

**A qualitative exploration of the nature of the medical model in self-management of mental illness: navigating paradoxes and forfeits**

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## Abstract

Self-management is widely promoted in policy and practice as a way to manage mental illness but, despite many years of effort, a wide variety of those who promote/use it perceive that it is not living up to expectations. I wanted to explore how self-management for mental illness was understood, more specifically whether the ‘person-centred’ model that is often promoted alongside ‘self-management’ was evident or if the ‘medical model’ prevailed. This may shed light on the way in which self-care is viewed and enacted by both policymakers and practitioners. I devised a three-stage qualitative study asking 1) how policymakers understand self-management for mental illness, 2) how people and healthcare practitioners understand it in relation to bipolar affective disorder, and 3) how a small group of people understand it more generally as it relates to mental illness.

After the three stages I concluded that, despite some differences, in policy and healthcare practice self-management is understood medically in a particular way, in terms of what is done, by whom, how, and why. Central to that understanding is a paradoxical epistemology which limits how much a person living with a diagnosis can know about themselves, and privileges how much other people know about them. The epistemic paradox is resolved in practice by what I have termed “epistemic forfeit”, whereby individuals living with a diagnosis share the task of monitoring their health with others on an ongoing basis. This means that self-management of mental illness is a task which must always be shared by healthcare professionals, and sharing is thus a condition of receiving care. The capacity to share this task is however restricted because services are under increasing financial, time, and caseload pressure. I argue that this may contribute to the sense that self-management is not working in practice. The thesis ends with a set of recommendations regarding how the healthcare system might adapt to provide the oversight medically understood self-management requires.

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# Chapter 1. Self-management and mental wellbeing

## 1.1 Introduction

This document marks the culmination of a lengthy academic exploration. In it, I have navigated a landscape of vague definitions, misunderstandings, ongoing presumptions, and a tussle between powerful and powerless as society reaches for a somewhat nebulous concept of nationwide happiness. As such, the ambition is vast and the challenges significant. It is perhaps unsurprising that the goal seems no closer. Through this document, I ask specific questions about this challenging situation in the hope that the added knowledge resulting from the study detailed in this document might help towards achieving such a laudable aspiration.

This opening chapter will describe how self-management is at the heart of Scottish Government's mental health policy, driving professional practice, and supported by people with lived experience of a mental illness diagnosis. It will also show, however, that in practice self-management has not lived up its promise. To consider how we might have found ourselves in this position, I will outline research questions which are intended to spotlight a situation where outward facing agreement may hide a problem that is not in plain sight. Central to this chapter and the thesis in general is a critical approach to language, terminology, and definitions. This is of particular significance because in this study I ask whether *mental illness*, *self-management*, and *results* are ambiguous terms which are open to interpretation in practice. If so, might it be that resolution of the ambiguity is an opportunity afforded to those with more power? This chapter provides an overview of a study designed to explore whether the surface-level agreement discerned on paper masks a deeper disagreement between all the parties involved in the self-management process.

## 1.2 A problem described using 'misery statistics'

In their 2016 paper, Michalak et al. opened with a telling statement, "*Many bipolar disorder publications begin with so-called 'bipolar misery statistics', speaking to the considerable disability and dysfunction associated with the condition. Indeed, most data in the field paint a bleak picture*" (p. 77). Convention requires that I follow suit,



perpetuating a negative ‘othering’ of those living with a diagnosis of mental illness from the very outset. The state of a nation’s mental wellbeing is a priority concern across society, and with reason. Globally, mental illness and substance use combined was estimated to affect over a billion people (Rehm and Shield 2019). In Scotland, a 2016 report by Public Health Information Scotland identified mental and substance use disorders as the second most common factor after cancers in the terms of national “*burden of disease*”, a term which “*aims to quantify the difference between living to old age in good health, and the situation in which healthy life is shortened by illness, injury, disability and early death*” (2016, p. 5). Poor mental wellbeing is associated with negative consequences for the individuals concerned and the tendrils of harm reach well beyond. For the individual, poor mental wellbeing is correlated with poorer physical health, unemployment, and lower levels of income and education (Das Gupta and Guest 2002). The extended impact is reflected in social and economic terms such as lost productivity and care costs. It is estimated that this amounts to £10.7 billion per year in Scotland alone (Scottish Government 2018b). With increasing numbers of people reporting poor mental wellbeing in the wake of the COVID-19 pandemic, these costs are likely to escalate further (Carr et al. 2021). These ‘misery statistics’ suggest that something must be done.

### 1.3 Self-management: the solution to a problem?

Self-management is promoted in policy and practice as a positive way to manage the negative effects of many chronic ill-health conditions. A paper produced by the Scottish Government in association with third sector and lived experience partners defined self-management as “*a person-centred, empowering approach in which the individual is the leading partner in managing their own life and condition(s)*” (Long-Term Conditions Alliance Scotland and The Scottish Government 2008, p.10). ‘Helping people to help themselves’ in this way involves the negotiation of complex power dynamics between the individual and the care-provider, with shared decision-making and power-sharing central to the formulation of realistic and meaningful self-management goals. Extending the use of self-management principles to mental wellbeing is not new (Anthony 1993). Literature spanning almost 30 years has emphasised its importance, and this is reflected in past and current policy and practice guidance (Scottish Government 2007, 2012, 2017, Long Term Conditions Alliance Scotland and Scottish Government 2008, NICE 2016, 2020).

