things that they weren't doing before and it seems like they are going back into old habits that they were doing before, but they didn't like what they were doing before," – 'Claire'.

3 - Professionalism

There were thoughts and ideas about professional behaviour in the group around the ideas of boundaries, training and personal skills. The main theme of 'professionalism' contains no sub-themes. The main theme comprises four constituent themes: boundary problems, I'm no expert, not trained and skills in the group.

3.1.1 - Boundary problems

Among the collaborators, there was discussion about professional boundaries. They seemed aware of the tension between the various roles that they were taking:

"It is hard to try and support somebody and know where your boundaries are really. Because you're supporting them, but you're their friend at the same time." - 'Claire'.

One collaborator was concerned about not being able to let go:

"But I do need to get more interests outside of [organisation] cos I end up with these people almost being my family which is possibly dangerous. From a personal point of view. And if I left [organisation] could I let go of it?" - 'Robert'.

Stepping back from involvement was also seen as a boundary problem of not wanting to always be putting forward an opinion and taking up other people's time:

> *"At first I was quite opinionated, but then I learned to shut my mouth a bit and kind of let people, other people bring and contribute, because I seemed to have an opinion on nearly everything" - 'David'.*

There has been at least one occasion when a collaborator has been taken advantage of by others in the group who have overstepped the mark:

> *"There's been a few instances where things have been inappropriate…but I guess, when you think about it, with a room full of people who are very mismatched and they've got mental health issues. So, I'm just very careful now and nobody gets my number ever. So yeah, I just don't and you end up feeling like you're being really unsocial and I know people can feel like you're being funny but I've had some weird texts, in the past, so yeah, I don't know." - 'Dawn'.*

3.1.2 - I'm no expert

Collaborators did not consider themselves experts in helping themselves, although they did consider other people, who had been in their position in the recent past to be experts and good at it:

> *"he could be a professional that guy and he gets through." – 'Tom'.*

On the other hand, some of them were able to say clearly what they had achieved or done:

> *"I'm nobody professional, I'm nobody, nothing, just like I say, life experiences, that's all I am, you know, and I can just say, 'This is what I did.'" – 'Camila'*

Some people were even quite disparaging about the efforts of the people who were in the group:

> *"Nobody is either qualified or willing or able to do anything about it." – 'Dawn'.*

There was an expectation that a professional, official or other expert would be on hand to do the work:

> *"I thought they would be more official and more professional." – 'David'.*

3.1.3 - Not trained

By making it clear that they are not trained, it is as if collaborators are saying 'even though I have not been trained, I can still be useful to my peers':

> *"I'm not trained to do anything. Like I say, I'm not. But that reassurance is there. It's a group thing again, isn't it, that reassurance is there." – 'Camila'.*

3.1.4 - Skills in the group

Collaborators recognised that they have skills that they use. Being a good communicator is one example:

> *"I think I'm a reasonably good communicator" - 'Robert'.*

There is a realisation that they have some very useful skills and that they are often not sure what to call them, but they can describe what they do:

> *"It's helped them because they've talked about it, you know, I've even said, 'Look, this is me, maybe I'm stepping over but this is me.' I've said, 'Look,' he was feeling a bit 'am I going to have a drink again'. I said, 'If you ever feel that urge do something.' I said, 'Ring me, it doesn't matter what time it is, ring me and I can give you a reassurance again.'" - 'Camila'.*

"I told him the other day on the first 'glad to see you [group member] I get so much out of meeting you' he said 'likewise'. And you do. Sometimes you don't realise, sometimes I get home and realise that somebody's said something and I think hey well that reflected." – 'Tom'.

Equally some have yet to find their skills:

"I don't know what skills I've got." - 'Claire'.

4 - Bad stuff

Things were not perfect and collaborators had something to say about the elements they did not like.

The main theme of 'bad stuff' contains no sub-themes. The main theme comprises six constituent themes: back stabbing, I don't like arguments, difficulties, spoken down to, undermining and what I don't like.

4.1.1 - Back stabbing

There were occasions in the group when people behaved badly. They were abusive towards one another:

"one particular lady was given a wooden spoon one day which really knocked her confidence for six" – 'Tom'.

Collectively they did not appreciate people taking subjects from the privacy of the group outside and talking about it in the wider community:

"like back stabbing and talking outside the group" – 'Tom'.

4.1.2 - I don't like arguments

"Yeah, yeah, there's certain things I do find difficult. I don't like arguments in the group…" – 'Camila'.

Arguments in the group can be the cause of anxiety and distress among some of the collaborators. Sometimes though they can help with personal growth and make people feel better:

"I wanted to tell him what I thought of him, but I thought I had to be the bigger person, you know. I don't like conflict and I don't, you know – if someone wrongs me, it normally doesn't agree with me. I normally react there and then. So that was a big thing to me that day" – 'David'.

There is an awareness among collaborators and group members about how their mood impacts their response to arguments:

"If my mood is low, then I am more likely to react in the wrong way, either verbally shoot that person down, make a show of myself, storm out, something like that." – 'David'.

Sometimes a response to arguments is strong and takes a long time to disperse:

"I hate confrontation. If there's any confrontation, I don't like it." – 'Dawn'.

"I have to bite my lip because I know that…I don't get annoyed often but I know when I get annoyed, I'll say something that I'd probably regret, so I have to go…but I take forever to calm down. It's awful." – 'Dawn'.

At other times it feels quite violent and they sort it out:

"He lost it with [facilitator] I think a couple of weeks…stormed out the meeting shouting his head off at [co-facilitator], at [group member], but they've made up. I've talked to [group member], he came to my house and I talked to him

and again helping somebody else. I reflected on my experience into his life." – 'Tom'.

4.1.3 - Difficulties

Some people found the lack of spontaneity in the group difficult and others did not like conflict or found the environment a challenge:

"But it means that I can't, I mean I'm a fairly spontaneous person" - 'Robert'.

"It's all very…it's quite childlike; it's like being at school in a classroom." – 'Dawn'.

4.1.4 - Spoken down to

Collaborators were fearful of the process, what might happen, who might be there, what might be said:

"I find it difficult even talking just to one person. So a roomful of people there's just no chance." - 'Claire'.

They were not respected as individuals:

"Two times I got spoken down to, off the people who were taking the group and I didn't like that." – 'David'.

There is a feeling that they are being done to and not given a choice or the power to decide how things might develop:

"that 'them and us' attitude and they're forcing us into this position and it's like well, they're trying to get a result but the result is a good result for you, everybody, so it's a good thing and I think there's a fear that it's going to be taken away, you know, if we succeed and we're taken out of this group then what can we do then, it'll all be taken away from us and then how will we cope?" - 'Dawn'.

4.1.5 - Undermining

Sometimes people have found that activities take place, not as part of the group, but out of it, that they feel is inappropriate:

> *"There's been a few instances where things have been inappropriate but that generally happens outside the group, where people have exchanged numbers and things are said or, you know" – 'Dawn'.*

For others it seems to be about rule breaking:

> *"I don't like all that backstabbing and tittle-tattle. When you come here you're told categorically that certain things are not to be said and not to be discussed. So that's the only thing I don't like about it." – 'Tom'.*

4.1.6 - What I don't like

Some of the processes of the group that took place, collaborators did not like. One collaborator mentions being unable to use the group in the desired way:

> *"I have gone [to the group] and I have needed to say something and we haven't done that. And I haven't had chance to say it. And then I have gone away … and I'm stuck then and that because I don't have anywhere else to say it. So, that's what I don't like." - 'Claire'.*

The process of needing to present themselves in an open way is not enjoyed:

> *"Yeah and you think that's not how anybody wants to portray themselves, even if that's the truth and your whole truth at that time; that's not all you want to show people and I just found it really uncomfortable." - 'Dawn'.*

5 - Being in a group

Many of the important elements that were highlighted in the interviews concerned being in a group, as well as ideas around friendship, and engagement.

The main theme of 'being in a group' comprises three sub-themes: group action, social network and belonging. Each sub theme comprises two or more constituent themes.

5.1 - Group action

There are elements of the process of group-based co-production which seem to be related to the action of the group itself:

5.1.1 - Acceptance

Feeling and being accepted into the group was an important aspect to it:

> *"But then everyone accepted me after the first lesson. They're saying, 'She's a woman, she might be able to bring a lot of positives into the group.'" – 'Camila'.*

Even being scared one collaborator was able to feel accepted:

> *"I would say first two weeks, I was very withdrawn, very scared but liking it. And I was feeling encouraged, I was feeling wanted, I was feeling, in a way, loved the way I was loving people after I got settled here." – 'David'.*

5.1.2 - Something better than nothing

There was a feeling that even though what they have, the group interaction, the group process and the control to do things themselves might not be perfect, it is better than nothing and they have the power to make it what they want:

> *"when you hear someone who has had a worse experience than you, within mental health, like a breakdown that was much worse than my breakdown or whatever, then that encouraged me to think 'wow', they have got the strength and they have done this and they have done that and they have done that and I am sat here, just moping and complaining about my problems." - 'David'.*

It might not be the best thing in the world but it is what there is and people take advantage of that:

> *"Just…even just the point of talking to them in the group, even if you're just talking about something, like what you've done in the week and it's not even relevant or it's not even too much personal information you know, that is still quite…it is more of an achievement than saying nothing." - 'Claire'.*

5.1.3 - Move the group forward

There was a feeling that the group needed to move forward for the benefit of everyone:

> *"I think everybody should be tasked to make them engage more, with coming up with something for each…maybe each session, maybe two people because if one or other doesn't bother or it goes horribly wrong and saying right, we want you to come up with one of your coping mechanisms, when you've used it; what it does for you; how you go about it for next week or such a body will and we'll discuss it and we'll all try to apply it that week, come and discuss how we failed, succeeded, whatever. So you are actually going away, learning and applying something rather than not really…" - 'Dawn'.*

5.1.4 - Group ownership

The members of the group including the collaborators owned the group and the process. They really took control of it:

> *"Yeah. And they weren't like family or friends that you'd had for 10-20 years, they were just people that you'd know for six weeks or…you know, they would…" - 'Claire'.*

People really did own the group:

> *"Well, since I said something it seems to have improved. It might be coincidental, I don't know. I don't know." - 'Camila'.*

They would use it for their particular benefit:

"I would say sharing of experiences, of life experiences and what got me, more than anything, and I think what helped me on the road to recovery, was listening to other people." - 'David'.

5.1.6 - Feel safe

Feeling safe in the group was important. People relaxed into the process but it was not immediate:

"I can come and share, talk about things that, you know, that I want to talk about, that I don't have anywhere else to talk about it. I don't have anybody else to talk about them with. So I can do that here. But it gives me somewhere to do that; that feels safe." – 'Claire'.

Others showed that it felt safe because they went back:

"So I said, 'I'm going back,'" – 'Camila'.

Collaboration was more than just an activity or a group; it was a new piece of the collaborators' lives. It filled a space in their lives like no other thing had done before:

"I think, it was not just because you would go yourself and sit in a room with these people that you didn't know and talk to them. You didn't know them really. But you felt like you did because they'd come and talk about their lives." – 'Claire'.

"And I just felt as though there was a missing piece". – 'Camila'.

5.1.7 - We know what it's like

The people who have taken part in this study as collaborators understand very clearly what it is like to feel isolated, lacking in confidence and self-esteem, to have poor mental health, to be excluded, to feel disempowered. Every one of them knows what

these feelings are like, how negative and destructive they can be. They know what the effect or influence of the group is:

> *"I think, depending on how bad you're feeling, sometimes just having got up and got dressed and left the house and come somewhere, you think, I've done something and that having somewhere to go, making yourself go somewhere that you feel it is a positive step because you know it's a mental health group thing, well I was here and I am pleased at myself that I just attended and just having done that, even if you don't particularly pick anything up that day, I think it gives me a boost afterwards because sometimes, I could stay in bed all day and not move and not want to see or speak to anybody, so it kind of gets you out of that; it forces people to interact; to be outside." – 'Dawn'.*

5.1.8 - It rescued me

One collaborator in particular felt strongly that this activity had been more than just important, it had been a saviour:

> *"I think it's something that [self-help group's manager] wanted doing, some work, you know, how would we describe [organisation] to some people. For me, I can describe it in one, you know, I just think it rescued me. You know, that's the way I feel." – 'Camila'.*

5.1.9 - Wanted to see me better

There was something a bit different about the action of the group. It was not all about individuals and their personal needs, although they were important. The group members wanted to see the other people in the group getting better and improving as well as them. It gave them a view of what it might be like for them, that it was possible:

> *"People wanted to help me, people wanted to see me actually get better. People wanted to see me rebuilt again and they wanted to help and some people would help more than others, but everybody helps to the degree they were happy to help with – so they would give what they thought they could give, without leaving themselves vulnerable" – 'David'.*

5.1.10 - Sense of being

Some people in the group felt satisfied with the influence of the group it made them feel better people:

> *"So again, and I digress but it's reflective on being here that's helped me from the violence coming out of my life." – 'Tom'.*

5.1.11 - The help

People talked about 'the help'. It was used in a very nonspecific way simply to describe what they were able to do for each other:

> *"So I'm trying to be a positive one for him. I'm trying to be…the help I've been given" – 'Camila'.*

…even though they may not have been given help by others:

> *"Well, it makes me feel good because I feel as though I've helped somebody because I didn't really get the help outside." – 'Camila'.*

…and what they could persuade non-group members to do for them:

> *"I will try and get you the help that I can get you" – 'Camila'.*

5.1.12 - Things liked about the group

Collaborators went on to talk about some of the things they especially liked about the group:

> *"I would say sharing of experiences, of life experiences and what got me, more than anything, and I think what helped me on the road to recovery, was listening to other people." – 'David'.*

5.2 - Social network.

Collaborators found the social aspects of the group important:

5.2.1 - Make friends

Some people used the group to make friends although that was not especially the idea. Having friends makes a positive influence on mental health:

> *"But one thing is, and it's a good thing but it might be…that the people in there soon became my friends." – 'Dawn'.*

It did start to create a dependence on the group that was unintended:

> *"But I do need to get more interests outside of [organisation] cos I end up with these people almost being my family which is possibly dangerous. From a personal point of view. And if I left [organisation] could I let go of it?" – 'Robert.*

5.2.2 - Dependent

Collaborators felt that attending the group was very important in their lives. It was often the loser in a choice between appointments or something else and that induced bad feelings in them. It gave them a feeling of connectedness, of value, of importance that they could not get elsewhere. Although dependent probably is not the right word, their comments do show that they prefer not to be quite so independent or isolated:

> *"I don't know if dependent is the right word. Well maybe because say if, I don't know like one week I couldn't go because I had an appointment or whatever, it would be a bit of a shitty week because I have not been and I have not had chance to go and talk with people. Or because it's like coming and seeing your friends and that. I didn't get to come and see my friends. And for me, it is somewhere to come and talk, because I don't have that anywhere else. I don't have any work or anybody where I can talk in that way. So when I started coming and I could come and talk to people in the group, if for some reason I couldn't do it, it was a bit rubbish because…" – 'Claire'.*

5.2.3 - Connectedness

Being connected was a big thing. Only one person specifically talked about it:

> *"And it's like you're not on your own anymore." – 'Claire'.*

Highlighting the importance of not being alone:

> *"It's like you're just not isolated anymore because you're sat in that group with these people" – 'Claire'.*

Importantly, the feeling of connectedness even stretched as far as home when not at the group:

> *"Because you're sat at home and you know that you're not the only one." – 'Claire'.*

5.2.4 - Laugh

Belonging to an important group that allows, even encourages, people to laugh together and from that they feel better, as if their problems are somehow lighter:

> *"Most of the time, we'd end up…the most inappropriate things but we'd find something to laugh at and we'd have a laugh and we'd leave and you'd generally feel better about everything, you know, that you can…even though things are horrible, you can still smile and laugh and you know, sometimes that'll be the only time I'll have laughed for a week, like I read these things and it was saying about adults and children and children will laugh up to 200 times a day; adults about 15 and I thought, I'm lucky if I laugh 15 times a week and yeah, it's getting better but I had to come here, it's mainly been the only time I'd laugh all week and you think oh my god, I feel a bit human;" – 'Dawn'.*

5.2.5 - Shame

Part of the reason for deteriorating mental health was shame at what had happened previously and the ability to share that shame helped to make it go away:

"I've coped with so much, I mean I was abused in approved schools, I was all kinds of stuff and I never, I just got over it, but this burglary knocked me for six." – 'Tom'.

"So I got beat up basically and that's the, it was the shame of that more. So I went as a recluse. Two years without washing, cleaning. I wouldn't let nobody in my house. Most people thought I was okay and then one day I just started shivering and I phoned the ambulance myself" – 'Tom'.

5.2.6 - See my friends

The relationships that built up were important to collaborators. They came not only for the benefit of the group but also to meet the friends they had made:

"it was a real friendship, but only for that day, you know, that particular day of the week, you know. And then some relationships would flourish from that and continue outside and some would just be inside, you know?" - 'David'.

It was not the sort of socialising they would normally do:

"socialising here is a different socialising to what I would probably do at home." - 'Camila'.

There was an excitement in anticipation of the group meeting:

"I'm going here and I'm going to see these people." - 'Dawn'.

And joy about how that group might develop:

"and sit at a big table and have a coffee and a cake and carry on chatting for another hour," - 'Tom'.

5.2.7 - Social media

Social media had desirable and undesirable impacts. On the one hand, it enabled people to keep in contact when they were not together:

> *"And we have got someone we can talk to when we are not at [organisation]" – 'David'.*

There was even opportunity to remain connected during the night:

> *"There's about ten of us on so we chit chat all the time on there. I haven't got a wife so most of them do it middle of the night they'll say 'is anybody there can I have a chat' you know what I mean?" – 'Tom'.*

Sending texts was also used in the group by some people to help them to manage difficult situations:

> *"People would get distressed or anxious or angry or mad or scared and I would either have a secret conversation by text message…" – 'David'.*

Sadly, it was misused by some people:

> *"it was very positive in the beginning, I don't think it is now," – 'David'.*

5.3 – Belonging

5.3.1 - Being part of something

Collaborators gave the feeling of their participation being more than just superficial; they really felt involved and participation was meaningful. It means having responsibility, gaining a sense of improving self-esteem, as well as not being isolated:

"I think being part of something … and not being isolated." - 'Claire'.

"But when you go to a group you can come away feeling as though your self-esteem has been risen. That's what I feel from it anyway. That's what I feel." - 'Camila'.

"You feel part of the group and there's a bit of responsibility as well" - 'Robert'.

5.3.2 - Familiar faces

Collaborators liked the idea that even though they might not know others they were confident that those others had similar feelings and experiences:

"but they're all in some way or another, have had the same feelings. Or the same problem, in a different situation or whatever, but it's in the same way. It's the same thing that you've had." - 'Claire'.

This in turn made them feel more comfortable:

"It's a very welcoming group. And when people do come in, I like to say to people, 'It's a nice group,' you know, 'just sort of make yourself comfortable'.' I like to make people feel welcome really." - 'Camila'.

The others in the group began to feel like a family to collaborators:

"I felt like people were actually happy to see me, returning every week, people were smiling. And that made a lot – it felt like I felt belonged, felt like I was part of, like – a lot of people here call this, like, the [organisation] family and it kind of felt like that" - 'David'.

People felt safe, confident, and supported to come along and looked forward to it:

"So I think looking forward to coming here, to the groups is the motivation not to harm myself. So it's a tremendous, tremendous help" - 'Tom'.