The adoption of self-management into policy and practice has been widely supported by individuals living with mental ill-health. This is partly because it aligned with the rise of the patient rights movement in the latter decades of the 20<sup>th</sup> century, which highlighted iatrogenic harms associated with healthcare, and advocated healthcare system change (Illich 1976, Chamberlin 1988, Parkes 2002). Self-management was part of this movement, reflecting a desire for power-sharing between patient and healthcare professional, and a move from paternalism to co-production of health in which people with lived experience were supported to manage their own wellbeing (Crepaz-Keay 2010; Power 2017). Since the initiative was supported by patients and practitioners alike, it suggested strong support for mental illness self-management policy. There was certainly widespread adoption in the NHS of the recovery model of mental health, a model of which self-management forms part (NHS Health Scotland 2016).

There is, however, evidence to suggest that self-management was a 'good thing' which never quite realised its potential in practice. Policymakers continue to create policy which seeks the expansion and improvement of self-management in practice, but healthcare professionals on the ground report challenges regarding how best to facilitate it. People with lived experience of mental illness diagnoses report that, despite a desire to self-manage, they still do not feel empowered to build self-management into their lives in meaningful ways (Armstrong 2016). Millar (2019) said that self-management was not meeting expectations and advocated cross-sector change across personal and professional boundaries towards lived experience-centred understanding and empowerment. These accounts build a picture of a gap between policy, practice, and outcomes (Leitan et al. 2015). There is no consensus about the cause of this gap. Policymakers, healthcare professionals, and people with lived experience look to each other for reasons for such lack of progress.

#### **1.4 Research aims and questions**

Thus far, a conundrum has been presented. I have shown that good mental wellbeing is widely considered to be a priority aspiration, and that self-management of mental illness is considered by many to be a critical way to achieve and maintain it. I have also presented a view which suggests that self-management is not meeting expectations. This state of play presents an important question; if self-management is widely acknowledged

as the way forward for mental wellbeing, with buy-in from a broad range of people who use and support it, why is it perceived not to be effective despite decades of effort? Why has nothing changed? This is particularly striking when returning to the thesis written by Parkes in 2002, in which she lamented the ongoing struggle to achieve empowerment and patient participation in mental health services. She wondered “*whether the preoccupation with participation and empowerment is merely a rhetorical device to indicate that change has taken place when it has not*” and reflected that, over the fifteen years prior to her own thesis, Church had written much the same (Parkes 2002, p. 3). Six years later in 2008, Pratt et al. (2008, p.209) had also wondered whether what they termed ‘self-help’ was understood in different ways, saying this resulted in “*great implications for referral to and implementation of self-help in primary care settings*”. Twenty years further on still, I am troubled to find myself repeating these unresolved concerns. Having determined to investigate further I developed a research study aimed at exploring how self-management is understood in mental health policy and healthcare practice by answering the following research questions.

### Research aim

To analyse the nature of the medical gaze regarding self-management of mental illness in mental health policy and healthcare practice.

### Research questions

How do policymakers, healthcare practitioners and people with lived experience of a diagnosis of a mental illness understand self-management?

How is that understanding reflected in the way that self-management is performed and supported?

How are any difficulties resolved?

The research questions appear deceptively simple. Although I have indicated that there is apparent consensus which could be broadly summarised as *self-management for mental illness is a great idea, but it doesn't appear to be working well in practice*, it seemed particularly important to understand what people meant when they expressed

that consensus. Each of the terms used in this statement is open to interpretation, so I needed to ask what people meant when they thought and talked about self-management. I wanted to explore any differences between interpretations i.e., is there disagreement regarding how self-management for mental illness is understood? This was important because expressing agreement to an abstract concept is all very well but, in practice, abstractions need to be translated into an agreed plan of work, action, or endeavour towards agreed goals. My plan here was to understand how consensus about the nature of self-management according to the medical gaze was reached, and then to explore how that understanding affected the policies that are made and the practice that is performed. Foucault in his work 'The birth of the clinic' (Foucault 1989) developed the concept of the 'medical gaze' which is the way in which doctors modify the patient's story and fit it into one that they understand, which is within a 'biomedical paradigm'. Finally, bearing in mind that self-management appeared not to be producing hoped-for results, I wanted to consider whether the consequence of that agreement produced difficulties in practice and if so, to consider how difficulties were resolved on a day-to-day basis.

### 1.5 A guide to the chapters

In this section the chapters of the thesis are introduced, and a rationale is given for organising it in a particular way. It is somewhat unconventional in structure, but that unconventionality is purposeful. By asking the questions just outlined, it was quickly evident that the thesis needed to cover a lot of interdisciplinary ground in a cohesive and structured way. Interdisciplinarity is common in the contemporary academy, acknowledging as it does that thorough exploration of many topics of interest cannot be contained comfortably within the expertise of one discipline (Davé et al. 2016). To work in an interdisciplinary way is challenging since each discipline has its own language, conventions of thinking and examining, and evidence base (ibid. 2016). The study designed needed to be effective enough to explore the questions, yet also sufficiently persuasive for policy, health, and social science audiences. To accomplish that task, it was important to be thorough yet pragmatic about the theories and methods chosen to explore the questions, yet mindful of the restricted space available to articulate them.