6 - Personal development

This main theme of 'personal development' is divided into two sub-themes: sharing and learning. Each sub theme comprises one or more constituent themes.

6.1 – Sharing

6.1.1 - Real life experiences

There was a strong emphasis on sharing real life experiences. Things that collaborators knew worked for them, that they had used and had experience of and shared them with others:

> *"I help 'em, if I've got any experiences in my life that reflect on what they're saying; I'll interject that with them, tell them." - 'Tom'.*

It was not only about things that collaborators had done or knew how to do. In addition, it concerned their ability to share their observations about the world around them:

> *"It made me, kind of, feel a bit stronger and a bit more content with my own life, knowing that I was inputting help into others, from my experience or my experience of seeing someone else in that situation and being able to bring reassurance to that person, or guidance." - 'David'.*

There was also the ability of the collaborators to share their experience of how to be:

> *"I think I made people feel comfortable in my body language. And I think people felt happy when they saw me, because they knew that I would look after them and look out for them and I had a caring nature about me." - 'David'.*

6.1.2 - Things that helped me manage

Sharing enabled collaborators to cope with the difficult experiences they had:

"Just their stories that relate to their problems, that reflect on my problems and the fact that I can help them. Where I've said something that's made them send me an email saying thanks [collaborator], know what I mean? I was down before I saw you today and I'm glad I came. I've got hundreds of them." – 'Tom'.

Collaborators have stories about how they have helped others in the group to manage:

"But we're getting there slowly but surely. And we're not professionals. He's had professionals to help him but I've actually asked this person, 'Have you got something out of it?' 'Oh,' he said, 'yeah, without a doubt.'" – 'Camila'.

6.2 – Learning

6.2.1 - Learning from each other

Most of the group time is focused on learning, but in two different ways. Group members talk about 'work' and 'going round' (or sharing). 'Work' is a formal activity that is in a fixed format such as learning to relax by mindfulness. 'Going round' is an informal part of the group time which allows group members to talk about how things have been over the past week, things that are bothering them, ask for ideas about how to deal with problems and so on. Each person in turn has the opportunity to contribute or not (pass), as they see fit. Collaborators sometimes complain about 'doing work' but others are very keen to do it. Sometimes the group is structured so that 'work' is done first, followed by a less organised 'going round'. Collaborators all have an opinion about which order these different activities should come in. Some like 'going round' first, others like to get the 'work' done:

"it got very disruptive, because people didn't want to do that, they just wanted the social part of that. So it spoilt it for the people who wanted it. But I didn't specifically want to come and do that, I needed to have the going round in the first half, to settle in to be able to focus on the second half." – 'David'.

In any event, the learning from each other was clear, as were the reasons for it:

> *"Yeah, okay, you take other people…you don't take them on board but you think, well, that's their anxiety, that's what's causing their anxiety so it's a learning fact, it's a learning…I'm just learning all the time what causes people…I just thought when I had anxiety it was only caused through that one thing. I didn't realise somebody else's anxiety could be because they've had a death, they've had a loss of an animal, it could be a partner, a break-up, it could be anything but your symptoms are all the same. Your symptoms are all the same." – 'Camila'.*

As importantly, it is the group members who they learn best from:

> *"I think it's meeting with groups and understanding problems other people have gone through as well, you can actually relate. Where if you could talk to a member of family, not immediate family but other members of family, they'd say, 'I don't know what you're talking about.' They've never experienced it but the people in the group have experienced it." – 'Camila'.*

Chapter summary

This chapter has drawn together and presented the findings, analysis and interpretation of the study, linking to evidence and discussion from previous chapters, underpinned by my reflexive position. Six main themes were identified from the body of data: being individuals, mental health, professionalism, bad stuff, being in a group, and finally, personal development. Details can be found in the code book (appendix 12) and the overall schematic conceptual framework (appendix 13).

I recognise clearly that other people (especially collaborators in this study) are not me. I have previously stated I am male, physically large, and hold a power role at the host organisation, this reflexivity is a 'recognition of the other' (Pillow, 2003). I recognised the otherness of collaborators by reflecting in the analysis of the data the

subject of role. My analysis shows that roles are taken, not given. However, for me, potentially the powerful one in this research, I have tried hard in a variety ways to relinquish power and enable collaborators to take it. Even though I made clear to collaborators at start up meetings that they could take roles (and be involved in other ways) if they wanted it remained for me to reiterate that. I continue to feel troubled that I have not truly been able to divest myself of this unwanted powerful role.

Each main theme has been illuminated by quotes selected from the transcripts of the interviews for that purpose. This process has brought the words and voices of each collaborator directly to the chapter and their collective voices; the words they actually used, make up over half of it.

It is notable that each theme links so closely to concepts generated from chapter two. In particular being in control, being a valued part of a community, being able to share skills and knowledge, being in meaningful relationships and being serious by turning up regularly. These are also extremely closely linked to the main principles of co-production.

The main themes draw together the links that can be made to the concept of co-production which will be developed and discussed in the chapter following.

Chapter Six - Discussion

Introduction

This final chapter builds on, draws together and discusses the ideas and concepts threading through this thesis. The work has explored the influence of the co-production process upon the mental health of the collaborators who have been involved in the project. I critique the work including the impact I have had and the impact on me of the research, concluding with an interpretation and description of the process of co-production. Six overarching themes: 'being individuals', 'mental health', 'professionalism', 'bad stuff', 'being in a group' and 'personal development' form the foci of the discussion.

Being individuals

Each collaborator or member of the group acted as an individual, behaved as an individual and benefited from the process of co-production as an individual. Of course, they were also other group members discussed later in the chapter. Chapter one highlighted that individuals accrue rights to be treated equally to their peers in the eyes of the law (Dewey, 1963; United Nations, 1948). Having rights suggests that individuals have responsibilities, a role (or more than one), and that they are involved in relationships with other individuals.

In relation to responsibilities, individuals have a responsibility to themselves and to others (Hobbes, 1998; Russell, 1946). They have a responsibility to understand themselves, to make themselves and their skills and abilities available to others, and to build on their abilities by sharing and learning. This suggests that responsibility is taken rather than being pushed onto individuals. Individual responsibility concerns a

person's behaviour to make a voluntary change so that their life improves in some way (Ampt & Engwicht, 2007). Such behaviour can be triggered in a number of ways including the realisation that it is possible or perhaps hearing about a trusted other who has made such a change.

Drawing on Stoic philosophy (Salles, 2001) they assert that there are things for which we can genuinely take responsibility and which depend on us. The Stoics say that the world and its actions are not totally pre-determined, so by our own actions we can do something to make changes. It is therefore the case that responsibility be personally owned and accepted. This also links to the idea drawn from the conclusion of chapter two that outcomes are better if people take part regularly and ought not to expect to receive if they are unwilling to give of themselves.

Roles

All of the collaborators talked about their roles in the group. Part of the function of a small group was to establish roles and that individuals may take on more than one role (Myers & Anderson, 2008). Members perform a specific function in the group that focuses on the functional communication between group members (Gouran & Hirakawa, 1983). Roles of the collaborators such as 'timekeeper' and 'welcomer' involved communication within the group.

These roles emerged from members as the group settled and such roles develop from the existing skills and knowledge that group members already had (Bormann, 1990). Nobody talked about taking a role immediately the group started and collaborators said that the taking of roles was linked to the confidence they developed and the role(s) that they adopted or played to their pre-existing strengths

and desires. For example, a ‘mother hen’ traditionally looks after people, makes sure that they are happy, content and gives everyone a bit of what they need. In this example, the role of mother hen was something that the collaborator concerned identified closely with.

It was noticeable that the roles were associated with providing support for and looking after one another, particularly, when it had been a difficult session. The group members playing the roles already knew what was expected of them when they assumed the role (Bormann, 1990) and roles were not given. Linked to this is the idea of Keyton (2002) that people’s self-concept drives the roles that individuals take and how they deliver them with the whole group helping them to establish their group identity. Collaborators did not restrict themselves to acting in two or more roles because if they had restricted themselves the group may have been less likely to succeed, because of a limiting behaviour called role rigidity (Benne & Sheats, 1948). This role-taking exemplifies the co-production principle of building on people’s existing capabilities moving away from a deficit approach.

The skills and experiences of the collaborators, which they were able to build on, were pre-existing in the sense that they had them already but being in the group situation enabled them to be brought forward for use. The collaborators then moved away from being passive recipients to being active and equal partners (Slay & Stephens, 2013). The taking of roles allowed collaborators to take control. It allowed them, for example, to ask for things – a break, a change of subject – on behalf of themselves or others in the group. At various times, this allowed group members to direct the activity of the group without actually being the facilitator. This is an important aspect of how the co-production operated. For example, it allowed group

members to use their own specific skills and knowledge to bring something extra to the session. It also enabled them to grow their own capabilities and develop their own confidence. This role-taking shows a more collaborative way of operating, by enabling group members to share what they know with others. This helped to bind the group membership together and ultimately allowing them all to move away from the traditional deficit-based approach of services.

Hollander and Offermann (1990) describe action in the workplace (and I think it works equally well in the co-production group). It gives employees (collaborators and group members) rather than managers, more power and control over their work as a team by taking roles as distinct from a work group. A team must have the power to control how it operates leading to more empowerment (Levi, 2007). This empowerment increases confidence (Ford & Fottler, 1995) and team members are better at accepting responsibility for handling problems (Kirkman & Rosen, 1999). Reflecting on this co-production group, it was of value that people adopted roles, which led to improved individual and group empowerment, met their own needs which benefited others in the group.

Power

Power, in the findings manifests in three different categories. The categories were power over their own mental health, power over the process of the group and feeling influential rather than powerful. First, collaborators were happy to discuss how they felt more powerful in for example their ability to manage their anxiety or depression. In this situation, power was being described synonymously with control. Collaborators talked about having control over their mental health where previously they had not, feeling happy and empowered about the control that they had.

The evidence (chapter two) indicates that for people who experience mental health problems, it is important for them to be in control of their situation. Freire (1996) raises the issue of how oppressed people (and their oppressors) both have their humanity diminished and talks about the 'banking model of education' as being oppressive. In this example, I want to use this banking model to highlight the inappropriate use of power. The banking model is based on the concept that people in power and holders of knowledge are able to deposit their knowledge into the empty receptacles of powerless people. They use the arcane knowledge of their specific profession and that profession's discourse to impose on a less powerful group of people what they must do and the consequences if they do not. This contrasts with the view of critical psychiatry that interpretation and pluralism 'admit as true' the meaning of the experience people bring to centre stage (Double, 2005; Hopton, 2006; Thomas & Bracken, 2004), contrary to the biomedical view.

Oppressors deny those oppressed people the right to say what it is that is helpful for them; they take away any vestige of control and in doing so damage those oppressed people. So much so that the oppressed actually begin to believe what they are being told, something that has happened over time (Burstow, 1988; Capponi, 1992; Chamberlin, 1990). It is interesting that collaborators in this study, through learning from each other, say that they have more power over their mental health without resorting to the banking model or a more coercive power. Freire's (1996) concept of internalization where the oppressed internalize the power their oppressors hold over them to behave in the way that they would have them do, seems not have worked well in this case. Collaborators have managed to treat one another as human beings in their collective learning.

Power over the process of the group manifested through collaborators feeling nervous about taking power; in the sense that it gave them authority over the others to make them do things they might otherwise not have. For example, when asked if she felt powerful in the group Claire said *"No, not really, I just feel normal".* On the other hand, considering the background of Camila, the bullying power held over her had a negative influence on her mental health and she was keen to avoid hurting anyone else in a similar way (Evans & Smokowski, 2015; Einarsen & Nielsen, 2014). Foucault (1981) holds that power is not something that can be held by certain groups or individuals, nor is it exclusive to intentional action.

Foucault's power/knowledge model was discussed in Chapter one. Where power is based on knowledge and makes use of knowledge; on the other hand, power reproduces knowledge by shaping it. In this study, power has been used as an essentially positive force that people were simultaneously undergoing and exercising. The fact that collaborators shared power indicates that there has been a collaborative sharing of power amongst them where they have taken great care not to become oppressors of one another in the Freirean (1996) sense. They have not been subject to the all-powerful and dominant discourses Foucault (1977) suggested they would be. What this meant for the collaborators was that they were able to deal with their problems and control the group in a way that made sense to them at that moment. For example, Tom says

> *"if there's any issues come up with people talking then I feel like I can help them and that gives me great pleasure in directing them in the right direction" - 'Tom'.*

In terms of the group, it means that they have collectively taken control for their own benefit.

Collaborators felt influential rather than powerful. The way that influence was shown was when collaborators decided not to be involved in a particular activity or to take part in a discussion. This activity was considered to be taking power or being empowered to do what they wanted. The way that collaborators reported their experiences seem similar to the way Freire (1996) emphasizes that democratic relationship between the teacher and students. Freire suggests that all parties to the activity have equal power in their democratic relationship. In a co-production group situation, power should thus be exchanged for control. What seems to have happened in this co-production group is that not everyone, no matter how involved they are, always wants to be involved in decision-making. This does not mean that people always want to give away their power and control, simply that they trust others with it from time to time. What was clear was that working as a collaborative co-production group means that leadership in the hierarchical, coercive and power-taking sense is not necessary. Co-production provides the opportunity to shape creative, democratic and innovative solutions based on the valuing of personal and professional knowledge. In doing, offers a method for the redistribution of power (Fisher, Balfour, and Moss, 2018).

The discussion of how the process of this co-production group has come together and operated is presented later in the chapter, making a suggestion about how it works.

Homophily and Relationships

Arnstein's model (1969) focuses entirely on the power of the citizen in their relationship with the state in respect of services being provided or delivered. Power is not always the only thing that citizens, or collaborators in this case, want (Tritter & McCallum, 2006). For instance, collaborators questioned that confidence-building was one of the aims of the co-production process, nonetheless, their confidence was built by attending.

There was something about knowing that others were in the same situation, mixing with them, taking a risk and talking to them, which helped collaborators to grow in confidence. Fundamentally, the newly-built confidence was initially only exercised in the group, but as time progressed, it also came out in other environments. Some described having the confidence to hold others to account when previously they had been frightened, if their behaviour was bad or inappropriate (discussed further in the 'bad stuff' section).

Lazarsfeld and Merton (1954) first used the word 'homophily' to summarise:

> *"the fifteen-word phrase, 'a tendency for friendships to form between those who are alike in some designated respect'" (Lazarsfeld & Merton, 1954, p. 24).*

Other commentators describe homophily as being associated with demographics from which the phrase 'birds of a feather flock together' was derived (McPherson, Smith-Lovin, & Cook, 2001). In this co-produced situation, the group members and collaborators were from different social and demographic backgrounds, yet were still able to fit into a group with people whom they shared poor mental health, the thing they had in common. Camila made the point that these were not the type of people she would normally socialise with:

> *"I'm quite open with things, you know, but socialising here is a different socialising to what I would probably do at home" – 'Camila'.*

David described this phenomenon when he said:

> *"it was a real friendship, but only for that day, you know, that particular day of the week, you know. And then some relationships would flourish from that and continue outside and some would just be inside" – 'David'.*

These short comments highlight that they were friends in the group environment but maybe not in others. They were not likeminded in the ways that we normally think about, such as having similar politics, interests or religion. The thing that bound them was their membership of the group.

The relationships that form between individuals are critical in the realm of group co-production and without them, individuals said they would remain isolated and there would be no connections made with other group members. The reduction of social isolation from the collaborators' lives was an important part of the co-production process, allowing people to start feeling as if they belong to something, worthwhile. The findings showed that friendships build, even if they are short term, time-limited or only for use as part of the co-production activity. Without these relationships, there would be no trust built between members. What was critical was that without trust people would not feel as able to open up or feel that the others were behaving genuinely. David made it clear that trusting others in the group was important when he said, *"personally, it meant I couldn't open up as much"*. Meltzoff (2002) discusses the idea that trust is built not just by language:

> *"We begin to 'only connect' via a common code, a lingua franca that does not depend on words. It is more fundamental than spoken language. This common code is the language of human acts" (Meltzoff, 2002, p. 24).*

This idea leads back to the principles of co-production that it works for 'people like us'. The principles of reciprocity, mutuality, and peer support networks enable those feelings of 'people like us' to develop and without which it cannot occur. It highlights the important idea that without trust there would be no benefit to anyone and therefore, there would be no co-production.

At this point I think it is helpful to reflect that mental health services are normally set up in 'marketised' and 'managerialised' settings (Davis & Davis, 2016). They offer a series of rationed, individualised and time limited interventions in an increasingly neoliberal economy. Essentially clinically reduced, atomised and entirely private. Something that Thomas Szasz and his ideas of medical individualism would have approved of. Peter Sedgwick was however said to have different thoughts (Davis & Davis, 2016) which brought humanistic and emancipatory responses to the fore, somewhat like this co-production group.

The key messages from these findings are that responsibility must be taken not given, roles will be adopted which benefit all. Hierarchical power is not necessary, newly built confidence will be used outside of the group, and trust is the important element in making co-production work.

Mental health

All of the collaborators experienced poor mental health and they all thought about how the co-produced group influenced their mental health, in similar ways. Everyone

talked about feeling calm, the opposite of how they often felt, in terms of their mental health. The did not generally use psychiatric or diagnostic words yet were still able to articulate clearly how good they felt; they knew that their mental health improved when they came to the group. If they felt nervous they noticed those nerves dissipating in the group. In terms of recovery, they noticed that it meant something different for each of them and they were concerned that their mental health might deteriorate again. Overall, the collaborators described their mental health improving during the course of the study and they felt good about that.

Collaborators did not generally use the specific words ‘mental health’. Only one of the collaborators talked about their diagnosis, although all had formal diagnoses. This suggests one of two things: either, the collaborators were anxious not to use those words because they felt stigmatised and discriminated against by them; or maybe the use of those words is somehow self-stigmatising. In medical situations, stigma around a health condition is influenced by two main factors: cause and controllability (Kelly, Saitz, & Wakeman, 2016). Mental health is highly stigmatised as it is, an attribute which ‘significantly discredits’ an individual in the eyes of others (Gray, 2002). When people use words that are stigmatising about themselves they are likely to experience self-stigma and are unlikely to be able to make changes in themselves or seek help (Tu & Cole, 2017). However, considering that the collaborators felt influential, had responsibilities and confidence, this seems unlikely.

On the other hand, the collaborators felt empowered in the environment they were operating in and those words did not seem relevant. The collaborators reported feeling confident and not feeling socially isolated. They had already achieved those things and they no longer agreed with the self-stigma (Corrigan, Larson, & Rüsch,

2009). They had tried and achieved what they were aiming for. Collaborators particularly talked about a sense of calm that they had not previously experienced, something over which they learned to have control. In fact, none of them talked about anything that they felt was not within their control. For example, there was no mention of doctors, medication or even counselling or other talking therapy. Two of the collaborators talked very clearly about how the social world had influenced their mental health, being bullied and beaten up. Attending the co-production group enabled collaborators and group members to gain a sense of calm both individually and as a group. The collaborators did not mention any thoughts about suicide, anxiety, self-harm, and other worries in the cocoon of the group process and all aimed to achieve the calm they talked about. What was important about this finding was that collaborators did not use the words mental health, rather they talked about control and a sense of calm.