Chapter 2 sets the scene for the study, showing that differences of understanding are very possible in this field. I explore how mental illness might be understood in different

ways, then suggest that different ways of understanding mental illness can have an impact on the related concept of self-management. Having demonstrated in Chapter 2 that ways of understanding might influence what people do as a result, I acknowledge my alliance with a constructionist philosophy of knowledge. In Chapter 3 this philosophy is explored in more detail because the implications of the philosophical stance of the researcher reach deep into how studies are designed. I take a view that people ‘construct’ their worlds in very different ways and this governs how they interact with their world. Under a constructionist view *what is*, is less important than *what it means to you and why*. Having suggested, therefore, that how people understand self-management for mental illness might determine how people ‘do’ self-management, it is important to acknowledge that my own understanding of the world shapes how I do research. It influences my belief about how I believe new knowledge is built, the methods used to build it, how that knowledge is interpreted, and how it is articulated. Chapter 3 then, explains *why* I did what I did, showing how disagreement might be exposed in a topic which is generally presented as agreed and how challenges introduced by the interdisciplinary nature of the study were considered. Chapter 4 is an account of the process of the research. It describes each of the three methods used, and the steps taken in each of those methods. Chapter 4 describes *what* I did.

Table 1.1 Exploring understanding of self-management in policy and practice

<p>Chapter 5. Stage 1. Policy theory</p> <p>How do policymakers understand self-management for mental illness?</p> <p>What are the implications of that understanding in terms of the way that self-management policy is made?</p> <p>How are any difficulties resolved?</p> <p>Chapter 6. Stage 2. Meta-ethnography</p> <p>What can previous research studies tell me about what self-management means for people managing bipolar affective disorder in healthcare practice?</p> <p>What questions do people ask themselves about mental illness and self-management to help them to construct their understanding?</p>
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What are the implications of that understanding in terms of the way that self-management is performed and supported?

How are any difficulties resolved?

### Chapter 7. Stage 3. Fieldwork

Can these questions be used as a basis for primary research?

How does a small group of people construct their understanding of self-management for mental illness in general?

What are the implications of that understanding in terms of the way that self-management is performed and supported?

How are any difficulties resolved?

Chapters 5, 6 and 7 present what was found when the process outlined in Chapter 4 was followed. In Chapter 2 I explore how mental illness can be understood in different ways and that the medical gaze is one of several ways of understanding it. I show how each way of understanding mental illness has implications for how self-management is performed. In Chapters 5, 6 and 7 I take a particular interest in the implications for self-management resulting from the use of the medical lens to shape policy and practice. In Chapter 5 I concentrate on the policy environment. I started by using policy theory to examine how policymakers understand self-management, how they use that understanding to create policy, and how they resolve any difficulties arising. Chapter 6 zooms in, considering what is already understood about self-management for mental health as practiced on a day-to-day basis. A qualitative evidence synthesis made it possible to re-examine studies that had already been done by using the research questions from this study as a different lens. By using the meta-ethnography method, it was possible to look at self-management in practice for one mental illness diagnosis: bipolar disorder. Here, I wanted to explore what previous research studies could tell me about what self-management means for people managing bipolar affective disorder in healthcare practice. It was important to determine what questions people ask themselves about mental illness and self-management to help them to construct their understanding, what the implications of that understanding are in practice and how any difficulties were resolved. Chapter 7 reports what I learned when I took those questions back into the field. Could they help me to explore how a small group of people constructed their

understanding of self-management for mental illness in general? Again, I wanted to consider the implications of that understanding in terms of the way that self-management is performed and supported and examine how any difficulties were resolved.

Each of Chapters 5, 6 and 7 contain a discussion of the stage of the study they present, but in Chapter 8 the findings from all stages of work are discussed as a whole. It reviews the findings through the specific lens of the research questions; how do policymakers, healthcare practitioners and people with lived experience of a diagnosis of a mental illness understand self-management for mental illness, what are the implications of that understanding in terms of the way that self-management is performed and supported and how are any difficulties resolved? In Chapter 9 the discussion points from Chapter 8 are used to suggest a coherent series of feasible responses about how policymaking and practice relating to self-management for mental wellbeing might be improved. In doing so, I review the challenges of turning research evidence into practice and creating impact beyond academia. Also discussed is whether the limitations of study design impact the conclusions and recommendations that have been made.

## 1.6 Positionality

In their 2019 paper Jacobson and Mustafa (p. 1) gave a clear account of positionality, saying that “*the position from which we see the world around us impacts our research interests, how we approach the research and participants, the questions we ask, and how we interpret the data*”. In Chapter 3.2 I agree, saying that positionality is important for this study because it is situated in a qualitative methodology which says that the researcher position is intrinsic to the work they do. Evidence among doctoral peers suggests many people undertake their studies because they have experience of the topic, and my own position echoes this. This study considers mental illness, self-management of it, and mental healthcare. I have experience of them all. I have lived with a mental health diagnosis for over twenty years and, in 2013, registered as a mental health nurse. These positions as patient and mental health nurse leave me in a contested role as an *insider*, yet also an *outsider*, within two important, but potentially divergent groups (Breen 2007).