In chapter three social constructionism (Anderson & Goolishian, 1988; Berger & Luckmann, 1966; Gergen & Gergen, 1991) illuminated how people 'exist' in language and that there are no 'real' external entities. Mental health professions have created a discourse that has led some people being transformed into 'the mentally ill' (Foucault, 1975). It was important to note that collaborators in this research moved away from positivist, bio-medical language towards much more normal language, saying that they 'felt calm'. Collaborators no longer felt the need to adhere to the societal norms, they had broken away from it, even if only temporarily (Walker, 2006).

I have discussed the utility of medical language in relation to mental health (chapter one). Attempts by psychologists to homogenise language classification and diagnostic systems (Marsella & Yamada, 2010) have fallen foul of cultures or rather

the social construction of feelings that individuals in a local area have made. Foucault (1977) talks about people simultaneously undergoing and exercising power. In this situation, the collaborators have not found themselves subjected to the power exerted by society in general as might have been expected. They have become empowered to use language which makes sense to them rather than that used by mental health professionals (Tew et al., 2012).

Collaborators talked about feeling good or feeling better; it was not just to do with their own emotions. It was possibly that feelings were infectious and thus for collaborators to 'catch' positive emotional states from others to (Hill, Rand, Nowak, & Christakis, 2010). Perhaps someone had smiled at them or said something funny. It allowed them to feel good as well. This finding showed that good feelings were not just about individuals, importantly there was something collective, which some collaborators described as being the [organisation] family.

Just being there among the others helped to make the nervous feelings the collaborators talked about go away. What was noteworthy about this result was that it supported the idea that being together was one of the vital aspects of the co-production group. This finding correlated strongly with those of Baumeister and Leary (1995):

> *"human beings are fundamentally and pervasively motivated by the need to belong, that is, by a strong desire to form and maintain enduring interpersonal attachments" (Baumeister & Leary, 1995, p. 26).*

This finding was also supported by other researchers who say that there are clear risks for not belonging (Cacioppo & Hawkley, 2003). They link greater risk of developing poor health behaviours, psychological distress, mental illness, self-harm behaviours and greater risk for suicide to social isolation and a lack of social support.

The notion of several different facets of recovery have been revealed. One collaborator thought about it as them not being cured, another talked about sharing experiences, a third about still needing to work things through, and fourth did not really know what it was, but it was working. This result was important, it showed that mental health recovery does not have a solid foundation in the minds of people who experience mental health problems. It remains personal and is interpreted individually. Many commentators and researchers have put forward views about recovery. Harper and Speed (2013) say the one size fits all approach to recovery and resilience is not adequate or appropriate. Trivedi (2010) proposes that personal recovery is 'self- evidently a good thing' but that it needs to take account of different perspectives, because for some it is not just a personal journey but also a social and political one. There needs to be a significant change in the roles of mental health workers, from experts directing someone's treatment, to collaborators supporting people to learn about the different choices available to support their recovery (Baker et al., 2011).

There was a discussion of human rights (chapter one), in particular, about how they are considered to be universal (Halverson, 1976; Nickel, 2014; Taitslin, 2011). Stoic philosophy, (Antoninus, 1634; Epictetus, 1750) was concerned with the idea that humans were to be considered equal to one another under the law. However, this research discovered that there is not a standard or normal way to experience being human. There is an idea of humans having equal rights according to the Universal Declaration of Human Rights (United Nations, 1948) but not equal ways of experiencing being human, and because of that difference, rights are not equal.

To try to illuminate this idea, I have turned to the experience of Hannah Arendt. Arendt (1951) wrote about her experiences of being a Jew in Germany during the Second World War period and having her nationality stripped by the Nazi state. She later realised that to have rights, a person needs more than to simply be a human being, they must also be members of a political community, in effect an organised nation state. This membership or citizenship opens the door to the enjoyment of rights. In this research group, members began as ordinary humans, with all the rights that accrued to that status. Once their mental health deteriorated, they became subject to a prejudice, stigma and discrimination. In my mind, this stigma and discrimination is akin to Arendt (1951) having her nationality stripped. It is only once the group members have recovered their 'group membership' (Nationality in Arendt's case) that they once again are able to enjoy the rights they previously had access to.

Professionalism

Collaborators discussed the concept of behaving like a professional and how the group perceived it. They were surprised to be in charge of themselves (in the group) and felt lost with the concept of 'professional boundaries' although they seemed to manage well enough. There was concern about being in different roles at the same time, that of being a friend and supporter. They felt concerned that they were not trained, did not have skills and did not know enough. Even so they were able to take an assets-based approach to things and gave what they had, while at the same time receiving what others were able to give. Some felt that they had skills and knew what they were; others did not know what skills they had to offer. Some collaborators said that they were not 'experts', when their actions and interventions showed that they were, in fact, 'experts'.

The collaborators talked about subjects that are usually considered the domain of professionals such as training, expertise, skill and boundaries. From a theoretical perspective professions occupy a position of moral importance in society, and undertake their work within a moralistic membership framework, such as a professional body (Parsons, 1939). They are trusted and held in high esteem by the community to do their best in favour of the community and individuals within it. As such, they are given 'carte blanche' to regulate, administer, and discipline themselves according to their own arcane system. Although a member of a professional body, the professional tends to practise as an individual. Moral superiority and acceptance is gained through such membership that aids in conferring an authoritative technical competence.

Authority is exercised in the way that a professional conducts him or herself and issues orders and advice. This authority is gained through a superior knowledge and competence of the subject matter under consideration. It is not related specifically to social or intellectual status, as very often the professional will hold authority over people of much higher social, financial, or intellectual status. Instead, it is related, to the professional's peculiar functionally specific authority over his own limited technical sphere of work (Parsons, 1939). This authority confers status to the service provided by the professional. Power over the work in this way is then used to exclude other occupational groups, establish professional boundaries, and demarcate labour. Freidson (2001) calls this skilled practical thinking, further reinforcing the notion that 'professional' implies 'skilled', which in turn implies specialised.

Illich, cited in Davies (2011b), proposes a counterpoint to this view. He says that the medical profession has created the illusion that only it can now do what individuals,

friends, families, and communities have done since time immemorial. He goes further to say that the medical profession conspires against the ordinary people, the very people who place so much trust and faith in them. From a different point of view again, Tritter and McCallum (2006), in their critique of Arnstein's (1969) model of citizen engagement suggest that professional health organisations such as Mental Health Trusts are enabled to disengage from user involvement because it has effectively been delegated to, such as VCS organisations. The impact of this is that, perversely, mental health trusts have moved further away from the people they seek to help.

Collaborators had received no training about how to behave in a professional manner, nor was there any expectation that collaborators and group members would behave in such a way. It was interesting to discover that they had arrived at this way of managing themselves as a group and what they were each doing. There was concern expressed that there were boundary problems and a lack of understanding or training about how to handle such situations.

To me, it seems perverse that group members were worried that they were not professionals when at the same time professionals are worried about de-professionalization (Fisher et al., 2018). Mental health professionals will begin to find themselves in new professional roles where the culture is different, more collaborative, less risk averse and less fearful. They will share their knowledge and skills in equal measure, reciprocally and inclusively with people they work with (Beresford, 2019).

Everybody in the group was made aware, well in advance, of the arrangements about how the group would run both in writing and in verbal discussion. Even so, collaborators and members had an expectation that a professional, official or other expert would be on hand to do the work. As part of the co-production process, there was such a professional role in place and available but not actually involved in the process of the group. What this meant was that people occupying professional roles were available to the group as a whole and individual group members if they were needed, rather than playing a weekly active role with the group. The professionals that were available were counsellors, cognitive behavioural therapists, mental health advocates, managers and administrators.

Mental health knowledge is dominated by professional knowledge, to the exclusion of the knowledge based on lived experience (experiential knowledge) that people with mental health problems can bring (Faulkner, 2017). As a result, the dominant paradigm in mental health care reflects the professional model which is predicated on the existence of mental illness as having biomedical origins. Whereas, collaborators talked about not having training and yet experiential knowledge, which they do have, is the best educator (Dzur and Hendriks, 2018). The outcome of the study supports this idea and links to the thoughts around health and social care professionals needing to receive training consistent with respecting and supporting people's rights and needs (Beresford 2019).

The key message from these findings is that group members had an expectation of a professional being on hand, and that somebody other than them would manage the perceived professional aspects of the co-production on their behalf.

Bad stuff

In a group that is based on co-operation and collaboration, it seems at first glance that bad things ought not to happen. There were some things that happened which the collaborators really did not like and which detracted from the overall good experience. Collaborators talked about backstabbing, being undermined and spoken down to. The idea of backstabbing was really about breach of trust when, for example, group members talked about what had happened in the group with a non-member of the group. Collaborators also found the arguments that happened uncomfortable, confrontational and distressing. They did not like the idea of being spoken down to, possibly reminding them of uncomfortable situations from the past when there had been power imbalances and they had been the less powerful party.

Collaborators reported some disheartening activities which took place during the research period and which came to light at the interview stage. These activities were not reported at the time they happened. A growing body of evidence shows that even ordinarily good people do bad things and that ordinary, unethical behaviour causes considerable societal damage (Gino, 2015). An accepted definition of unethical behaviour is:

> *"acts that have harmful effects on others and are either illegal or morally unacceptable to the larger community" (Jones, 1991, p. 367).*

This bad behaviour is surprising in that there is empirical evidence that highlights that people normally value honesty, believe strongly in their own morality, and strive to maintain a positive self-image as moral individuals (Gino, 2015). Intentional, unethical behaviour (Sezer, Gino, & Bazerman, 2015) covers the idea that people are unable to resist the temptation to behave in an immoral or dishonest way. Usually, people

consider themselves to be moral and honest and sometimes do not even recognise the actions they are undertaking. Most of us believe that we are ethical and unbiased, but we are not (Banaji, Bazerman, & Chugh, 2003). We just do not realise our biases and lack of ethics. This behaviour may not be conscious but it is, at least in part, due to implicit biases which are widely prevalent and just having a desire not to behave badly does not make the problem go away (Banaji et al., 2003).

We are subject to predictable ethical blind spots. So although we may not mean to exhibit bad behaviour, bias and ethically dubious behaviour, we nonetheless do so (Chugh, Bazerman, & Banaji, 2005; Bazerman & Tenbrunsel, 2011). Sadly, for the moment at least there are no reliable and tested strategies for resolving this problem (Sezer et al., 2015). Even sanctions do not appear to have positive impact and may actually make matters worse (Tenbrunsel & Messick, 1999).

The collaborator, Camila, said that some of the males in the group had used vulgar language in the group and she had felt offended. This information only came to light much later when interviews were being conducted. She felt that collaboration with the group had given her the confidence to reprimand them. The key feature of this finding is that even though people had felt offended, they equally felt able to take offenders to task about their behaviour, when previously they had stated that they found talking in the group difficult.

The key messages from these findings are that ‘bad stuff’, immoral or dishonest activities, had a galvanizing effect on collaborators to take action on behalf of the whole group. In view of what Tenbrunsel and Messick (1999) have said about how

difficult it is to resolve these problems on an individual basis, a group approach may have actually been effective.

Being in a group

Collaborators felt accepted by others in the group. Even though the group may not have been perfect it was theirs and better than nothing. There was a collective ownership that helped to move the group forward. People felt safe in the group and could relax among friends. The people in the group filled a hole in people's lives and rescued them from loneliness. Everyone in the group was there for a similar reason, they knew what their situation was and wanted to make changes. The group members took a level of responsibility for each other and collectively they wanted the mental health of everyone to get better. The group was able to provide unspecified help and support and gave people a sense of being.

There are certain things that went on in the group which were simply about people being in the group together, things like feeling accepted, feeling valued and feeling safe, even though collaborators had little personal knowledge about one another. Maslow (1943) describes a theory of motivation, why humans do things. He developed this idea into a hierarchy of needs (usually depicted in a pyramidal form) in which he describes physiological needs at the bottom followed by safety, belonging, esteem and finally self-actualisation at the top. Maslow defined self-actualisation as:

> *"man's desire for self-fulfilment, namely, to the tendency for him to become actualized in what he is potentially. This tendency might be phrased as the desire to become more and more what one idiosyncratically is, to become everything that one is capable of becoming" (Maslow, 1954, p. 46).*

The theory says that to move from one need level to the next, the previous need level must have been largely met (Maslow, 1943). It is reasonable to assume that the physiological needs of collaborators in this research such as food, water and sleep had been met, for example, they all had places to live and an income. However, establishing that collaborators' safety needs had been met was not so easy. After all, each collaborator and group member were experiencing mental distress at the time. Maslow's thesis suggests that because they were in an emotionally distressed state, they could not have experienced emotional safety. If they had not felt safety they could not have moved to the next level in the hierarchy, belonging (Maslow, 1943). The findings of the research showed particularly in the 'being in a group' theme that the group was meeting needs which previously had not been met; at the same time meeting safety needs. However, because they were mentally distressed, the emotional safety needs of collaborators could not possibly have been fully met. As a result collaborators ought not then to have been able to address the next level in the hierarchy, the needs of belonging. However, this co-production group showed they were not only able to meet this need, but the two levels safety and belonging operated in unison, challenging Maslow's theory.

In his critique, Neher (1991, p. 109) says: *'there is probably more linkage between various need levels than Maslow proposed*.' The fact that collaborators had needs not met in both hierarchy levels but nonetheless they were gaining feelings of safety from participation in the group in both levels, supports this notion (Neher,1991). Collaborators said these feelings of belonging and feeling safe made them want to come back next time.

Baumeister and Leary (1995) in their ‘Belongingness hypothesis’ say that people form social attachments readily in most situations, that belonging has strong effects on emotional patterns and that the need to belong is an extremely powerful and essential one. The research illuminates and supports their hypothesis (Baumeister & Leary, 1995) that lack of belonging is linked to a variety of ill effects such as well-being. It is the case then, that the feeling that you belong is a powerfully driven need and that it is not a requirement to have that need met prior to addressing other needs that might be wanting.

All of the collaborators knew what it was like to feel like an outsider, excluded and disempowered. It was reported that the group almost had a life of its own and that it developed for the benefit of everyone. That came from feelings of group ownership and group control. Again, there was a disconnect to the theory, Maslow (1943), suggested it was not to be possible to move between hierarchy levels:

> *“Human needs arrange themselves in hierarchies of pre-potency. That is to say, the appearance of one need usually rests on the prior satisfaction of another, more pre-potent need” (Maslow, 1943, p. 3).*

What was found in this research was that, in fact, it was possible to be in three Maslow (1943) hierarchy need levels (safety, belonging and esteem) at the same time. This finding suggests that these needs are not separate and independent from one another but rather joined and linked in some way that they can be addressed and worked on at the same time rather than sequentially.

The reality theory of Glasser (2003) proposes that humans have five genetically programmed needs: survival, love and belonging, power, freedom and fun, similar to the proposition of Maslow (1943). There was no sequencing that needs to be

followed, unlike Maslow's theory, such as climbing a hierarchical pyramid of needs. If individuals were to gather into small groups and use the theory, they would be able to heal themselves without the need for psychiatry and drugs (Glasser, 2003). The Glasser (2003) theory seems remarkably close to the ideas of a co-production group especially in that it is person-focused and eschews psychiatry.

Personal development

Collaborators enjoyed sharing their personal experiences with other group members. This sharing was not just of tips and techniques about how to manage their feelings, for example, or reporting on ideas that they had picked up from the group previously and tried out. They also shared their observations about others in the group, such as how they appeared to be progressing. The sharing that went on enabled collaborators to cope with their own experiences and show how they had helped others. Finally, collaborators were able to learn from each other and thought that the best learning was from people like themselves.

The co-production group built on the existing capabilities and skills of the collaborators. This was formed on the reciprocal relationships born of both sharing with and learning from each other (Putnam, 1995). There was strong emphasis on the sharing of real life experiences; there was no mention of things that collaborators said worked in theory. This sharing of experience reflects the ideas which Freire (1996) expresses when criticising the 'banking' approach to learning.

What the research findings point out is that the collaborators are not empty vessels to be filled with knowledge provided by others who are considered to have more expertise. Rather, collaborators co-produced a mutual and reciprocal approach to

education encouraging a co-created, jointly worked on and shared knowledge. Collaborators were able to share observations as well as relating the experiences they actually had. Stern (2009) in his critique of Freire, points out that Freire's thesis is not actually about pedagogy at all. It is actually about enabling the 'oppressed' to develop a pedagogy that will enable the people to be permanently liberated. The collaborators have managed, at least in part, to achieve liberation from oppressive mental health services.

The theory of social learning (Bandura, 1977) helps to underpin the findings of this research. Social learning theory hypothesises that people learn from one another, via observation, imitation, and modelling. People can achieve this both directly and indirectly, by observing others. In order that this learning becomes absorbed into their repertoire of behaviours, it needs to be positively reinforced. The social learning approach places great significance on learning with other people, through interpersonal interactions. This is the exact method that the co-production group used in their face-to-face encounters. For example, collaborators said that knowing others had been through similar situations helped them to manage. This could be linked to the social learning theory idea of modelling (Bandura, 1977), in that one group member 'models' a certain behaviour or explains a way that they have behaved to meet a certain need. In this way, the group learned from each other and it was something they enjoyed. At some points, everyone in the group was either a sharer or a learner, sometimes both at the same time.

Theory acknowledges the interrelationship between the individual, the environment, and behaviour. In social learning theory, this phenomenon is termed 'reciprocal determinism' (Bandura, 1978);

> *"Because people's conceptions, their behavior, and their environments are reciprocal determinants of each other. Individuals are neither powerless objects controlled by environmental forces nor entirely free agents who can do whatever they choose" (Bandura, 1978, pp. 356-357).*

The group members are not just passive recipients of information. The awareness of collaborators in the group and their behaviour all mutually influence one another. In a co-production group environment where people feel safe and supported, it seems reasonable that their experiences would be what Bandura (1977) describes as a bidirectional influence on each other. Group events in the form of modelling, instruction, and social persuasion affect the collaborators, and they in turn evoke different responses from the environment. Learning in the group was achieved in two ways.

As previously mentioned, the group members preferred one method or the other, either by ‘work’, a more formal learning activity, or by ‘going round’ a structured sharing process described shortly. ‘Work’ included programmed activities such as a group study of confidence boosting ideas. This was a facilitated activity, described as being a key tenet of the theory (Grusec, 1992), which is: ‘Learning is not purely behavioural; rather, it is a cognitive process that takes place in a social context’. Clearly, everything in the group takes place in a social context. ‘Going round’ enabled members to take turns informally to either share with or learn from the others. In essence, it provides the opportunity for introductions and a brief update of what has happened for each person in the time since they last met. This process enabled learning by observing a behaviour and by observing the consequences of the behaviour termed ‘vicarious reinforcement’ (Bandura, Ross, & Ross, 1963).

This style of learning involves observation, extraction of information from those observations, and making decisions about the performance of the behaviour. Learning can therefore occur without an observable change in behaviour. Finally, Grusec (1992) says that reinforcement plays a role in learning but is not entirely responsible for learning.

The key message from these findings was that they clearly showed several of the principles of co-production: taking an asset-based approach by sharing and learning as equal partners which meant facilitating rather than delivering; by making the environment feel safe and supportive; giving the members the opportunity to participate. It also meant blurring distinctions by making it unclear who was a provider (sharer) or a recipient (learner) at any one time and reciprocity and mutuality by group members sharing roles with one another. The findings supported social learning theory (Bandura, 1977) and the oppression proposition of Freire (1996).