Dwyer and Buckle (2009) discuss the merits and demerits of being an insider, noting that there is a view that personal experience of the phenomena I choose to examine should exclude me from doing so. Yet, in their recent open forum article, Jones et al. (2021) argue a position which is diametrically opposed, saying that inclusion of living experience in mental health research settings must be encouraged. The duality of my position is not unique and in Chapter 5.6.3 I show how *insider-outsidership* confers challenge and opportunity when advocating for policy and practice change. Dwyer and Buckle (2009) are not the only authors to agree that those with personal experience should be included, concluding instead that reflexivity is key wherein the researcher is aware of the challenges and opportunities their position confers (Berger 2015, Jacobson and Mustafa 2019). This explains why I state my positionality here and why, in Appendix 3, I have given an expanded positionality statement which provides further background. I know that my lived experience lends insight to the challenges faced by a variety of people involved with self-management, improves transparency, and influences the desire to introduce balance in this document. To compliment this, in Chapter 8.8.2, I discuss how this positionality has created limitations that should be reflected upon.

Positionality also impacts my choice of language. The notion that language is an articulation of who we are, and are not, and that it reveals what we believe and think is not new. In Preece's 2016 book, the author introduces the field of Applied Linguistics which examines this, and in Chapter 2 of the book, Baxter (2016, pp. 34-49) introduces scholars such as Foucault who argued that language articulates power and oppression. In Chapter 2.2.2 of this thesis, I show how the term "*Mad*" has been re-appropriated and in Chapter 5 argue that mental health policy language can be performative, i.e., denoting acknowledgement without action. Language in this field matters. Noting this, the concept of person-first language was introduced, though its use among practitioners is inconsistent (Crocker and Smith 2019). Opposing this, Gernsbacher (2017) has argued that person-first language is stigmatising. This suggests the issue of appropriate language is not yet resolved. Nonetheless, guidelines exist which aim to aid journalists in using non-stigmatising language (National Union of Journalists and the Scottish Government 2014). In a field shaped by how language is used, the choice of terminology in this thesis has been vexing. As the Consultation and Advocacy Promotion Service (CAPS) notes, "*no term is neutral, not mental illness, mental health problem, madness, or any other term*" (The Consultation and Advocacy Promotion Service 2010, p. 13). I



am an ‘insider-outsider’ and my shifting vocabularies are illustrative of my shifting positions. I have carefully considered where I have used the terms mental health, mental illness, madness, crisis, lived experience of a diagnosis, peer, patient, person and individual. For instance, I know that I have rejected the use of *service-user* and *consumer* merely because *to me*, they suggest a choice which does not exist. It is important to note my use of the term *self-management for mental illness* rather than *self-management for mental health*. This is intended to make the distinction between what a person does to stay well, versus what a person does to manage illness. As Chapter 2 shows, mental illness is a contentious term, but key here is the notion of managing a state of being which is distressing to the point that it is classifiable under the terms of the International Classification of Diseases (World Health Organisation 1993) or The Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association 2013). Throughout this work, I have tried to use accessible language, explaining terms and concepts as clearly as I can. I do not want my work to languish on a shelf, unread by all but the most determined. I have tried to be inclusive for the wide audiences of my work but, as the quote above from CAPS suggests, I recognise it is a challenging task.

Relatedly, I would like to explain my use of the first person. This is a linguistic device denoting positionality which Pollock (2007) finds challenging, as do I. My use of *I* in this work is indicative of my personal growth during the PhD. My decision to use it came after a long period of reflection where I challenged the conflicted identities I inhabit. My nurse training finds me resisting the first-person narrative because it taught me to strive for a knowable truth which existed whether or not I believed it to be true. At that time, I sought an impartial distance from my work which allowed me to deduce the ‘truth’. As I comment in Chapter 3, the constructionist stance I have adopted since suggests I use *I* because *I* can never be removed from the work I do. I look for meaning, my own and that of others. I look for the truth *as it is understood* by others, and I look for my own truth. I am integral and indivisible. This seemingly innocuous shift to the first-person represents what was, to me, a momentous final decision in the final stages of the PhD process: to accept who I am, acknowledge how I sit with that knowledge, and own the truth as I understand it to be and share with others.

## Chapter 2. Ways of understanding mental health

### 2.1 Introduction

In Chapter 1 I showed that self-management for mental illness is widely considered to be a good thing, yet also suggested that self-management continues to fail in practice. To understand why this might be, this chapter suggests that there are many different ways in which mental illness *could* be understood. Shared understanding of mental illness cannot be presumed. As I will demonstrate, not only are there many models of understanding mental illness, but also many approaches to care and self-management within each model. The overall result is considerable difficulty in knowing how people interpret self-management and put it into practice. Nonetheless, people must still make choices about how to interpret, perform and support self-management within that complexity. This chapter distils the approaches into archetypes from perspectives which situate the problem that self-management is intended to address within an individual (Chapter 2.2.1), outside them (Chapter 2.2.2), and in Chapter 2.2.3 I give an example of a hybrid approach that seeks to draw on both.