Critique of the work

Impact of me

My Power

My role in my day job is considered by some to be powerful although it usually does not feel like that to me. For example, I often find myself subject to the needs of other people. I hold a senior role in the host organisation I do not use the associated title because I am aware that many find it daunting. Instead, I use a title that feels more accessible and less intimidating to me.

The strategies I use to try and reduce intimidation (chapter three), work well and people report that they do not find me intimidating. People tell me that they find me one of the least scary people that they know, but I do appreciate that some people would not tell me if they thought otherwise. On the other hand, the perception of my power in my job role is more difficult to handle. Again, I have a range of strategies that I use, including those already mentioned. In particular, as a qualified counsellor and mediator, I have interpersonal skills in communication. These enable me to reassure people that I am listening and that I am trying to understand them and I always defer to them and never engage in verbal bullying. I apply the core conditions (Rogers, 1957) of unconditional positive regard, empathy and congruence and find that this puts people at their ease. Nonetheless, some people persist in adopting a submissive attitude, in this study one collaborator did exactly that. I tried to reassure the collaborator concerned that I did not want or need what was being offered.

Eventually (in chapter four), I was able to evidence that collaborators all talked about the same things and as such there was a reduced likelihood of collaborators saying what they thought I wanted to hear. Of course, they could all have had the same strategy of ‘tell him what he wants to hear’.

Impact on me

Work

One of the advantages of undertaking a professional doctorate rather than a traditional PhD is that it is part time, flexible and is designed to be able to fit round other commitments, especially work. In my case, it also relies on my pre-existing experience in professional practice. The main difficulty I have experienced is that overall, my research has taken much longer than originally planned, due to being

distracted by the demands of my day job. Instead of taking six weeks (as planned) to consider the co-production group it turned out to be around six months.

The main problem was that there were a variety of other ‘more pressing’ activities to spend time on such as bidding for funding in order to keep the organisation going, recruiting new staff and volunteers, developing new ideas and a host of day-to-day activities which come with my role. There was no real alternative to letting things run on. I was, for example, unable to pause my work activities to get on with the research. As Wellington and Sikes (2006) say, I was operating in ‘two different communities of practice’, which do not really fit well together. Overall, this meant that I was unable to give the research as much time as I had planned in that phase.

There is evidence that professional doctorates are good at developing and enhancing doctoral level practice (Costley & Lester, 2012; Wildy, Peden, & Chan, 2015), but there is little critique in terms of what the actual problems for students might be in the delivery of the work. The nearest anyone gets to it is Wellington and Sikes (2006) but even they consider the academic, personal and professional aspects and give no concern to the practical aspect. In the end, data was collected at a time when the group was still in operation, something I expected would have finished.

Mental health

I am somebody who experiences poor mental health. Realistically, it would not be possible for me to work for a peer-led, mental health charity if I did not. I have had these experiences to my certain knowledge since the early 1990s when I met my first psychiatrist. I do not have such experiences all of the time, but certainly from time to time. I do not have ‘florid’ psychotic experiences and in no sense do I feel that I am

defined by my experience; to my way of thinking, they just get in the way of getting on with things, sometimes.

During the course of this study, I have found myself struggling with a variety of mental health difficulties which perhaps it is ‘normal’ for people undertaking doctoral study; it certainly seems so and many people write about it (Andrews, 2019; Levecquea, Anseela, De Beuckelaerd, Van der Heydenf, & Gislef, 2017; Pain, 2017). I want to make it clear that my personal experiences have had an impact. It has made the course of study more difficult and longer than I had anticipated. I believe that my experiences have made me more empathic (to the collaborators and process) and able to see a little more clearly how others have felt and engaged. It has enabled me to put myself more truly in their shoes and feel what it was like for them because I have been in that situation. I have been able to imagine how liberating it was to not have been constrained by ‘treatment as usual’ and an almost childlike excitement of taking control of destiny. I have struggled emotionally but on a positive note, my struggles have made me feel more as if I must complete this work, for my own peace of mind.

Dyslexia

Part way through the research element of the professional doctorate, I was assessed by an educational psychologist. That assessment found that I meet the diagnostic criteria for a specific learning disability called Dyslexia. This came as a surprise in some senses but also as a revelation. Suddenly, all of the difficulties I was having with my academic (and other) work began to make sense. I began to understand why I could not make contemporaneous notes, why I could not recall what people had said to me a moment ago, why my writing repeated itself, almost word for word, on

consecutive pages and I did not realise, and why I can see clear links between two or more apparently unrelated concepts and others cannot.

This was both a huge revelation and very exciting but at the same time struck me to the core. I became a formally ‘disabled’ person. In the context of my study and in view of my philosophy about it, I was lost. This was the case even though I knew, and know, perfectly well how to get on with study. I hold undergraduate and postgraduate degrees; I am a director of several organisations and hold other positions of responsibility, yet I still felt that I must wait for ‘experts’ to tell me what to do, to give me the answers and to help me. This helps me to imagine the situation of the collaborators in this study and the empowerment they may have felt when they took control of their destiny. I am certainly more able to say what I need and what works for me. At the very least, people who I work with can take account of my stated needs even if they are unable to completely meet them.

This change in my status as a researcher led to a new group of experiences and challenges. I was at once a labelled person and a person investigating labelled people. I feel that this new label has helped to make me a better researcher. I am more empathic and really feel as if I am ‘one of them’ even though I did not think I was different in the first place. This relates to the way that I have tried to conduct the study from a methodological point of view as related in chapter three. Earlier in this chapter, I discussed the idea of homophily (Lazarsfeld & Merton, 1954) and at this point I have realised that I have a certain ‘they are like me’ relationship with other people who are described as dyslexic. I am less inclined to the McPherson et al. (2001) idea of ‘birds of a feather flock together’, mainly because there is no flocking, but without a doubt they are all like me by virtue of their diagnosis. In fact, I have

found myself going out of my way to support the needs of others similarly described by 'outing' myself, providing ideas and equipment. This also reminds me of the Meltzoff (2002) idea that being a member of a group is much more than the language.

There is also a power element to how I feel. Previously, I was not labelled and now I am. That power insinuates itself into how I think about this work. Someone else has defined me, which I have very little power to resist or challenge. In chapter one, I related how strange it is that certain mental health professionals have power to direct and restrict a person's activities under the law based on a diagnosis those same professionals allocated. The power someone has to define you and put you in a category can, I imagine, feel like abuse.

I had never thought of myself as disabled. Importantly it puts me in a position where I am now, contemporaneously with the collaborators in my study. It reminds me that people who have challenges in their lives are defined not by what they are, but by what they are not, what they lack. Again, I return to the deficit way of thinking which through this work I am trying to challenge by emphasising the asset-focused way of doing things and building on people's capabilities. As I grew accustomed to the feelings, I was able to get on with things myself, find tools to help, develop strategies that worked, and so on. Now I have a variety of aids, some of which I have found myself, some are provided via the university and others via the Disabled Students' Allowance. This process has helped me to reflect on the study that I now report on.

Shortly after the assessment – I still find it hard to even write, let alone say 'diagnosis' – I found myself seeking out my 'new' community of similarly impacted people. There

was relief in finding that there are many others undertaking study, including doctorates. I was able to learn from them, mostly through ‘You Tube’ videos about how they had coped and dealt with the various problems. Watching and listening to those videos helped me to realise that I am not alone, that there are others who have similar difficulties and we can collectively share our experiences and solutions. This reminds me very much of the way that the collaborators described how they were able to share their experiences and knowledge to the benefit of the whole group.

Many were much younger when they came to their assessments and in many ways had had much longer to develop useful strategies. Even so, I have found myself able to share my own experiences and knowledge with others to their benefit.

Perhaps like the collaborators in this study, I have felt safe and supported by my environment, specifically academic colleagues and the University generally. What I feel seems to relate to the collaborators, feelings about the host organisation and the people in the group. I have been happy to share, talk and even write about dyslexia and how it influences me, just like they have done about their mental health. Many others feel that saying anything about their dyslexia, particularly in an academic environment, is excessively risky to their prospects, to their confidence and emotional wellbeing.

This information is important to my study because it puts me in a similar position to all of the collaborators. It adds to the authenticity of what I have been doing, to the trustworthiness and the empathy that I have with the collaborators. It makes it more likely that I have ‘walked a mile in their shoes’ and know what it is like for them and that in my view makes the work more trustworthy.

How does co-production work?

Earlier in this chapter, Arnstein's (1969) ladder of citizens participation was discussed and it was highlighted that the model is somewhat rigid in that it only focuses on the power relationships in play. Tritter and McCallum (2006) provide a useful critique to the Arnstein (1969) model and illuminate some of the shortfalls but they do not give any indication of how a process such as co-production may actually work in practice.

The opportunity to conduct this study in an organisation whose values and structure were so well aligned with the methodology was crucial. It would have been difficult, if not impossible, to undertake such work in a more autocratic, risk-averse, procedurally focused organisation. The fact that the people who volunteered to take part and who contributed to a successful outcome already understood the nature of the organisation contributed to a successful outcome. The collaborators were able to just get on with it without needing anyone to tell them what to do or how to behave.

I discovered quickly that my ideas about what might be good to do, especially in terms of data collection from a researcher's point of view, were rejected out of hand. Collaborators decided that they did not want to collect data before the start of each group session and nor did they want to keep diaries (chapter three). Similarly, I had hopes that collaborators would get involved more actively in the review of the data they had produced and the dissemination process.

Investigating a process such as co-production in a group environment is not that easy from a researcher's point of view. Everything was done at arm's length and there was no opportunity to even observe. For example, I was never invited into the process, so I personally could not experience what was happening. I only got the opportunity to

try and find out what had happened when I was collecting data at the end of the process. It felt like I was both in the research and not in it at the same time. I found that exclusion frustrating.

Now that I have conducted this research activity I think it is helpful to attempt to describe the process of co-production in a group setting starting with how it emerges moving through to it working and having an influence on the people who have collaborated.

Initially, it is necessary to describe the types of actors in the process and there are essentially two, although there may be many of each type as shall be seen later. Type one, I call an expert by experience (EBE), a service user, or a group member. Clearly, many other words are used to describe this type of actor in a group co-production process. The essence is that they are all people who have personal experience of using mental health services (could be other types of service in different situations). It does not matter if their experience is of primary, secondary, tertiary or any other variety of mental health service, just so long as they have that experience.

The second type of actor is expert by profession (EBP). The essence of an EBP is that they have professional expertise. The expertise they bring may be administrative, financial, that of a mental health professional, or organisational expertise. Any professional expertise that might be useful in the running and operation of the group and support of its members. It is reasonable that EBP may also be EBE in this situation. It is normal for people with professional skills to experience poor mental health but in this situation, they may not be acting as EBP.

Great care must be taken to avoid describing the role of EBE until the group has coalesced. It is important that any roles are taken rather than allocated as it adds to the democracy, building on existing capabilities and contributing assets to the group.

The process of the development is presented in a diagram (appendix 18), shows round faces, one orange and the other blue. Each face represents an EBE in orange and an EBP in blue. Step one is that a small group of people come together. I have used two EBE in this diagram but it could be more and there is no reason why an EBP cannot be included at this stage. They find some common ground, interests, problem or things that annoy them, for example. It does not matter how the EBE know one another as there are myriad reasons why people who have such experiences know one another.

Step two is that the small group get together and think about how to deal with their common problem. They generate an idea. They realise that they need skills that they do not have and so they ask for some EBP help. Step three that other EBE hear what is happening, want to help develop the idea and get involved. A group begins to form around the idea that they all like and want to take part in. Step four that the group coalesces to take the idea forward and get something happening. The group develops their idea collectively.

The EBP can continue to help, if required, or withdraw and stay on the side-lines. They can also support other groups to provide them with the same or similar skills and help. EBE will have the opportunity to take on specific supportive roles within the group that may operate on a rota or fixed basis. In our organisation, this is called

‘Taking On A Simple Task’ (TOAST). The types of role (other than the facilitator or co-facilitator roles) which people may take on could be, such as ‘time keeper’, ‘brew monitor’, ‘encourager’, ‘praise giver’, ‘hand outs’, ‘active listener’ and so on. The roles of facilitator and co-facilitator can also be taken by any of the EBE or EBP. These roles need specific training to undertake them successfully and avoid the problem of trying to deliver something, which is not how co-production works. Irrespective of the role that each person decides to take or not, they all hold the same level of control within the group.

Step five is that the group develops and continues to operate. Individual EBE and EBP grow in skills, esteem, awareness, ability to deal with their difficulties and so on. People may leave and others may join. The co-production group continues at this level until it stops. At this stage in the process, the diagram shows different faces. The small orange and blue faces change to a background of a much bigger red or blue face in which the small face is situated. This is meant to show that the actors are gaining skills, knowledge and growing in themselves. The actors then leave the group as big red or blue faces. This represents the newly grown EBE and EBP who have participated in the process and gained from it.

Chapter summary

The chapter has enabled a discussion and critique of the findings of my research. There has been consideration of the roles that collaborators took and the power that they gained and exercised. Lazarsfeld and Merton (1954) helped illuminate the idea of being in a group by providing thoughts on homophily and being able to make and develop relationships. Collaborators mental health was always a focus and ideas about social aspects of mental health, rather than biological, discussed. This linked to

thoughts about stigma and how getting human rights required group membership (Arendt,1951). The discussion considered how Maslow's (1943) heirarchy of needs were met, the outcome being for this group of collaborators this theory did not work, needs were met but not in a hierarchy. The importance of personal development through sharing and learning was highlighted, and my influence on the work and how it had impacted me. My view of how co-production works in a group setting using a narrative linked to a schematic (appendix 18) was presented and discussed.

Chapter Seven – Conclusion

Introduction

To close, I review whether the study answered the questions posed and can be trusted. I move on to outline and discuss recommendations for policy, practice, education and future research.

Answering the question

The study considered the influence of co-produced, peer-led, self-help groups on mental health. It was designed as an exploratory piece of work with four related questions as follows:

- How has the mental health of collaborators, from their personal point of view, been influenced by being part of the co-produced group?

The collaborators said they exhibited a deeper understanding of their mental health and they were able to discuss the problems that they experienced eloquently. Individually, collaborators were able to track their mental health through, for example, feelings of fear and nervousness to feelings of calm. All of the collaborators mentioned encountering a sense of calm through the process because of their collaboration. It was this sense of calm that they all valued. Some of the collaborators discussed concerns that they might slip back, their mental health deteriorate and that they might lose the calm they had achieved. There was a realisation that maintaining their good mental health is an ongoing process.

- How ready to engage were collaborators in a process which required collaboration rather than simple attendance?

The interviews with the collaborators gave an in-depth view of the ways that they got involved with the action. It is important to remember that being involved, leading, making decisions, taking roles, being collaborative - is not something that people did all of the time. People did not always want to be active in a role, but that did not mean they were not collaborating, it simply meant that at that precise moment they were sitting back for a time. Collaborators engaged in the activity in a way that was more than just turning up. The collaborators engaged in the process were active and made the most of the opportunity. There were opportunities to collaborate, best shown by the readiness with which collaborators took roles in the group. They all had at least one role and in some cases two or more. The roles were not given but taken making them totally voluntary and in every respect there to meet a need. Claire illustrates this when she says:

> *"if somebody new comes, we will try and make them feel welcome and things like that, I'm not the only one. There are a few. There are a few of us that do the same thing." - 'Claire'.*

I think that this shows that collaborators were ready to support others in roles that they could do when there was a need and they did not have to be asked. Those needs may have been to do with the role-holders' innate need or desire to be supportive. Equally, the role holder may have noticed a need in someone else that they felt they could meet.

- How were collaborators able to create the environment that nurtured collaboration?

Collaborators took their roles seriously. All of the collaborators were supportive of other group members. Collaborators said that they felt as if they belonged. These feelings were engendered through group members saying that they liked to come along and see familiar faces so that they could see their friends or make friends. They felt accepted and because they all knew what it was like (experiencing poor mental health), they felt safe in the group. Collectively, they took ownership of the group; they influenced the way the group ran; they influenced how they felt and they influenced how others felt. The group created a setting that nurtured the collaborators; they said: ‘it rescued me’, it ‘gave me a sense of being’ and ‘it was a missing piece of my life’.

- Did the collaborators experience any harm by engaging in the process of co-production?

The section under the theme of ‘Bad stuff’ (chapters five and six) discusses the elements of harm that collaborators experienced during the study. There is no doubt that they all experienced some harm whether it was feeling spoken down to, being back-stabbed or being undermined. These harms were eventually uncovered during interviews and the analysis process but none of the harms were reported at the time they happened. Collaborators who had concerns still came along to the sessions though some made their feelings known in more overt ways such as by holding perpetrators to account but others were more passive in their resistance. In all of the bad things that happened, there was nothing that might have been considered outside of the normal rough and tumble of life. Ultimately, since the end of the study – many collaborators and group members still pop in to say ‘hello’ – there have been no reports of ongoing harms experienced following the period of the study.

If, by undertaking research such as this, it can be seen at least by me, that helping people to deal effectively with their mental health problems using a fairly simple, organic process, makes me question why it is not being facilitated more widely. This research shows that people have the strength and capacity to grow and develop using the process of co-production in the right environment.

Trustworthiness

It is important that this thesis is trustworthy and that readers think it credible. Chapter four considered this, and the work would be considered trustworthy using the criteria by which trustworthiness is judged (Guba, 1981; Lincoln & Guba, 1985). This view is the view of the writer, the final judgement at this stage, it is the reader who needs to be convinced. There is also the point of view of the collaborators to be considered. This is, after all, a study concerning the influence of co-production and I am just one part of the process. Collaborators more or less withdrew from the process after taking part in the data collection stage (chapter four). It is they, however, that hold the final pronouncement on whether or not the process and the reporting of the research is trustworthy, because they are the only ones who were there at the time.

Recommendations for future research

As this is the first piece of research within the area of co-produced, mental health self-help groups in relation to qualitative experience, it is worth seeing this as a stepping-stone to further research. It will allow findings to emerge rather than being classed as an end result.

The study of co-production is still very much in its infancy so the questions of how co-production develops and how the process acts upon people's perception of mental health, wellbeing, physical health and social behaviour still need to be considered. If improved mental health is inherent in the co-produced relationships that are formed with professionals working more collaboratively, it is worth looking at and considering why this is the case and where it has come from. There are also significant issues to be investigated concerning how different 'psy' professions think about and work in co-production environments.

Further research still needs to be completed in relation to the mechanisms of co-production. As Kabat-Zinn (2003) explains, it is common for the first generation of studies in relation to a particular phenomenon to be descriptive rather than the understanding of mechanisms and pathways of change. A greater understanding of the specific elements of co-production need to be explored and developed to create a deeper insight into what is actually so useful about the co-production process. Questions surround principles like 'Building on people's existing capabilities' (Slay & Stephens, 2013); what is it about this principle that makes it contribute to the co-production process, if this principle was excluded what would be the effect on the co-production process?

I am aware from participating in recent meetings of the Greater Manchester Voluntary Community Social Enterprise sector assembly: Co-Production Network that many people are confused about how to facilitate co-production. They expressed their anxiety that because there was not a fixed process for doing 'it', they were anxious not to try in case it did not work. I have put forward my thoughts and what I think happens in group situations (chapter six). To help break this inertia, the network is

keen to exhibit ideas and projects that are doing great things, including what went wrong along the way and the things they have learnt. This is rather than saying ‘this is how you do it’, because that would not be a co-productive way of doing things. In this way, co-production will be shown in all of its various forms and others can begin to experiment, collaborate and ultimately co-produce.