### 2.2 What is mental health/illness?

First, is to ask a question that has been asked many times: what is mental illness? It is important to understand the nature of a problem i.e., mental illness because that defines how the problem could be addressed, and by who i.e., whether self-management is possible, how it should be done, and by whom. Accordingly, it is important to understand what causes a person to experience what is termed mental illness so that the right people and strategies can be employed in its management, whether by the self or others. This is complicated by the fact that there is little certainty to be found about the nature of mental illness (Read and Dillon 2013). The lack of clarity results in different ideas about how it might be managed, if at all, and has profound implications for practice which are explored throughout this thesis. Ways of thinking about mental illness and self-management of it might be divided into approaches which seek to resolve a problem which is situated within an individual i.e., *fix me* (Chapter 2.2.1), or resolve a problem which exists beyond them i.e., *fix the world I live in* (Chapter 2.2.2).

### 2.2.1 Fix me

In his biography review Faria (2020 p. 4) offers a quote by eminent Professor of Brain Science, Eric R. Kandel where he says that “*all mental disorders, including those categorized as “functional” (or psychological) will be found to have a structural, biochemical, and/or molecular basis, and that the old subjective criteria for psychiatric illnesses will completely give way to the new biological “science of mind.”*” Kandel’s view lies at the heart of biological models. Biological models of understanding mental illness have been in existence for a long time. There are many texts which trace its long history, from black bile and leeching long ago, through insulin therapy in the 20<sup>th</sup> century, to the polypharmacy of the present day (Porter 2002, Bentall 2003, Arnold 2009). The biological model continues to dominate contemporary discourse, policy, and practice. Through this model it is argued that what is experienced and witnessed as madness is a sign of abnormal biological function: this is termed *mental illness*. As may be expected by this illness explanation, the model is strongly supported by the medical establishment, to the point that it is often referred to as the medical or biomedical model. Medical models are built around an ethos of helping people and keeping them safe within the medical system (Chambers 2017). Much of the language used to describe the way human minds operate comes from medical ways of viewing the world. Thus, *patients seek treatment from doctors for their illness*, so that they may *recover* and be restored to *health*. In this type of scenario, the role of the mentally unwell would be to accord with what they are advised/told to do by healthcare professionals because healthcare professionals are the experts in all things medical. Self-management becomes a task or series of tasks delegated by the expert healthcare professionals to patients who must then find ways to incorporate the tasks into their lives. Baart and Widdershoven (2013) note that people who favour a disease construction of mental health are less inclined to believe that self-management is possible or desirable because, in this analysis, the illness is an aspect of their biology over which they are powerless. A substantial, powerful, and profitable industry has grown around the model (Whittaker 2010), and the lexicon of mental illness permeates culture (Cosgrove et al. 2019, Beresford et al. 2010).

Despite this dominance, the claim to mental illness expertise has, more than any other medical field, been subject to intense debate and scrutiny. Porter (2002, p. 2) for example argues that psychiatry sought to achieve “*easy solutions for problem people*” through the authority of scientific method. Much of this criticism centres around a lack of

evidence for a clear biological mechanism of action, of the type Kandel described in the quote at the top of this section (Faria 2020 p. 4). Many other illnesses can be defined according to consistent, generalisable and observable symptoms and confirmed through tests which verify a disruption of normal biological function (Fred 2013). Despite years of research, there is still no biological test which will confirm the presence or absence of any of the mental illness diagnoses the biological model bestows. The chemical imbalance theory of mental illness rose in the 1950s, then fell 30 years later when the burden of proof could not be met (Leo and Lacasse 2008). Though Pies (2019) has since blamed pharmaceutical manufacturers for the persistent trope, commenting that psychiatry never promoted the theory in the first place, it persists as a causal explanation (Lacasse and Leo 2015). Images are available across the internet which show the *depressed brain* and the *not depressed brain* (Mayo Clinic 2021). Yet, while the depressed brain indicates altered levels of activity which may be construed as evidence, it is not clear whether it demonstrates cause or effect, or if it is a useful image at all (Dumit 2003). Nonetheless, the search for a biological seat of madness continues, as is witnessed in the emerging field of Precision Psychiatry (Fernandes et al. 2017, Zhang et al. 2018, Underwood 2019).

While there is no clear understanding of the pathology that causes mental illness, there is also little regarding the mechanism through which psychoactive drugs and/or treatments resolve it. For example, Yantham et al.'s (2005) paper talks about possible mechanisms of action of atypical antipsychotics for bipolar depression and calls for more research. The 215 papers since which cite Yantham et al. continue to search for such mechanisms. The search for a mechanism is complex but important if we are to understand why medication might be warranted. Fictitious patient *John's* experience of depression might resolve with the benefit of the entire arsenal of psychoactive treatments, while *Jane* reclaims her sanity with none. Many research hours are spent discovering what it might be about *John's* biology that makes treatment work for him, but without understanding the mechanism that causes the problem in the first place the process is challenging. The issue is further complicated by the financial symbiosis of the medical and pharmaceutical industries. Frances (2013) condemns psychiatry as predatory, attributing it in part to profit-driven pharmaceutical alliances. Moncrieff, Rapley and Timimi (2014) explored the influence of the pharmaceutical industry on escalating rates of diagnosis of ADHD. Read and Dillon (2013 p. 395) note work done by

Foley in 2012 which showed that pharmaceutical giant GlaxoSmithKline were fined a substantial sum for subverting evidence in an attempt to promote sales of psychiatric drugs. The toxic side-effects of medication, and the lack of understanding regarding its mechanism of action have encouraged Whittaker (2010) to argue that medication exacerbates and possibly causes mental illness rather than cures it.