Recommendations for practice

In practice, co-production is about people taking equal control (with professionals) of their services. This concept is at odds with the traditional way of designing, developing and delivering mental health services highlighted in chapter one. There is a philosophy behind co-production that is concerned with democracy, the sharing of power, reciprocity and mutuality, blurring distinctions, and building on people’s skills (Cahn, 2004; Ostrom & Whitaker, 1973). Arnstein’s (1969) ladder of citizen participation (chapter one) proposes eight levels of involvement of service users ranging from manipulation (where people have things done *to* them) through consultation (where people may have things done *for* them) and finally to citizen control (where people are done *with*).

The idea of co-production is underpinned by the principles of Arnstein’s (1969) ladder concerning the relative distribution of control and power for both service users and professionals. In service delivery, what actually happens is that there is a bit of ‘real’ co-production where there is a genuine service being ‘done with’ service users. More often than not, this equality and democracy fizzles away into services being ‘done for’ service users, and ultimately services being ‘done to’ service users (Bradley, 2017).

Mental health service-providing organisations are using co-production as a way of legitimising what they do when actually there has been no meaningful change in the way they do things (Bradley, 2017). There has been a proliferation of ‘recovery colleges’ and similarly styled activities by NHS Mental Health Trusts (Morgan, 2017). These are often run on good co-production grounds but they are peripheral to the main business of the Trust. Organisations that say they co-produce a service and it is a service that ‘does’ to the service user, in which they are never really involved, continues to make service users invisible.

An idea and schematic about how a co-produced group activity comes about was presented in chapter six. It is not driven by Arnstein’s (1969) ladder model but it is much more akin to the ideas put forward by Tritter and McCallum (2006) which is much less static in structure. The proposed model is based on collaborative activities where people who want to do things join together to make the idea happen, whatever it is. There are no fixed positions, no hierarchy, everything is fluid and in many senses roles and activities are blurred.

Before any new projects are developed, an active engagement process is initiated. This process has two parts. The first part is about canvassing the existing membership to find out if there are any projects or ideas they want to develop. If there are, then these are taken forward as a joint effort to development. The second part concerns ideas and projects which originate outside of any potential collaborators. The only real difference is that the ideas are generated in different places. This process has begun to be more inclusive of the people that will be collaborating in them. The benefit of this gives potential collaborators the opportunity to have power in the development they might previously not have had.

Local funders of services such as the NHS and local councils are keen to ensure that they fund services and activities that the people who might use them have been intimately involved in developing them. It means that services and activities that are developed are exactly what those people involved want and need.

Mental health service providers (not just NHS but all of them) need to review the ways that they facilitate how co-production takes place. There follows seven recommendations about how this can be achieved:

1 – People wanting/needing mental health services must be included from the beginning of any service or pathway design process. There is no point in professionals doing the initial groundwork and then getting others involved later. This process is not co-production but it assumes that the professionals know best and people will (eventually) have something done to them.

2 – Those people must have equal power to commissioners, clinicians and other professionals. The power balance must be equal. As a simple example, if there are, say, five professionals, there should be five non-professionals to prevent either ‘side’ from doing what they want, or ‘forcing ideas through’. The equal numbers may help to support the idea of a collaborative, agreed solution, which in turn helps to make sure that decisions are made in a collaborative spirit.

3 – The collaborative activity must not be tokenistic. We know from work on user involvement in service planning and delivery, dangers of tokenism also exist. User involvement in research may be viewed as a `box' to be `ticked' on research

proposals (Rose, 2002) rather than as a strategy for achieving change and improving conditions for mental health service-users (Morris & Faulkner, 2002). I can imagine that ensuring a collaborative approach is difficult if it is to be trustworthy. One way to help ensure a collaborative approach, particularly in services, is to use collaborative language in the description or specification. It is difficult to write a proposal as if it is collaborative when it is not. The writing of a collaborative specification requires much more consideration and thought than a hierarchical one. There will be a need to describe who is involved, in the sense of what their experience is and what they want out of it: what roles are available and how they shared out, for example.

4 – The activity must be collaborative and not competitive. The process of co-production does not work unless a collaborative model is used. Competition requires that someone wins or comes first which means that everyone else, of necessity, loses. Competition discourages the collaboration that requires everyone to take part and give of themselves. This is quite difficult to achieve as people often expect there to be a winner and often take part with this in mind. It is important that collaborators do not believe or think that co-production is a ‘zero sum game’ (Rozycka-Tran, Boski, & Wojciszke, 2015) where one wins and the others lose. Co-production is actually more like a non-zero sum game where gains and losses can be made by all without affecting others. Considering comments about social constructionism in chapter three, it is important to remember that co-production (at least in this study) is a local activity, not global, and therefore what happens is a local truth not a universal truth.

5 – Facilitators to ensure fair play. Co-production is not delivered in the way that services have traditionally been. There is nobody that says: ‘Right you lot, this is what we are doing‘. The process is much more organic where people realise jointly and

collectively that there is a problem to be solved or something that could be done better jointly. Facilitators are like a social grease to the project: they help gather skills when they are needed, they make arrangements, they invite and include others who might be interested, they enable the flow and ensure that the process is not waylaid and they help the activity to flourish and arrive at an acceptable end. Facilitators need to behave objectively in the process because if they do not they may become directive and the work will not be co-productive.

6 – There must be ways to encourage collaborative action in service delivery. As we find new ways to move towards the idea of collaborative services, we may move away from the idea of winners and losers. Collaborators may come to realise that the more they give the more they get and to forget the expectation that they will win or gain something at the expense of others. Collaborators may come to the understanding that they do not need power or control over things but they need to work together. In chapter one, I mentioned Ken Wilber (1996) and his ideas about everything being linked to everything else. We tend to forget our interdependence with everyone and everything around us, so much so that we stop caring about them.

7 – An effective way of enabling professionals to share their power more equally needs to be found. In keeping managerial control over a process of co-production and the maintenance of professional standards, a dilemma or dualism develops: occupational versus organisational, professional versus managerial, or agency versus structure (Noordegraaf, 2011), which requires a different or non-traditional approach. My own experience of working in an organisation that prides itself on working in a team-like fashion and containing only three professions is that demarcation lines are drawn and professional discourse applied.

Power-sharing as described by Lijphart (1968) as consociational, in democratic countries, if it were adapted to a local, organisational small scale, may be an effective method of attaining such power-sharing. However, given the current situation with regard to the power dynamics in UK mental health systems, it will inevitably require considerable adjustments to legislation, especially the Mental Health Act (HM Government, 2007). This approach is not without criticism as McGarry (2008) says:

> *"Consociational theory is also widely criticized. Most criticisms are from an integrationist perspective, which sees identities as malleable rather than resilient, and which is distrustful of power-sharing among segmental elites. Integrationists believe that agreements among segmental elites are likely to be unattainable or unworkable. Agreements that are attained, it is argued, are likely to be counterproductive, as they allocate political resources to elites who have an interest in maintaining division" (McGarry, 2008, p. 691).*

According to McGarry (2008), the integrative vote-pooling method of Horowitz (1985):

> *"supports power-sharing because it facilitates coalitions of moderates and such integrative power-sharing coalitions are more likely to work than consociations because their members are more likely to compromise." (McGarry, 2008, p. 692).*

On the other hand, the integrative power sharing methodology of Horowitz (1985) appears much simpler requiring pooled votes among different groups.

Recommendations for policy developments

The UK Government has included the idea of co-production in several policy initiatives (chapter one). It has named 'co-production' as what it aims to achieve, despite several implementation difficulties remain.

To address the issue of definition, I supplied four different definitions (chapter one), all four offer a flavour of co-production, but different organisations and groups have preferences no doubt to support their own interests. This variable group of definitions adds confusion, not clarity. We already know, organisations use the lack of clarity in definition to say they are providing something co-produced when they may not actually be doing so. If a clear and agreed definition of what co-production is were provided that would be helpful. Among other things, it would aid a common understanding of co-production. Definitions become important when resources are at stake. Resources include things such as money, space, and time. Organisations and individuals could then agree what co-production actually means and resources could be allocated appropriately to ensure it happens.

There are vested interests in all areas (Royal College of Psychiatry, British Psychological Society, NHS Mental Health Trusts, Survivor/User groups, Carers groups, and Pharmaceutical companies) few of whom are likely to be keen on giving up their power, money or jobs. All of these groups have differing views about how best to identify and define the problems in the first place much less how to go about resolving the conflicting interests which they have.

I have no idea how to influence policy without having a ‘must do’ authoritarian approach. An authoritarian approach is antithetical to the concept, philosophy and practice of co-production. Simply providing evidence that the outcomes speak for themselves is unlikely to be enough to convince policy makers to be more forceful. The quantitative evidence that is likely to be required is not available. The idea of moving away from a policy of what must be done (task-oriented activity) to a policy of what must be achieved (goal-oriented activity) might be one solution.

Organisational structures of the NHS, social services and policymaking bodies are not conducive to enabling co-production. The Five Year Forward View (5YFV)' (NHS, 2014) explicitly states:

> *"patients will gain far greater control of their own care" (NHS, 2014, p. 4).*

The 5YFV unequivocally supports co-design (NHS, 2014, p. 26). Within the same document, however, the NHS expects to remain a process-driven organisation. It is unclear to me how two systems, one process-oriented [current and planned NHS] and one person-oriented [co-production] are compatible, and how policy action can bring these together.

A solution to addressing all of the above policy difficulties appears at first glance to be impossible and conflicts abound. Plurality of thought could be brought to bear on the problem of deficit-based thinking and doing, by involving as many people as possible into developing strategy and policy. Such a development could be co-produced. As an example, since 2013, with the inception of 'Healthwatch' (HM Government, 2012) interested citizens, professional or otherwise, have been enabled to get to grips with making decisions about how to develop services as a whole and not just mental health. Healthwatch is the most recent in a series of attempts by government to give people the opportunity to take part, offer their knowledge and experience, and hold power to account with power of its own. It is not perfect but it is a start.

Recommendations for education

The issues and recommendations discussed thus far have implications for professionals working in the mental health arena. Those professionals may be entirely new to the work or have many years practical and educational experience.

Professionals will need to establish and think about new ways of working and in particular new ways of thinking about mental health. If, as this study shows, there is no requirement to have a professional mental health worker directing the work, the roles that they will undertake are not the same as they were originally taught. That does not mean mental health professionals have no role only that their roles in future will be different. Rather than being deliverers of service, they may find themselves as facilitators and guides. These adapted roles will require the development of a different suite of skills that will mean a different sort of education. Education will need to be person-focused; it will need to be about each individual they work with and it will need to be about their needs and only their needs. Mental health professionals of the future will need to be even more adaptable and flexible to meet the needs of the people who come to them for help. They will need to move away from the traditional psychiatric discourse and embrace a more inclusive methodology in their work.

The people with whom mental health professionals work, may not have had the benefit of the same education and may be unaware of how things are supposed to work. They may never have been taught that there is a firmament of different, sometimes conflicting, theories, attitudes and beliefs about the causes, cures, and meanings of what our society calls ‘mental illness’. Often they are vaguely aware of something called psychiatry, ‘sectioning’ and the medication it offers. The collaborators in this study have managed to achieve good results for themselves

without direct input from mental health professionals. Both the National Collaborating Centre for Mental Health (2011) and Beresford, Nettle, and Perring (2010) recommend improvements in education.

Concluding remarks

The purpose of this study was to explore the process of co-production in a group-based mental health environment. It came about because I wondered why the UK Government had decided to introduce the concept of co-production to policy. I questioned what it was about this process that was so appealing yet there did not seem to be any evidence.

The findings of this study clearly demonstrate that being individuals is a requirement in a co-production process as is being in a group. Neither of these apparent opposites are more important; they are important in equal measure. Sometimes, it is important to be an individual and share knowledge or skills; at other times, it is equally important to be a receiver of that sharing. It is the idea that we are all individual and different in so many ways that brings the process of co-production to life. Homophily, the act of being in a group of likeminded individuals brought the contrast to individuality. It was this group of people that helped one another. Through their individuality, they developed the knowledge and skills – control, through taking roles, building confidence, self-esteem, and trust – that enabled them to reach a state of calm. Being in a group of like-minded individuals, with similar objectives, and starting from a similar place is life-affirming. It creates a strong network of peers who can understand your point of view without you needing to explain, sometimes known as homophily (Currarini, Matheson, & Vega Redondo, 2016; Marsden, 1988; McPherson et al., 2001).

Collaborators originally talked about their mental health and there is no doubt in this study that they found a level of calm (as they began to describe their improving mental health) through the process that they valued and was the reason for taking part. Throughout the process, there was no mental health professional directly involved and the group members made these achievements by themselves for themselves.

Collaborators do not need to have training, the co-production process works without. Although there were no mental health professionals directly involved in this study, it is recommended that, in future, they will best be able to help people improve their mental health through good facilitation rather than treatment in the ways that they have traditionally been taught. This can be achieved by redeveloping training for mental health professionals to focus on what people can do rather than what they cannot. This way forward will enable the breaking down of barriers so that practice in mental health services will change to enable the sharing of power between experts by experience and experts by profession and transform the way that mental health services in the UK are thought about and conceived.

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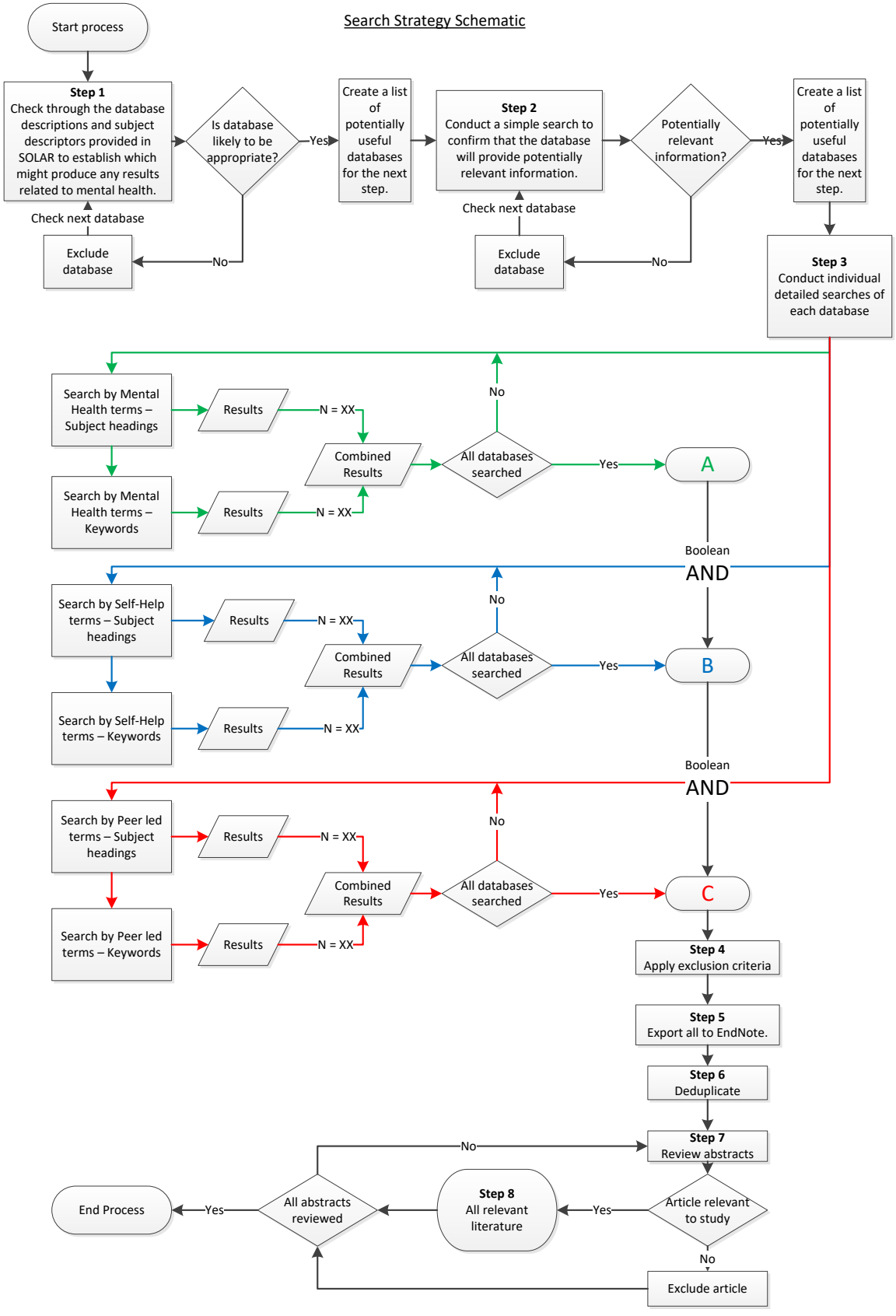
Appendices

Appendix – 1 – Literature search schematic



Step Number	Activity
1	Sequentially check through the database descriptions and subject descriptors provided in the University of Salford SOLAR database listing to establish which might produce any results related to mental health. Create a list of all potentially useful databases for step 2.
2	Conduct a simple search of the databases identified in step 1 to confirm that the database will provide potentially relevant information. Create a list of all potentially useful databases for step 3.
3	Using the search terms shown in appendix 1 sequentially conduct individual detailed searches of each database identified at step 2. These are shown in green (mental health), blue (self-help) and red (peer led) in the schematic.
4	Apply exclusion criteria detailed in the literature review chapter.
5	Export to EndNote to enable easier management of article's and accurate citation.
6	Deduplicate the EndNote file to remove articles that are the same.
7	Review abstracts to ensure that each article is relevant to this study.
8	Create list of relevant literature for further review and analysis.