Diagnosis itself is characterised by shift and subjectivity across time and culture. Categorising abnormality under the umbrella of science validated the need to indulge in what Foucault (2001), writing in 1966, saw as the need to classify. This was witnessed in the evolving diagnostic manuals, with the International Classification of Diseases (ICD) first incorporating mental health categorisations into its 6th edition in 1949, now in its 10th iteration (World Health Organisation 1993). The Diagnostic and Statistical Manual of Mental Disorders (DSM) fulfilled the same function in America in 1952 and is now in its 5<sup>th</sup> iteration (American Psychiatric Association 2013). For practitioners, diagnostic manuals have some utility. In a tweet on 30<sup>th</sup> July 2019, a member of the taskforce for the 4<sup>th</sup> DSM manual, Frances, pointed out that the categories were merely labels which facilitated care saying, *“Nice someone understands what DSM is/what it isn’t. Mental disorders are constructs, not diseases. Descriptive, not explanatory. Helpful in communication/treatment planning, but no claims re causality/homogeneity/clear boundaries. We wrote this in DSM-IV Intro- no one read it” [sic]*. While it may be that the ongoing expansion of the ICD and DSM is evidence of diagnostic and treatment progress, it may also be that they reflect a cultural shift in which more behaviours are pathologised. Perceived abnormality was subjected to ever finer gradations and the *psychiatrisation* or *medicalisation* of normal behaviours was witnessed (Spandler 2014). The shifting boundaries of diagnosis which have seen diagnoses of homosexuality unequally applied across class and gender boundaries, then fall from diagnostic favour altogether, gives further cause for doubt (Drescher 2015, Allsop et al. 2019, Carr and Spandler 2019).

The shifts reinforce an argument levelled at psychiatry which says that diagnosis is a form of discriminatory social control (Chapter 2.2.2). The extent to which the biomedical model has been complicit in this is uncomfortable, and an historical alliance with eugenics does little to dispel a fear that social control is occurring (Hidden Persuaders

2019). This sense of social control is compounded by an awareness that psychiatry alone, of all medical specialisms, has the power to coerce, treat and detain individuals, often on the basis of the *potential* for people to cause harm to themselves or others (Mental Health (Care and Treatment) (Scotland) Act 2003, Chambers 2017). Returning to the fictitious patients, in the absence of tests, and with only subjective assessment of symptomology to work with, *John* may find themselves diagnosed with a range of illnesses and compulsorily detained and medicated, depending on the doctor they see, the symptoms they describe, and the emphasis they and their doctor place on each. *John's* religious preoccupations and visions may be construed as mad or religious, depending on their job. *John's* ruthlessness might be the sign of a strong businessperson, or evidence of a personality disorder, depending on their success. *John's* inherited wealth may dictate whether they are described as delightfully eccentric or mentally unwell.

Despite these critiques, the biological model prevails in discourse to the present day. I have argued so far that the biological model fails to convince, yet its primacy in contemporary culture is evident and it continues to dominate discourse, policy, and practice. Supporters have continued to deflect criticism levelled at the model (Huda 2019) and, in some cases, there are indications that individuals in the profession have become more entrenched and defensive, rounding on their critics (Szasz 1994). Citing Voronka, McWade (2019, p. 154) noted that the contestability of the main arguments of psychiatry, its association with oppression and the high financial and reputational stakes, has led to a situation where psychiatry is engaged in a desire to “*constantly promote itself to maintain and increase its market share of the mental health industry*”. It is perhaps this that led Beresford (2019, p. 251) to argue that “*the prevailing medical model has remained essentially unchallenged for at least half a century*”. In the main, the model survives attacks well. Its ongoing dominance leaves little money, effort, or debate to devote to other ways of understanding, and this model is now the contemporary orthodoxy.

It is important at this juncture to mention psychological models because they stand astride biological and social models and take as a starting point a view that social context produces mental abnormality in individuals. As Kinderman (2005, p. 206) says “*disruption or dysfunction in psychological processes is a final common pathway in the*

*development of mental disorder*". This means psychological models are built around a judgement between normality and abnormality. Like biological models, in psychology diagnostic labels exist and the focus of interest is within an individual rather than the social context which surrounds it. Rather than taking a view that illness is situated in the biology, psychological models suggest that mental illness are errors of thinking or coping with life. Interventions commonly focus on talking therapies. Self-management becomes the labour of the individual to correct these internal errors. In this regard, they take a similar view to biological models, and Boyle's statement about their alliance is damning.

*"In following psychology in minimizing context, clinical psychology gains the added advantage of placating psychiatry... In fact what we seem to have are three very insecure groups who have implicitly agreed not to expose the operation of power in return for academic and professional privileges"* (Boyle (2011) cited in Read and Dillon (2013) p. 399).

As Pilgrim notes, the alliance between psychology and psychiatry is uneasy; sometimes supporting, sometimes opposing the biomedical position (Pilgrim 2014).