Appendix – 2 – Search Details

Self Help Element

Database	Limiters	Subject heading search terms	Number of hits	Keyword search terms	Number of keyword hits	Subject heading and keyword total hits
AMED	abstracts and English	exp Self help groups/	95		0	95
ASSIA	Language: English	SU.EXACT.EXPLODE("Selfempowerment") OR SU.EXACT.EXPLODE("Mutual support") OR SU.EXACT.EXPLODE("Selfcare")	1495		0	1495
CINAHL	Abstract Available; English Language	(MH "Support Groups+")	5508		0	5508
MEDLINE	Abstract Available; English Language	Self-Help Groups/	9861		0	9861
ProQuest Social Science Journals	Language: English	SU.EXACT("Support groups")	1354		0	1354
ProQuest Sociology	Language: English	SU.EXACT("Support groups")	780		0	780
PsychINFO	English language and abstracts		0	Self help	8978	8978

Mental Health element

Database	Limiters	Subject heading search terms	Number of hits	Keyword search terms	Number of keyword hits	Subject heading and keyword total hits
AMED	abstracts and English	exp Mental health/	1178		0	1178
ASSIA	Language: English	SU.EXACT("Mental health") OR SU.EXACT.EXPLODE("Mental illness" OR "Neuroticism" OR "Psychoticism") OR SU.EXACT("Psychiatric disorders")	34662		0	34662
CINAHL	Abstract Available; English Language	(MM "Mental Disorders+") OR (MM "Mental Health")	220835		0	220835
MEDLINE	Abstract Available; English Language	exp Mental Health/	315730		0	315730

ProQuest Social Science Journals	Language: English	SU.EXACT("Mental health") OR SU.EXACT("Mental disorders")	35852		0	35852
ProQuest Sociology	Language: English	SU.EXACT("Mental health") OR SU.EXACT("Mental disorders")	20299		0	20299
PsychINFO	English language and abstracts	exp mental disorders/ or exp mental health/	556254		0	556254

Peer Led Element

Database	Limiters	Subject heading search terms	Number of hits	Keyword search terms	Number of keyword hits	Subject heading and keyword total hits
AMED	Abstracts, English		0	Peer support	173	173
ASSIA	English	Peer led support groups	12965		0	12965
CINAHL	Abstract Available; English Language	MH "Peer Group"	7178		0	7178
MEDLINE	Abstract Available; English Language		0	Peer support	5967	5967
ProQuest Social Science Journals	English	Peer led support groups	36418		0	36418
ProQuest Sociology	English	Peer led support groups	26068		0	26068
PsychINFO	English language and abstracts		0	Peer support	3732	3732

Appendix – 3 – Data extraction table

Number	Illness	Mental health specifics	Symptoms / Problems	Study	Theme	Location	Sampling method	Style	Numbers	Methodology
1	Mental health	Not specified		Coatsworth-Puspoky et al., 2006	4	Ontario, Canada	Purposive	Qualitative	10	Ethnonursing
2	Serious Mental Illness	Not defined	Irrational, Isolated, Lacked spirituality, Immature, not activated, Hopeless, Unsettled, Not act ordinary, Hurt others, lacked self-worth, lacked insight, denied help	Corrigan et al., 2002	3	USA	Purposive	Qualitative	22	Emergent grounded theory
3	Mental health	Intellectual disability and / or mental illness	Not feeling good about themselves, lack confidence, lack independence, feeling vulnerable	Lloyd, 2007	5	Australia	Purposive public promotion	Qualitative	100	Participative action research
4	Carers	Family and friends of people with SMI		Lucksted et al., 2008	2	Maryland, USA	Purposive	Qualitative	31	Constructivist grounded theory
5	Dual diagnosis	Mental illness and Dual diagnosis	Stigma, Poverty, Social isolation, feeling judged	Schutt & Rogers, 2009	4	Mid-Western City, USA	Purposive	Qualitative	26	Retrospective self-reporting
6	Voice hearers	Voice hearing		Dos Santos & Beavan, 2015	5	New South Wales, Australia	Purposive	Qualitative	4	Interpretive Phenomenological Analysis
7	Mental health	Various including voice hearing, depression and alcohol & drug dependency	Self harm	Boyce et al., 2018	5	United Kingdom	Purposive	Qualitative	8	Qualitative case study. Thematic analysis.
8	Serious Mental Illness	Psychosis, Major affective disorder, Substance use disorder, Anxiety, Other disorder.		Chinman et al., 2001	4	USA	Purposive	Quantitative	79	Repeated measure experiment
9	Serious Mental Illness	Not specified	Lack of: hope, choice, self-determination, empowerment, community integration,	Eisen et al., 2012	2	USA	Purposive	Quantitative	240	Randomised with 3 groups
10	Dual diagnosis	Schizophrenia, Bipolar disorder, Major depression, schizoaffective, post-traumatic stress disorder and		Laudet et al., 2000	3	New York, USA	Purposive	Quantitative	310	Cross sectional prospective
11	Multiple sclerosis	Depression		Uccelli et al., 2004	2	Italy	Purposive, Snowball	Quantitative	44	Prospective
12	HIV positive	Depression		Simoni et al., 2007	1	Bronx, New York City, USA	Purposive	Quantitative	136	RCT
13	Serious Mental Illness	Psychosis	Poor self-esteem, social networks, social support, self-efficacy	Stant et al., 2011	5	The Netherlands	Purposive	Quantitative	106	RCT
14	Serious Mental Illness	Psychotic disorder, Affective disorder, Anxiety disorder, personality disorder		van Gestel-Timmermans et al., 2012	2	The Netherlands	Snowball	Quantitative	333	RCT
15	Serious Mental Illness	Schizophrenia, schizoaffective disorder, bipolar affective disorder, major depression, anxiety disorder, and personality disorder		Lawn et al., 2007	2	Australia	Convenience	Mixed	35	Non randomised longitudinal experiment plus
16	Serious Mental Illness	Psychotic disorder, Major mood disorder, Alcohol use disorder, Drug use disorder, Other disorder		Rowe et al., 2007	2	North Eastern USA	Purposive public promotion	Mixed	114	Prospective, longitudinal RCT plus

17	Mental health	Postpartum depression		Prevatt et al., 2018	5	Southeastern United States	Purposive	Mixed	197	mixed-methods, community-based participatory research
18	Mental health	Bereavement, Chronic mental health, Depression & Anxiety		Pistrang et al., 2008	SR	Various	Unknown		Various	Systematic review

Themes

1 - Peer based self-help being used by medical professionals

2 - Peer based self-help following a predefined, structured programme of activity

3 - Adapted 12 step programmes

4 - Peer led organisations

5 - Self-help groups being established and led by peers

Appendix - 4 – Recruitment Poster

Research Recruitment

The influence of co-producing, peer led, mental health self-help groups.

Who can take part?

Calling all Adults who live in [place] who experience mental health problems, and who are interested in finding ways of helping to improve their own mental health.

When will it happen?

The research study will run for **X** weeks (or months) between **Date 1** and **Date 2**.

What will it involve?

You are invited to take part in some research as a collaborator.

The idea is to form a peer led self-help group in which you use your knowledge and skills to get the group up and running. Group members will take control and decide what to do. The group members will support one another.

You will have the chance to take part in a weekly group meeting of 2 hours.

You will have the chance to take part in at least one 1 to 1 interview and focus group.

You will have the chance to help in activities and events to share the findings of the research.

What's in it for you?

1 – Development of skills, knowledge, and confidence.

2 – The possibility to regain control of your mental health.

3 – The possibility for you to help others regain control of their mental health.

4 – To learn about and take part in the processes of co-production and action research.

Call to action

If you would like to take part and want to find out more about it contact Melvin Bradley:

Email – m.j.bradley@edu.salford.ac.uk OR Phone – [phone number]

Come to one of the information meetings at [organisation], the dates are:

Date 3; Date 4; Date 5; Date 6

Appendix - 5 – Collaborator Information Sheet

Collaborator Information Sheet

Study Title

An investigation into the influence of co-producing, peer led, mental health self-help groups.

Invitation

I would like to invite you to take part in a research study as a collaborator. Please take time to read the following information carefully. Ask if anything you read is not clear or you would like more information, please come to one of the information sessions. Take time to decide whether or not to take part.

What is the purpose of the study?

For you to use your own knowledge and skills in the process of creating a self-help group. Of interest is 'How the mental health of collaborators has been influenced by being part of the co-produced group'.

Why have I been invited?

Adults who live in [place], who experience mental health problems, and who are interested in finding ways of helping to improve their own mental health are being asked if they want to take part.

Do I have to take part?

No it is up to you to decide if you want to take part and taking part is entirely voluntary.

You will be asked to sign a consent form to show that you understand and agree to take part in the study.

What will happen to me if I take part?

The study will run for **X** weeks (or months) between **Date 1** and **Date 2**. The study will take place at [organisation] and it will be the same place every week.

You will have the chance to come to the group every week. This could mean helping by saying how you have managed a certain situation or it could be that you are able to suggest other ideas about how things should work in the group.

What will I do?

You will be taking part in a self-help group in the usual way. In this case you will also take on the role of a collaborator. This means that you and the other people involved

use your knowledge and skills to create and develop the group which is best for you. Group members will take control and decide what to do. Group members will support one another.

You will have the chance to:

- Take part in a 90 mins – 2 hour weekly group meeting.
- Take part in at least one interview, likely to be about one hour long.
- Take part in at least one focus group, likely to be about one hour long.
- Keep a diary.
- Be recognised as a joint collaborator.
- Take part in collecting and verification of your data.
- Help on activities to share the findings of the study.

You will be provided with the support you need to do these things.

Are there any downsides or risks to taking part?

The study is focussed on the effect of the process of co-production not what happens in the group. The main drawback is not to do with the study but what may come up for you from exploring and discussing delicate issues as part of what happens in the group.

What are the possible paybacks of taking part?

There is no promise that taking part in this study will help you. You might get the following benefits:

1 – Growth of your own skills, knowledge, and confidence.
2 – The chance to regain control of your mental health.
3 – The chance for you to help others regain control of their mental health.
4 – To learn about and take part in the processes of co-production and action research.

What if there is a problem?

In the first instance if you have a concern about any aspect of this study, you should speak to the researcher who will aim to answer your questions and resolve any problems or difficulties who can be contacted on [phone number] or via email m.j.bradley@edu.salford.ac.uk or in person.

If you not happy you may contact my supervisor, Dr Elizabeth Collier at the University of Salford on 0161 295 2729 or via email e.collier@salford.ac.uk.

If you remain unhappy complaints about research should be sent to Anish Kurien (A.Kurien@salford.ac.uk / 0161 295 5276), Research Centres Manager at the University of Salford.

Will the information I share be kept confidential?

Yes, confidentiality is very important and the information you share will be kept confidential. The information used in my doctoral report and in any subsequent

conference presentations and publications in professional journals will be anonymised in order to protect your confidentiality.

What will happen if I don't carry on with the study?

You are free to withdraw at any time, without giving a reason. You will not be excluded from any [organisation] services now or in the future. If you pull out of the study all of the data collected up to that point involving you will still be used and will remain private.

What will happen to the results of the study?

It is planned that the results will be published as part of a doctoral thesis and possibly in academic journals. It is expected that findings will be produced in 2018.

Who is arranging the study?

Melvin Bradley is arranging this study as part of the needs of his professional doctorate.

Further information and contact details:

You can contact Melvin Bradley (the student) by phone [phone number], or by email m.j.bradley@edu.salford.ac.uk.

Appendix – 6 – Collaborator Invitation Letter

Collaborator Invitation Letter

Date

Dear **(insert person's name):**

This is an invitation ask you to collaborate in a study I am leading. The study is part of my professional doctorate degree at the University of Salford.

The title of the study is 'an investigation into the influence of co-producing, peer led, mental health self-help groups'.

Taking part in this study is voluntary and you may decide to pull out of the study at any time without any negative results to you just by letting me know.

Attached is a sheet containing more information about the study.

Information sessions will be held at [organisation] which you are welcome to attend to find out more detail about what is planned. The dates are:

Date 1, Date 2, Date 3, Date 4.

If you have any questions about this study, or would like more information to help you reach a decision about taking part, please contact me on [phone number] or by e-mail at m.j.bradley@edu.salford.ac.uk **.**

I look forward to meeting you and thank you in advance for your help in this study.

Yours sincerely,

Melvin Bradley
Professional Doctorate Student

Appendix – 7 – Research Consent Form – Focus Group

Research Consent Form – Focus Group

Title of Project:	An investigation into the influence of co-producing, peer led, mental health self-help groups.
Name of lead researcher:	Melvin Bradley

I confirm that I have read and understood the information sheet for the above study (version 2.15.1 – dated 10/12/2015) and what my contribution will be.	**Yes**	**No**
I have been given the opportunity to ask questions (face to face, via telephone and e-mail)	**Yes**	**No**
I agree to take part in focus groups and keep what is shared confidential.	**Yes**	**No**
I agree to the focus groups being sound recorded	**Yes**	**No**
I am aware that although I can withdraw from the study, my contribution to the group up to the point of withdrawal will remain part of the data	**Yes**	**No**
I understand that my collaboration is voluntary and that I can withdraw from the research at any time without giving any reason and that my withdrawal will not affect my care.	**Yes**	**No**
I agree to take part in the above study	**Yes**	**No**

Name of participant	
Signature	
Date	
Name of collaborator taking consent	
Signature	

Appendix – 8 – Research Consent Form – Interview

Research Consent Form - Interview

Title of Project:	An investigation into the influence of co-producing, peer led, mental health self-help groups.
Name of lead researcher:	Melvin Bradley

I confirm that I have read and understood the information sheet for the above study (version 2.15.1 – dated 10/12/2015) and what my contribution will be.	**Yes**	**No**
I have been given the opportunity to ask questions (face to face, via telephone and e-mail)	**Yes**	**No**
I agree to take part in interviews.	**Yes**	**No**
I agree to interviews being sound recorded	**Yes**	**No**
I am aware that although I can withdraw from the study, my contribution up to the point of withdrawal will remain part of the data	**Yes**	**No**
I understand that my collaboration is voluntary and that I can withdraw from the research at any time without giving any reason and that my withdrawal will not affect my care.	**Yes**	**No**
I agree to take part in the above study	**Yes**	**No**

Name of participant	
Signature	
Date	
Name of collaborator taking consent	
Signature	

Appendix - 9 – University of Salford ethics approval

University of Salford MANCHESTER

Research, Innovation and Academic Engagement Ethical Approval Panel

Research Centres Support Team
G0.3 Joule House
University of Salford
M5 4WT

T +44(0)161 295 2280

www.salford.ac.uk/

27 January 2016

Dear Melvin,

RE: ETHICS APPLICATION HSCR 15-121 – An investigation into the influence of co-producing, peer led, mental health self-help groups.

Based on the information you provided, I am pleased to inform you that application HSCR15-121 has been approved.

If there are any changes to the project and/ or its methodology, please inform the Panel as soon as possible by contacting Health-ResearchEthics@salford.ac.uk

Yours sincerely,

Sue McAndrew
Chair of the Research Ethics Panel

Appendix - 10 – Host organisation approval

[redacted]

To whom it may concern

This letter provides consent from the governing body of [redacted] for Melvin Bradley to conduct a research project concerning self-help groups using our premises, resources, and the people who use our services, if they offer themselves. Such permission is subject to the agreement of the University of Salford ethics committee.

Yours faithfully

Peter Pendlebury

Peter Pendlebury
Director

Appendix - 11 – Interview starter questions

Sample prompts which will be conversation starters for the unstructured interviews.

Has this process had any influence on your mental health?

What has been your experience of the group process up to now?

Have you found anything difficult or a challenge?

Have you found anything easy?

What do you think you are getting from the process?

What do you think the other members have got from the process?

What has happened which you didn't expect?

Are you surprised about anything that has happened?

What have you like most?

What have you liked least?

Why did you decide to get involved in the project?

How have you managed in the group?

How have you been involved in the group?

How has the group been going?

Which parts of the process have you enjoyed?

Which roles have you taken in the group?

When did it all start to seem to make sense?

Have you tried to encourage anyone in the group?

Are there any benefits to the co-production process?

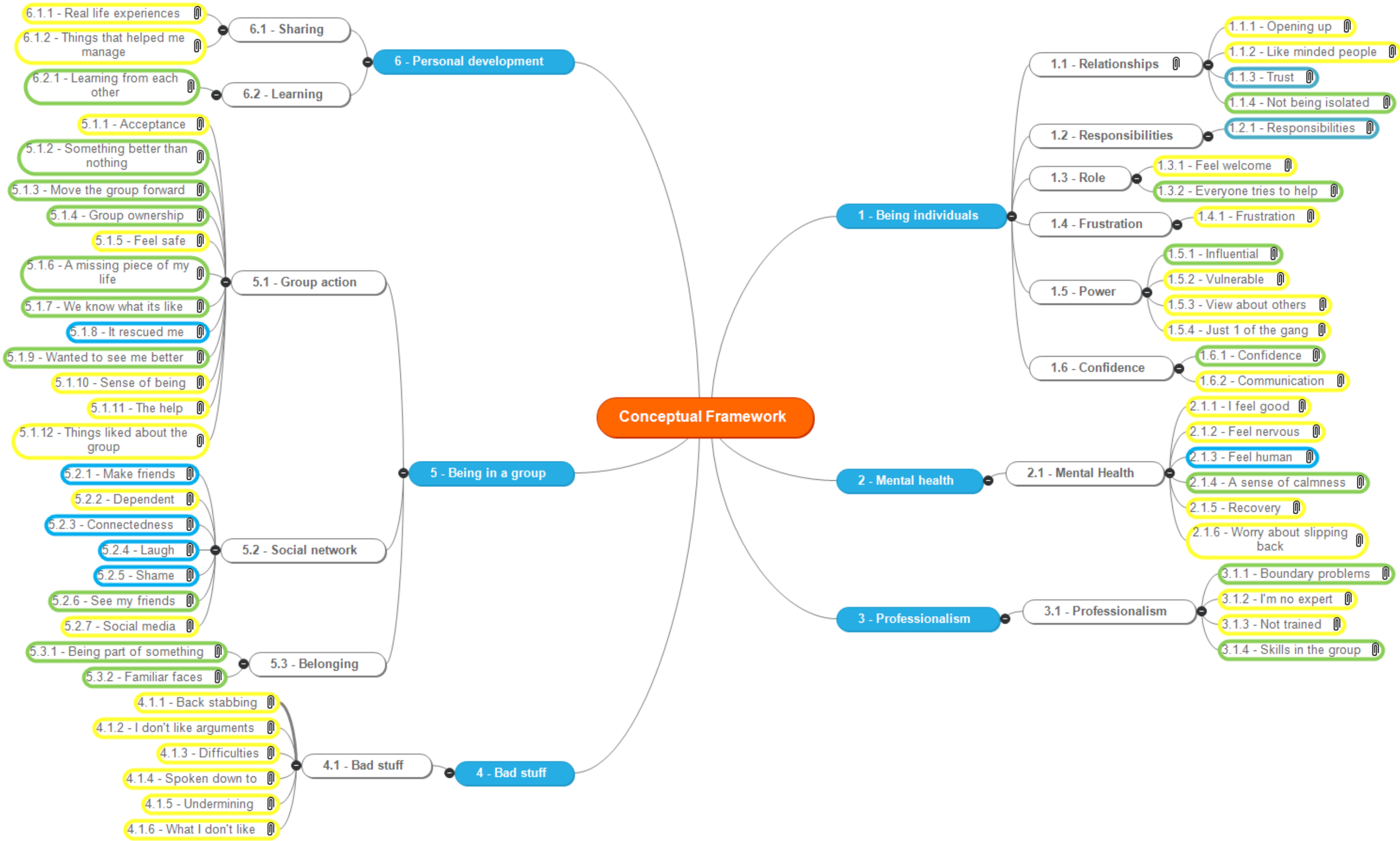
Appendix - 12 – Code book

Code Number	Code Title	Subjective – The collaborator actually said it	Observed – What the interviewer interpreted it to mean
1	**Back stabbing**	Description of abuse either in the group or by group members. The action needs to be deliberate. It could be something like being ignored, spoken to sharply or down to, excluded, or backstabbing. NOT - When collaborators mentioned that they have been abused or experienced abuse outside of the group.	
2	**Acceptance**	Overtly says that they were or felt accepted by the group,	Were welcomed in to the group formally or informally, being pointed in the right direction and shown what to do by other group members. Reporting feelings or experience of encouragement. Group members sharing their experiences freely with others. Group members being genuinely interested in you. Group members being happy to see others, smiling, showing other signs of welcome and acceptance. Not feeling isolated.
3	**Being part of something**	Saying that they felt part of something.	Made to feel part of the group. Feeling accepted. Feeling that there is meaning in it. Having a connection with it
4	**Familiar faces**	Saying that they felt they belong.	Describing a connection between themselves and others in the group. Shared experiences, activities, feelings, etc.
5	**Something better than nothing**	Saying that they have a benefit and what it is.	Description of something that they get an advantage because of group membership or attendance.
6	**Boundary problems**	Specific mention of boundaries or professional boundaries	Description of breaking boundaries such as over stepping the mark, feeling uncomfortable because of an activity, comments about professionals, social rule breaking.
7	**Communication**	Talking about communication.	Description of communication methods
8	**Confidence**	Specific mention of confidence improving, getting better, being more, etc.	Descriptions that indicate changes in the colaborator's confidence.
9	**I don't like arguments**	Talking about conflict within the group between group members.	Descriptions of conflict situations.
10	**Influential**	Specific mention of feeling in control or control over something improving	Description of situations where collaborator has taken or been in control
11	**Difficulties**	Description of thing which collaborators are finding or have found difficult in the group	Situations or activities that have been found difficult.
12	**Move the group forward**	Specific mention of something which made it possible.	Descriptions which talk about situations or activities which have been or are enabling within the co-production process.
13	**Group ownership**	Specific mention of taking part or engaging in the process of co-production.	Descriptions which show taking part or engaging in the process of co-production.
14	**Spoken down to**	Specific mention of fear.	Descriptions of events and activities where fear is being felt.
15	**I feel good**	Specifically discuss feeling better.	Descriptions of situations and events where collaborators feel better.
16	**Feel nervous**	Specific mention of feeling nervous or having nerves.	Descriptions of situations and events where collaborators displayed nervous feelings
17	**Feel human**	Specific mention of feeling normal.	Descriptions of situations, activities and events which seem normal.
18	**Feel safe**	Specific mention of safe or safety.	Descriptions of situations, activities and events which seem or feel safe.
19	**Feel welcome**	Specific mention of feeling welcomed or of being welcomed.	Descriptions of situations, activities and events where collaborators has been welcomed or felt welcomed.
20	**Make friends**	Specific mention of friends in the group, making friends, developing friendships	
21	**Frustration**	Specific mention of frustration in the group	
22	**A missing piece of my life**	Specific mention of something which the group does	Something that happened because of the group process
23	**Dependent**	Specific mention of dependence on the group	Descriptions of feeling dependent on the group

24	**A sense of calmness**	Specific mention of improving mental health or saying that anxiety, depression, etc has improved during the group	Descriptions of improvement in mental health like being on the road to recovery.
25	**We know what its like**	Specific mention of the effect of the group	Descriptions of events, actions, activities that happen because of the group
26	**Connectedness**	Specific mention of feeling isolated, lonely, not knowing anyone and not being included or not including others in the group or because of the group	Description of feelings of being the only one or on your own, loneliness, situations where collaborator does not know anyone and where it seems that people are being excluded in relation to the group
27	**It rescued me**	Specific mention of being rescued by the group	
28	**Laugh**	Specific mention of laughing in the group	Description of situations where laughter happens because of the group
29	**Learning from each other**	Specific mention of events, actions, activities that have promoted learning in the group	Descriptions of things that have been learned in the group
30	**Real life experience**	Specific mention of sharing life experiences in the group	Description of how life experiences have brought something positive or negative to the group
31	**Not being isolated**	Specific mention of not being on their own in the group	Descriptions of situations where people are not on their own in the group
32	**I'm no expert**	Specific mention of there not being professionals in the group or the group not being professional	Descriptions of situations in the group where it is like or not like having a professional, behaving professionally in the group
33	**Not trained**	Specific mention of not being trained to do something in the group	Description of situations in the group where people are not trained to do the action
34	**wanted to see me better**	Specific mention of the group being a nurturing environment	Description of situations in the group when it has felt nurturing
35	**Opening up**	Specific mention of opening up in the group	Description of situations in the group where people have felt able to open up
36	**Just 1 of the gang**	Specific mention of power being used or displayed in the group	Descriptions of situations where power has been used or displayed in the group
37	**Like minded people**	Specific mention of the group providing reassurance	Description of situations where reassurance has been used or felt within the group
38	**Recovery**	Specific mention of recovery in relation to the group	Description of situations of recovery in relation to the group
39	**Relationships**	Specific mention of relationships in the group	Description of situations in the group where relationships come into play
40	**Responsibility**	Specific mention of taking or feeling responsible in the group	Descriptions of situations, activities, events where people feel responsible in the group
41	**Everyone tries to help**	Specific mention of roles being taken or given in the group	Description of roles that people took in the group
42	**Sense of being**	Specific mention of feeling satisfied in the group	Description of events, actions, activities where satisfaction in the group was felt.
43	**Shame**	Specific mention of shame in the group	Description of shameful events, actions, activities which happened in the group
44	**Things that helped me manage**	Specific mention of sharing in the group	Description of events, actions, activities where there has been sharing in the group
45	**Skills in the group**	Specific mention of skills being developed in the group	Description of skills which have been useful, have developed or grown or been used in the group
46	**Social media**	Specific mention of social media being used in the group	Descriptions of using social media in the group
47	**See my friends**	Specific mention of socialising with the group	Descriptions on socialising with group members
48	**The help**	Specific mention of the group supporting or group support	Description of events, actions, activities which are supportive
49	**Things liked about the group**	Specific mention of things that people like about the group	Description of events, actions, activities that indicate things people like about the group
50	**Trust**	Specific mention of trust in the group or between members	Descriptions of situations where trust seemed to be important
51	**Undermining**	Specific mention of the group being unsocial	Descriptions of situations that have seemed unsocial
52	**View about others**	Comments specifically about what collaborators think about other people in the group	
53	**Vulnerable**	Specific mention of vulnerability of people in the group	Descriptions of situations where collaborators felt vulnerable
54	**What I don't like**	Specific mention of what collaborators do not like in the group	Descriptions of things that collaborators do not like in the group

55	**Worry about slipping back**	Specific mention of collaborators worsening mental health in the group	Descriptions of mental health deterioration in the group

Appendix - 13 – Conceptual framework



The colours of the nodes indicate collaborator contributions – Green, all collaborators, Yellow, some collaborators, Pale blue – one collaborator.

Appendix - 14 - Extract of transcript of interview with Tom

Collaborator in **bold.** *Interviewer in italics.*
So anyway. Sample prompts…so I need to say also this is an unstructured interview, that means that there's no kind of, I'm not going to ask you any particular questions and if things as we're talking come up, it's quite okay for you to just butt in or whatever you like. So it's not going to be how many times have you been, I can look that up and apart from that it doesn't tell me what I want to know. So has the process of being involved in the group had any influence on your mental health?
Massively yeah, yeah. Before I came here, why I came here was because I tried to kill myself 12 months ago, it's 12 months since I started anything. I was depressed, I was lonely, I'd been burgled, I locked myself away in my home, I ended up with pneumonia, septicaemia, I didn't wash or clean for nearly 2 years…
Really?
I was in a totally depressed mood.
Okay.
And I isolated myself from everybody, family, friends, I was rude to them, nasty to them. I didn't particularly want anybody in my home helping me. And after the last suicide attempt, I took a load of paracetamol I didn't die, I expected to, I came round the next day with a thumping headache which was ironic really cos I took paracetamol…
It is a bit ironic…
Fortunately I had an appointment with my diabetic doctor that day…
Right…
And she noticed that I was pale and a bit, not quite right. She asked for the reasons so I told her. So she phoned an ambulance immediately to take me to hospital, did all the test on me and it came back I was okay. But then they got me a psychologist and a social worker to help with my house.
Right…
The social worker recommended that I came here. He was called, was it [social worker]?
Could have been [social worker]…yeah, yeah, [social worker].
I came in here and had an interview so he put me on the team here. Then I saw somebody called [person], no, no [person] at [organisation] so I go there once a day, once a week sorry on a Wednesday, Creative Writing. And I come here yeah.

Oh right.
[group facilitator 1], [group facilitator 2] and I used to come with the other [group facilitator 3] who's had a heart attack.
Yeah.
And I've been helping facilitation…
He'll be back soon won't he?
I'm glad yeah cos he's a lovely chap. I've been helping facilitate that group when there's been nobody been there, they've volunteered me to take over.
Really?
Yeah so that was most of the facilitating yeah. They just, they sent lovely comments on email that they enjoy coming cos I'm there. So it's calmed me down cos it's a million per cent, it's a million percent, it's one hundred per cent plus.
Right.
Stopped me killing myself, stopped me wanting to kill myself.
Just by being involved in that group process?
In that group yeah. Like Saturday, Sunday, Monday are like the old days, nightmarish days cos I've got nowhere to go and it's reflected in some of the other people in the group we all, the new guys, [group member] and [group member] and that we all reflect on the fact that coming here is keeping us sane for a better word.
Yeah.
Just…you lose, when I'm on my own, like when I'm on my own Friday, Saturday, Sunday and Monday I get that depression again. I'm bipolar.
Right.
So I get the highs and the lows and on the lows I just want to, I was just saying in the group this morning since coming here, 12 months ago before I ever came here I'd probably try and kill myself again, whether it's a cry for help or whatever I don't know I don't know what it is, but now Friday…Saturday, Sunday, Monday I want to kill myself but I don't want to kill myself, it's in a Robin Williams speech, I don't want to die. So I think looking forward to coming here, to the groups is the motivation not to harm myself. So it's a tremendous, tremendous help even though now, after 12 months I'm getting frustrated in some of the groups cos there's people that…at first I didn't let anybody know cos I thought well we're all poorly and then after a bit you get a bit complacent with everything and things start to annoy you. But I'm learning, I walked out of one of the groups a few

weeks ago cos I thought someone was having a personal attack on me. They were, they apologised. They shouldn't have done cos it's in the rules isn't it, so they apologised and we've made up, I've gone back. But I felt silly for walking out, like a petulant child I'm not staying here. And I've also done the facilitating course here with [trainer] and I got a certificate for that which I'm well proud of.
Oh good.
So 99% of the time now my mind's a lot clearer, a lot less destructive against myself. I still have issues otherwise I wouldn't still be coming. If I had no more issues I wouldn't come anymore. But going back to your question yeah it's helped me tremendously and being able to express my thoughts, instead of sitting in my own home dwelling and dwelling and dwelling I should have said this, I should have done that, get out to a group and once you've had your little speech I've noticed a lot of us as well, we all just calm down. Over the last six months most of the groups now are six or seven of us, there was ten of us the other week, we go in the market where I've just been now…
Yeah…
And sit at a big table and have a coffee and a cake and carry on chatting for another hour, all through the break and all Thursday afternoon, we were just chatting by there. Which is another good thing, I think we meet outside of here which is good in itself being here is the only place we can come. But then to be…
So that kind of group process has enabled you to go out and socialise that you weren't doing previously?
No. No I wasn't no. And at first it was just me going in and then [group member] joined me and then [group member] joined and then [group member] joined and then [group member] and [group member] and then there was 12 of us in the market all morning having a cake and a coffee. So yeah and that, we've got a social website between us all now, called Friends with Depression.
Okay.
There's about ten of us on so we chit chat all the time on there. I haven't got a wife so most of them do it middle of the night they'll say 'is anybody there can I have a chat' you know what I mean…
Really?
Yeah [group member] a bit stressed out now so at the weekend we were all talking to her and telling her to calm down and I offered to visit her. I've got a bus pass, I said look you won't be putting me out, I'll come and see you.
You had nothing much else to do.
She said I can't have you in my house it's not tidy. I said well we'll meet in a café or meet and socialise. So it's all developed on the internet it's all developed from being here. I think another, for want of another better word it's a life step.

Okay. So moving on a bit from that, what do you think you've liked most?
Comradeship. Camaraderie.
Yeah. Comradeship yeah.
It's a tough word isn't it? Yeah meeting of like minds. You go to university you meet clever people, you come here you meet people who have poorly minds.
Yeah.

Appendix - 15 - Extract of transcript of interview with Camila

Collaborator in **bold.** *Interviewer in italics.*
So this is particularly about the group and your involvement in it. So what I'm interested to know, and this is kind of…so I've got a list here of sample prompts and the first one is has the process of the group had any influence on your mental health?
Yeah, it actually has. Yeah, because…you want me to give an example? Well, I think it's meeting with groups and understanding problems other people have gone through as well, you can actually relate. Where if you could talk to a member of family, not immediate family but other members of family, they'd say, 'I don't know what you're talking about?' They've never experienced it but the people in the group have experienced it.
Okay.
So, yeah, in that way, I do feel as though the group has done me some good.
And how do you think it's influenced you? What…
I think because it's a group as well, I think it's another confidence build…
Right.
…because you're mixing with people. Again, you know, it's like through all my experiences, I've been like bullied and things like that, it's building a confidence up again with people…
Okay.
…because your self-esteem gets so knocked back, you know, so it's building a confidence thing up. I mean it has given me a lot of confidence, the group, you know. And I hope I've passed on some of this confidence to other people. That's the way I feel about the group. That's what I feel.
Okay.
I don't know whether that is what you wanted me to ask?
That's fine. There are no right or wrong answers to this.
Right. Okay.
It's simply about your experience of it, how it affects you. So just talking there about confidence in the group…
Yeah.
…how are you actually involved in the group, would you say?

Well, I've actually read a lot of books…
Okay.
…on anxiety and I like to be able…in the groups, as we go around, I like to be able to pass what I learn onto somebody in the group like, as an example, everybody can have anxiety in the world, everybody.
Yeah.
And it's the triggers. But when you first go through anxiety you do not know what the triggers…you know the symptoms but you don't know what's happening to your body. It's all fuzzy, muddly-duddly and you don't understand what's happening to your body. But I've done a lot of reading, books, mindful books and things like this and the mindful books have been so helpful as well. Now, I've actually passed that onto the group and said, 'You must get this book.' It's been…in fact, I'll be honest, [interviewer], I've had this book for two years, I take it on holiday, it comes on holiday with me, I think I'll have a good read and then I think, 'Oh I'll just read one of my doom and gloom books and I just realised in the back of this mindful book there's a CD in the back of it and I carried around for two years and it's all broken and chipped and everything. I didn't know it was there. So I'm not able to use the CD but I'm reading this book and I'm finding it so good. And I keep saying to everybody, 'You must get this book,' because that and the group and talking amongst people is a therapy and it's given me the confidence, it's given me personally confidence.
So what role have you taken in the group, do you think?
I'd like to do something much further, I think, in the group which I've actually put in for the facilitator. Unfortunately I couldn't make it on last Thursday because we had family from Normandy. I explained that to [self-help groups manager] and she said, 'Don't worry, I'll put you down on another one,' which I really would like to have gone on, you know?
Yeah.
So really in a way that group has built that confidence up in me because a lot of people, I shouldn't say this, a lot of people do, I can't say rely on me because I'm not anything, I'm just me, I'm just one of the group, you know. I do keep in touch with some of them to see how they are and things like this, especially if they've left the group and they've been a bit low.
Yeah.
So I've kept in touch with people that way, you know? People have been in touch with me and said, 'Oh [collaborator], I need help with this,' no names mentioned, I wouldn't do that, but, you know, I've tried to help them. And the other thing that I can pass on is really life experiences, you know, that's the only thing I can pass on to other people. I've had lots of different life experiences…

Yeah.
…you know, I've experienced when my daughter was 16 she left home with the wrong type of person, which a lot of people can relate to that as well in a group. I've had all sorts really. Like I've suffered major anxiety and things I didn't know what was happening to me.
Yeah.
Where I know the first signs now, I know when I'm going to be off…
Yeah.
…if you like. And I won't call…I will not say that I've got an illness, I won't put a label on it and what I actually say is, 'I'm having a blip.'
Right.
I won't put a name on it at all.
Right. Okay.
You know? And I just try and focus on the good things. I've had experience with, can I say, assault.
Right.
When I say assault, I mean sexual things. I'm going through a major thing; something happened to my grandson only a few months ago, I'm trying to help him recover from that and he's been guarded and guarded and guarded. My daughter never let him out of her sight, something's horrible's happened to him. So I'm trying to be a positive one for him. I'm trying to be…the help I've been given, should I say, for anxiety, I'm trying to build that inform and try and put that in him.
Yeah.
And I'm trying to say…I say things to him like, giving kisses and cuddles and that, I tell him nothing was his fault, nothing, because nobody did that to me, nobody did that to me.
Right.
So I feel as though I've had therapy from here, because [counsellor] was a counsellor that I had, he was very, very good. Very good. So I try and…I try and put myself in his chair and I'm no expert, I'm no expert, all I can show them is things that have happened to me in my life, how I dealt with things. And I'm saying to him, 'You're innocent, you have done nothing wrong, you've done nothing.'

So what I think I'm hearing you say is that you're able to share with the group your experiences…
Yeah.
…which are quite broad.
Only if they want me to.
Yeah.
Only if they want me to because some people in that group, some people in that group have had family that have hung themselves and things like that, some people could be sexually assaulted, it could be rape, it could be physical abuse by a partner, it could be anything. I've not been through that thankfully but there's been a lot of things that I've gone through in my life. I mean I'm nearly [age] so I've been through quite a lot of things in my life. I've come out the other end.
Yeah. So do you have a formal sort of role in the group, do you see or not?
I'm just one of the group, really. But people do come to me and people have come to me in the past and said, 'Can I talk to you?'
Right.
Which…when [self-help team leader] was here, we used to…he said, 'If anybody wants to talk, you know, you can go…
Yeah.
…and just speak to that person.' I mean there was one particular person here, which I won't mention his name on tape, but he was having problems and he only wanted to talk to me and I took him in a side room…
Yeah.
…and I said, 'Before I leave here today, I will try and get you the help that I can get you.' And I went into the office and I asked, and I think you'll know who that person is, but he did get the help eventually. He did get the help. I like to follow things through. Like I said, I'm a bit that way. I like to follow things through.
So I don't really want to put words in your mouth…
No, no, by all means say it how you say it.
So I'm just…when you do that kind of activity, and I guess it's not a formal role, is it, to do.
No, no.

But when you do that kind of activity how do you feel about it?
Well, it makes me feel good because I feel as though I've helped somebody because I didn't really get the help outside. And I think it…if you can talk about your problems openly and openly to somebody else, because I'm only one of the group, I'm nobody professional, I'm nobody, nothing, just like I say, life experiences, that's all I am, you know, and I can just say, 'This is what I did.' I think there's somebody in the group that's got a daughter that's a bit distant and one thing and another and I had all that and I just said, 'Give her time, she will come back, just give her time but you can't condemn her,' you know, but that person at this moment can't understand that. She wants to drill in and drill in and you can't do it. You can't do it. So a lot is life experiences.
Okay. So in terms of the group process, in terms of how it works, how does that work for you? Is it easy to deal with? Is it difficult to deal with?