### *2.2.2 Fix the world I live in*

Social models are so-called because they consider as central the social context of the person experiencing madness. The social way of understanding says that expressions of what is described as mental illness are the result of the pressures of living in a world which creates barriers for those living with mental difference. In this situation, self-management is challenging without wholesale political and social change, both of which are beyond the scope of the individual to achieve. Social models are stratified across a variety of theories (Rogers and Pilgrim 2005) but the role of society in expressions of madness is not new. In 1878 (p. vi) Henry Maudsley said it was "*proper to emphasise the fact that insanity is really a social phenomenon and to insist that it cannot be investigated satisfactorily and apprehended rightly except it be studied from a social point of view*". R.D. Laing, widely cited as the anti-psychiatrist's psychiatrist was (in)famous for (allegedly) saying that *insanity is a perfectly rational adjustment to an insane world*. These views reflect the cornerstone of the social models which argue that

we are the product of the culturally defined and constrained world in which we live, where society might be a normative force, a co-producer, or an oppressor.

### 2.2.2.1 Society as a normative force

Across history there is a sense of madness as a signifier of 'difference' from the majority. Existential philosophers introduced and fought against the idea that it is a basic requirement of society for a person to be perceived as rational, such that their ways of being are comprehensible to others (Solomon 2013). Pilgrim (2014, p. 33) introduced the "*intelligibility rule*" which states that a person's behaviours and actions should be intelligible to those around them. This broad need for rationalism suggests that when a person's behaviour is not comprehensible, society tries to attribute their behaviour to other things, be it God, the Devil or madness (Porter 2002). Writing in 1961 Foucault (1988) suggested that to label an individual as Mad was an act of power over those whose behaviour is in some way not normal. Yet exactly which behaviours were, and continue to be perceived as, abnormal, non-rational, or incomprehensible, is subjective. A pivotal argument in Foucault's 1961 (ibid.) exposition is that madness is not a constant truth. He says that madness does not exist in a way that is independent of understanding, but instead is a construction of the time, place, and society in which it was experienced. He suggests that madness is an artefact of when and where the norms are established. This temporality may explain why slaves were diagnosed with *drapetomania*, a mental illness causing them to flee captivity or *dysaesthesia aethiopica* which made them lazy (Warren 2016). It is argued that the effect of being seen to exhibit signs of abnormality sanctions intervention. Othering, discrimination, and oppression are facilitated, and society becomes a powerful normative force. It becomes a mechanism through which women, ethnic minorities, the poor, and other counter-cultural undesirables have been controlled by others. Rapley (2013 p.400, cited in Read and Dillon,) argues that "*the medicalisation of suffering and difference thrives because it sanitises and simplifies.*" In short, medicalisation of madness creates distance between *us* and *them*. It means that *they* are the problem not *us*.

With such powerful consequences for transgression from normality, the drive to perform, and *to be seen to perform* according to temporal and cultural norms, is strong. It was Goffman (1990), writing originally in 1956, who extended the Shakespearean concept of



life as a stage on which we are all actors playing a part representing the self we feel we should be to an audience of our peers. In his later 1961 book *Asylums*, Goffman (1991) quotes Szasz who argued that what was perceived as mental illness was in fact failing to play the role society felt was appropriate. On that basis, one can only conclude that the act of sanity is performative. For those who fail or choose not to perform sanity, consequences follow. Goffman argues that the confinement of those perceived as mad to hospital rips from them their own identity, and foists upon them a new one, that of *patient*. There, performativity continues. In this new setting, individuals play their role under the omnipresent gaze of others. The total institution and the rigidity of the hospital setting ensures that individuals are always front stage, with no opportunity for backstage relief.

In a similar vein, Foucault (1991), in his book first published in 1975, introduced the concept of the initially literal and later metaphorical panopticon of constant observation. In it, the omnipresent gaze of others is a sign of management by them. Ultimately, individuals moderate their own behaviours in order to meet the expectations of the social theatre in which they find themselves, and self-management is produced. In this view of the world, power is dispersed and not simply rained down from above. The role of madness is policed from above, between, and importantly, within the individual themselves who strains to be perceived as fitting in to a society that seeks to reject them. As Chamberlin (1988 p. 77) observed, *“During their institutionalisation patients must believe (or appear to believe) that the hospital is a helpful place in order to be considered ‘well’ by the staff. To be discharged, a patient must confirm the psychiatric version of reality, including an acknowledgement that hospitalisation has been necessary and beneficial”*. She quotes Attorney Bruce Ennis (Chamberlin 1988, p. 233) who observed that, *“I think that most people don’t like mental patients. They don’t like anyone whom they cannot categorise neatly into an acceptable niche that is comfortable for them. I think if it were put to a public referendum the people in this country would favour massive custodial warehouses where people are swept off the streets and kept for the rest of their lives and drugged, tranquillised, shocked, whatever necessary to keep them off the streets”*. Though Chamberlin’s book, first published in 1977, was written over four decades and many anti-stigma campaigns ago, this view remains persistent (Giandinoto et al. 2018, Mehta et al. 2018, See Me 2021).