Appendix - 16 - Extract of transcript of interview with David

Collaborator in **bold.** *Interviewer in italics.*
Yes. There has been a lot of understanding, sharing of other people's problems, where they have been where I have been. A lot of understanding and a lot of guidance in to ways to move forward, things to try. A lot of encouragement. A lot of caring. And a lot of ideas of how to get past things, how to get past problems and to deal with things. So a lot of constructive criticism, but at the same time a lot of positive help, you get pointed in the right direction, you get shown what to do, like mindfulness, we got told how to do that when we was in a state of panic. Some people swap numbers with us, so if we needed someone to help, outside of [organisation] or late at night, stuff like that, we could phone or text and say look, I am feeling down, I am feeling suicidal, can you help me and, you know, it was good.
So there is, kind of…
Like a support network.
Like a support network, actually within the group and outside of it as well.
Yes.
And would you say that you had a role within that? What would you say that the kind of the role was that you…?
I was mainly the top chief at the time. I am not any more. But at that time, I am the one who kind of brought it all together. [Group member] came up with the idea and I basically got everybody involved and basically kept on chasing people up outside of the groups, checking everybody was alright, feeling okay and getting people to open up and interact with other people. So that worked well.
And how did you go about doing that?
I just shared the idea of – it was mainly at cigarette and brew time, because I didn't want to, like, promote it, like, in [organisation] because it wasn't everybody's cup of tea, WhatsApp and social network, people are a bit funny about it. So we were having a cigarette and I would say me and [Group member] have come up with this idea, [Group member] has come up with it, I have come up with a name. And we have got someone we can talk to when we are not at [organisation]. You know, we might be at a loose end, might just want to have a general chat, might feel desperate, might feel suicidal and you can just pick up the phone and someone is going to be there to, you know, help you if they can, if not point you in the right direction. And one by one people joined, I think about eight people joined in total, you know, so that was – it was very positive in the beginning, I don't think it is now, but at the beginning it was, yes.

So that is outside of the group?
Yes.
So you have got, kind of, a group within a group, in a funny sort of way.
Yes.
So within the actual formal group, not the WhatsApp group, within the formal group, did you have a role within that would you say?
No. At first I was quite opinionated, but then I learned to shut my mouth a bit and kind of let people, other people bring and contribute, because I seemed to have an opinion on nearly everything, because I have got a vast – I used to work as a church leader, a trainee church leader. I used to help the homeless in London and Manchester, years ago. So I dealt with a lot of people, so in a way it was like doing [facilitator] job and I kind of had to shut myself up and just let people bring it and then if no one brought something, then I would bring some advice or direction. And I would use the opportunity of having a cigarette or a coffee break to then give my opinion to that person, as an extra support, an extra direction.
So it wasn't so much you didn't have a formal role – it wasn't so much that you didn't have a role, sorry, it was just kind of a bit, I don't know quite what the word is – it is kind of more informal and a bit not so overt, because I can imagine there might have been a bit of conflict, in fact judging by the look on your face, when you were saying that, that I can imagine that there was, perhaps, what are you doing saying that, it is not your place type of thing going on.
It was. Yes. I think a few times I could see I was cutting [facilitator] up and a few times he actually said well, if you are not frigging happy with the way I am running the group then you run it, and stormed out. And then came back in and apologised, yes. And that was because he wasn't paying attention to people. And it was a split group, that particular day and it was the day the women spoke to you, weren't here on a Friday, we are going back two months…
A couple of months ago. Yes.
And they asked to speak to him and someone was speaking, who doesn't normally speak, and he just got up and left and I went [facilitator], you can't do that. I went [group member] is speaking, I said, you know, it is rude. I went, at least wait until it is finished. I said and then excuse yourself. If you are not fucking happy with the group, you fucking do it. And then he came back in and apologised. I didn't want to take the apology, but I knew it was the right thing to do. I wanted to tell him what I thought of him, but I thought I had to be the bigger person, you know. I don't like conflict and I don't, you know – if someone wrongs me, it normally doesn't agree with me. I normally react there and then. So that was a big thing to me that day. I will just go and get a drink of water.
Okay. So let me just have a quick recap, I think, of where I think – so we started off by thinking about the influence that the group has had on your mental health, which

you described. And then we talked a little bit about your position in the group, in terms of the WhatsApp thing but then we began to think about the, kind of, the more informal assisting within the group and that is something I am quite interested in, in this. Not the informalness of it, particularly, but the fact of it. So what I am interested in, I suppose, is what was your experience of, kind of, doing that informal support for other group members?
How did I feel?
Yes.
It made me, kind of, feel a bit stronger and a bit more content with my own life, knowing that I was inputting help into others, from my experience or my experience of seeing someone else in that situation and being able to bring reassurance to that person, or guidance. So I felt like I was unofficially like a counsellor or something on that role. Like it made me feel like great self aware, so when I went home and I actually knew that person was going to be a bit safer or I knew that person was thinking more positive or that person was going to make a difference to their own life or to whatever situation it was involving others or themselves. I knew in a way that when I saw them next time, they would be a bit more, less burdened or happier or content within their life, so that made me feel like I had achieved something, but not like in a big way like big-headedness, just feel happy for helping others.
Yes. So it was kind of almost in a sense, if you like, an unrecognised thing, but you know that you have done it and they know that you have done it…
Yes. But the teacher doesn't care anything. Yes.
Okay. So one of the things you also said was that there was kind of a bit of conflict, perhaps a bit underground but maybe sometimes overt as well. And I am a bit interested in that and how – did you find that difficult? Is that difficult for you to do, or is it a challenge or…?
It depends on my mood that day. If my mood is low, then I am more likely to react in the wrong way, either verbally shoot that person down, make a show of myself, storm out, something like that. I tend to storm out instead of hitting people, which I think is better, you know. I used to hit people when I was younger, so I try not to do that now. And if I am in a positive mood, I seem to be able to challenge that person in the correct manner with maybe not the right words, but it comes together in the end. So I might not be able to use the big words and the technical terms and stuff like that, but I seem to get my point across and seem to challenge anything really. And I feel really in control and that nothing could – basically I will win hands down, no matter what. Because when I am in that frame of mind, I know how to do it. But if I am nervous or I am in a low mood, then it will just higgledy-piggledy, if

Appendix - 17 – Extract from Framework analysis

	K : What I don't like	S : Isolation	AV : A sense of calmness	BV : Boundary problems	CD : Relationships
Claire	I have gone and I have needed to say something and we haven't done that. And I haven't had chance to say it. And then I have gone away. And you kind of bottle it up and save it for next time. Yeah. And I'm stuck then and that because I don't have anywhere else to say it. So, that's what I don't like.	And it's like you're not on your own anymore. It's like you're just not isolated anymore because you're sat in that group with these people Because you're sat at home and you know that you're not the only one. Normally I would have just been sat at home doing nothing. And not being isolated.	didn't know anybody and I was feeling nervous I was nervous the more I sat there and listened the nerves just go So the fact that I could do that, you know, made me feel better.	It is hard to try and support somebody and know where your boundaries are really. Because you're supporting them, but you're their friend at the same time. did I overstep the mark by going to his house to try and help or not. Was that too far? You know what I mean	
Camila	There was a difficulty in the group. Everybody can have their say and say what they think but I'm not offensive with it. So I felt as though she'd put me through all this stress. I said, 'Oh I'm going home.' I said, 'I don't need this added anxiety.' I'm not here to hate people, I'm here to…if I can help somebody in the group if they're suffering the anxiety that I'm suffering and I can give them my experiences.		the process of the group had any influence on your mental health? Yeah, it actually has. So, yeah, in that way, I do feel as though the group has done me some good. No, the group itself, that helps me with the anxiety because you actually listen to other people and you think, 'well, I've had that, I've had that.' ' instead of saying you can't go you can go. You can do it. You can do anything if you battle it. You can do anything.' I go for me because I feel as though I'm getting something out of it.' I really do. So I get support from that group as well.		

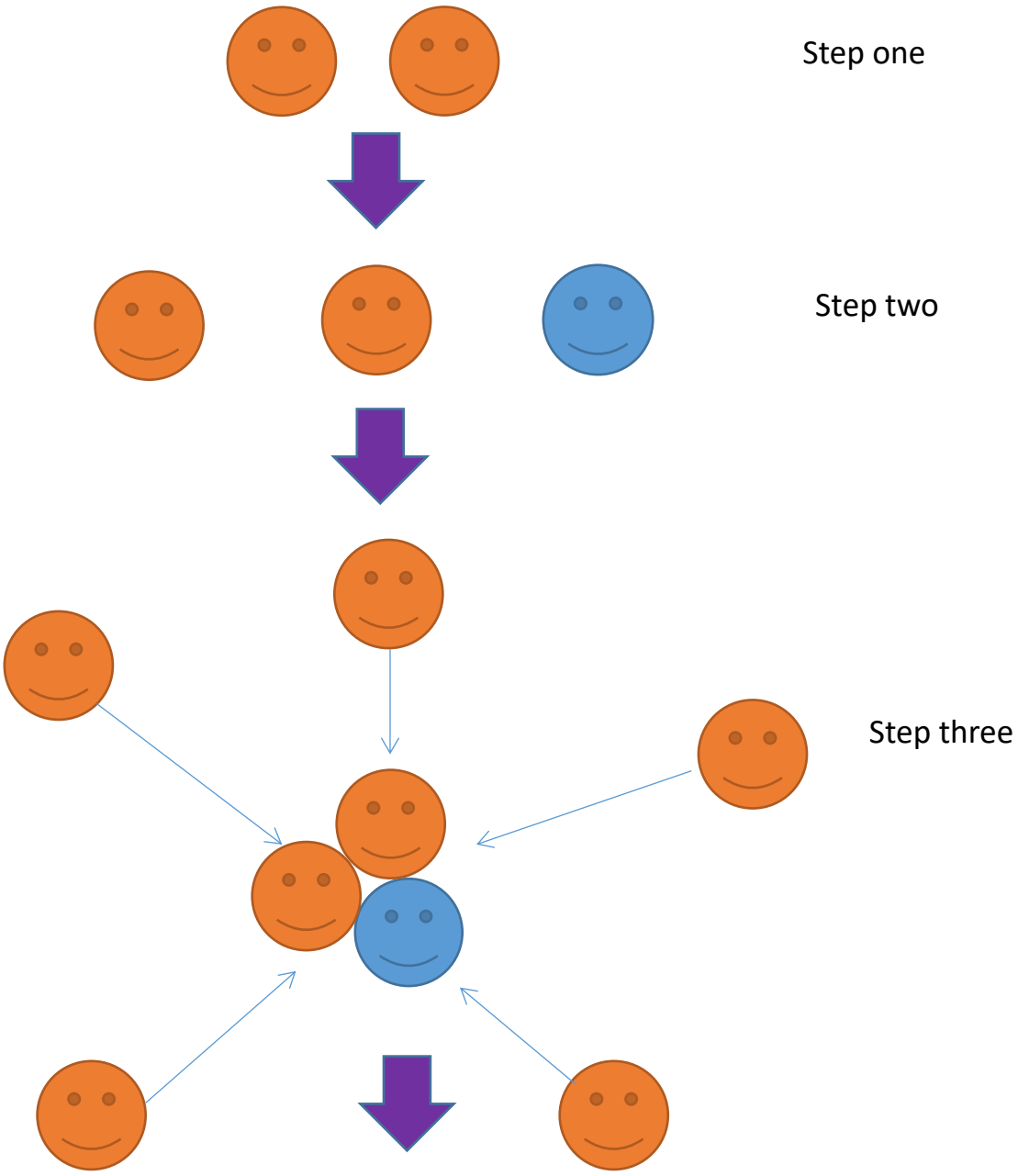
David			Yes, that has had a great influence on me. I would say sharing of experiences, of life experiences and what got me, more than anything, and I think what helped me on the road to recovery, was listening to other people. It could be just tidying up or going for a walk or making a friend or making a phone call or visiting someone**.**	At first I was quite opinionated, but then I learned to shut my mouth a bit and kind of let people, other people bring and contribute, because I seemed to have an opinion on nearly everything, Yes. I thought it would be more, I thought they would be more official and more professional. People would get distressed or anxious or angry or mad or scared and I would either have a secret conversation by text message…	…it used to hurt me, because when you grow friends with people and you create relationships, to a certain degree. In a way it is like on the ground encouragement to help that person feel comfortable by making them feel wanted and, I don't know, show a bit of compassion. And it was a real friendship, but only for that day, you know, that particular day of the week, you know.
Dawn	Yeah and you think that's not how anybody wants to portray themselves, even if that's the truth and your whole truth at that time; that's not all you want to show people and I just found it really uncomfortable. Yeah, but it wasn't helpful that, in any way, for me. I remember one of the first comments in one of the groups, was: 'Once you've got depression, you've always got depression, it'll never go away; you'll never get better' and I was like: Oh my god and I think I went home at that point. I was like: I don't need to hear that. Yeah, it just didn't…		… there's an impact in that you're happy you've done it. You think: I've done it; I've done something positive but generally, we used to have fun … the group's definitely helped me move along and knowing it's there, even if you don't always go, no it definitely helps. I think even just knowing how other people are getting along. It's just that link isn't it of feeling like you're not alone because	There's been a few instances where things have been in appropriate So, I'm just very careful now and nobody gets my number ever. So yeah, I just don't and you end up feeling like you're being really unsocial and I know people can feel like you're being funny but I've had some weird texts, in the past, so yeah, I don't now. Yeah people who have huge boundary issues.	No. It's all very…it's quite childlike; it's like being at school in a classroom. It's like the emotions are…it's very much a lot of people are in that state of being quite…well who's favourite and who's…you know, and you're friends with Teacher and you're this and…Yeah, I mean, at one point, everyone was sure [facilitator] and I were an item which, I just went: Yeah, whatever and [facilitator] was like: let them think what they want to think, you know.
Robert			It's greatly improved it yeah. Greatly, yeah. It's made me more patient with people. And being more thoughtful with people which is a good thing. Well I used to regularly get really anxious and get panic attacks and so on. And for the first six, eight, ten weeks I used to sit there having a panic attack. But now I don't. stuff that minimises, helps me manage it like NLP, visualisation, meditation, mindfulness and so on. … to have a reduction in symptoms or…	I think the good things are that people probably see me as a friend I think because they're friends as well it also helps me to realise that I've got to treat different people differently which is a good thing but it can be difficult in a group because they could say well why did you turn a blind eye to such and such and what he's saying that and you told such a body about that you know. But I think it tells me, in my personal life I need more than [organisation]. Suddenly oh you've only got two sessions left and then you're	So this is something actually that I've not thought about before which is about the relationships that you're sort of describing. What I think you're saying is I think that the group have come together as a group and throughout this period of time you've developed friendships with them.

				chucked out in the snow aren't you. And that's it.	
Tom	I don't like all that backstabbing and tittle tattle. When you come here you're told categorically that certain things are not to be said and not to be discussed. So that's the only thing I don't like about it. … he said 'right these talks been going on too long and he pointed at me and said no crap about your mortgage anymore cos you're yacking on about it'. In that tone, not in a nice tone so I said 'hang on', he said 'no I've had enough of it' and everybody was laughing in the room this morning.		Stopped me killing myself, stopped me wanting to kill myself. … I think looking forward to coming here, to the groups is the motivation not to harm myself. So it's a tremendous, tremendous help. 99% of the time now my mind's a lot clearer, a lot less destructive against myself. … being able to express my thoughts, instead of sitting in my own home dwelling and dwelling and dwelling… yeah I've got my sense of wellbeing back. A sense of who I am, identity. built my confidence back, self-esteem. It's calmness for me.	I said, even then I took her aside, I said 'listen, if whatever I said, whatever it was either really bad or not so bad, if it upset you, please tell me'. Know what I mean?	I have a one to one with a psychologist, that didn't help as much as actually being in a situation where there's likeminded people. So this morning I just politely just went out into the kitchen and I was getting angry, not angry, frustrated, a bit well [facilitator] stop this and I wanted to do what you just said is '[facilitator]' and when I sat in kitchen I thought next time I see him personally, one to one, I won't do it in the group, I'll just say '[facilitator] you asked us not to bang on about personal issues and all that, but that's all you seem to talk about'. I will do it. It's that progression again in my own mental state as to, I'm slowly like I said to you, climbing up that hill. I'm not there where I'm confident enough to approach him yet, on a one to one and tell him but I will. I know it's there. It's in my mind.

Appendix - 18 – How does co-production work?

Expert by Experience / service user / Group member (EBE)

Expert by profession (EBP)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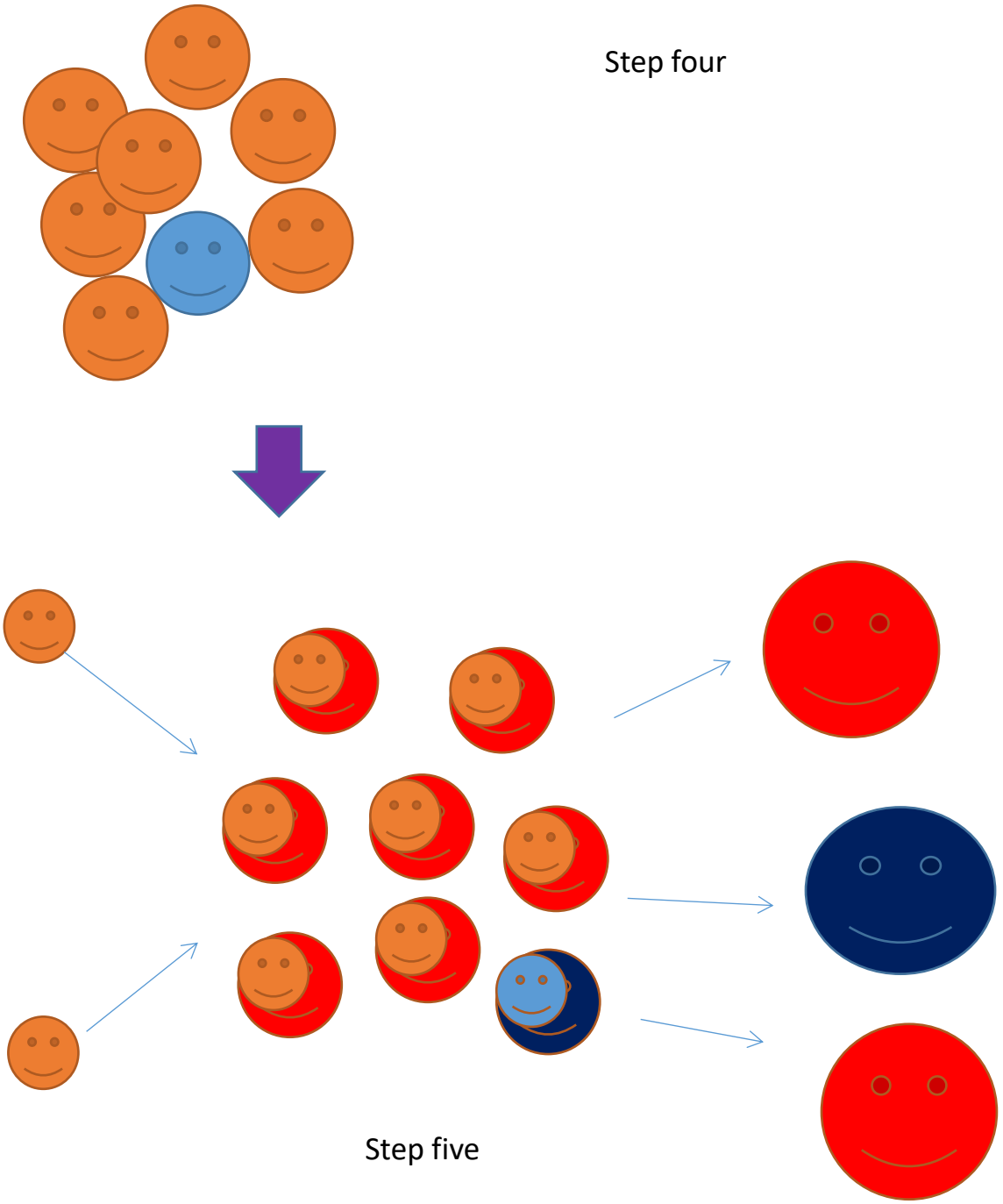
Step two
Step three



Step four

Step five