### 2.2.2.2 Society as a co-producer

The role of society as a producer, or at least an exacerbator, of mental distress is seen in Wilkinson and Pickett's book (2010), which advanced the notion that wealth inequality was implicated in spiralling mental ill-health in neoliberal societies. Neoliberalism is presented as a form of social Darwinism, where only the strong, rich, conformers survive. Esposito and Perez (2014 p. 418) cite Harvey's 2005 comment which describes neoliberalism as a political and intellectual movement which sees "*the free market as an apolitical force that fosters personal liberty, encourages individual responsibility, ensures the most efficient utilization of all social and economic resources, and promotes an optimal way of life, [where] the market [is] the arbiter of human life*". Both sets of authors reflect a wider view that the effects of neoliberal policies as a factor in mental illness could not be ignored (Cosgrove and Karter 2018, Bell 2019). Anti-stigma campaigns have been promoted, intended to reduce cultural antipathy towards people living with a diagnosis and resistance to accessing treatment (Evans-Lacko et al. 2014, Henderson et al. 2018). Trauma-informed care considers the importance of traumatic experiences such as sexual violence on mental wellbeing and acknowledges the risk of re-traumatisation posed by conventional mental healthcare practices (Rosenberg 2011, Reeves 2015).

Human rights legislation (Equality and Human Rights Commission 2018) has facilitated system changes which position society as the co-producer of health. This included the rise of patient rights (Patient Rights (Scotland) Act 2011), strategies ensuring patient/healthcare professionals partnership working and co-production of health (Scottish Government 2012b, 2017), and the ascendancy of the lived experience voice (Mental Health Welfare Commission 2021, Scottish Recovery Network 2021). Person-centred approaches, with their roots in the lived experience voice, flourished. A significant development was the recovery movement. Smith-Merry and Sturdy (2013) traced its path in Scotland and described its original vision as a way of working which was intended to support individuals to move towards a personally defined life that was meaningful and satisfying to them. Mental health nurses in Scotland were taught the ten essential shared capabilities (NHS Education for Scotland 2011) which included partnership working towards recovery, hope, respect and strengths. Recovery found its way into policy and healthcare service and third sector practice (Scottish Executive 2006b, Brown and Kandirikira 2007, NHS Education for Scotland and Scottish Recovery

Network 2007, MacKeith and Burns 2009, Scottish Government 2009a, Leese et al. 2014, Scottish Recovery Network 2021). The Capability approach (Hopper 2007) took a rights-based approach to care which asked, *what could you achieve and what is stopping you from achieving it.*

Yet faith in the original intentions of the person-centred lived experience-informed approaches was sometimes shaky due to their potential for misinterpretation and co-option. Pilgrim referred to the recovery approach as “*old wine, new bottles*” (Pilgrim 2014 p. 120) and Tew (2015, p. 78) asked whether “*a certain lack of slipperiness and lack of conceptual clarity has allowed for subtle (and not so subtle) colonisation of the idea of recovery by professional interests*”. Leese et al. (2014) noted that working in this way demanded time nurses did not have. Recovery was seen in some quarters as a neoliberal device, co-opted by the state, intended to responsabilise an individual to the point that they were productive workers no longer dependent for support, and a mechanism through which to blame individuals in the event they continued to need support. Spandler (2016, p. 8) termed the net result of recovery ‘psychiatric neglect’ asking, “*if the asylum era was synonymous with psychiatric abuse, will the recovery era become synonymous with psychiatric neglect? Certainly ‘recovery’ is increasingly used as a justification not to provide support and services*”. Recovery communities, sometimes called therapeutic communities, were originally conceived as groups of people with experience of mental distress living together in an environment of mutual support, (Chamberlin 1977, Baron 1987, Spandler 2006, Soteria Network 2021). Reports of their efficacy as a complementary model of support were good (Calton et al. 2008) but over time it has been argued that, in many cases, they too have been co-opted to the point they become mirrors of the healthcare system they sought to reject; an asylum by another name.

While these initiatives suggest that social factors have been increasingly acknowledged, it is important to note that many of these measures are still intended to work within a predominantly medical model. Many try to find more collaborative, and/or less traumatic ways to fix a problem which sits within individuals, rather than focus on the factors beyond.

### 2.2.2.3 Society as an oppressor

Some with lived experience of mental healthcare took a more radical social position regarding the problems they faced. They saw mental healthcare as an instrument of oppression, violence, iatrogenic harm (Illich 1976) and power. The latter 20<sup>th</sup> century saw the rise of activism against viewpoints for which the focus is to *fix me* rather than the society which makes living so challenging, particularly when fixing included compulsion and coercion. Parallels can be seen with other emancipatory movements which seek to liberate marginalised voices, such as those concerned with the rights of women, people from LGBTQ+ communities, people of colour, and disabled people, which located the problems they faced within their wider world, rather than within them (Fisher and Freshwater 2015). As just noted in the section above, concepts such as recovery, co-production and partnership working were perceived as having been co-opted by healthcare services as a way to *perform* change (Parkes 2002, Rose 2014, Fisher and Lees 2016, Woods et al. 2019). As a counterpoint to the individual focus of recovery, Recovery in the Bin (2016) offered the social justice focus of “*unrecovery*”.

Key among emancipatory social models of mental illness was the Mad Movement. In the latter years of the 20<sup>th</sup> century people aligning with the Mad Movement sought to reclaim the pejorative ‘Mad’, advancing a model of mental existence which was strongly social in origin (Cutler 2019, Beresford 2020). Though many definitions abound, Bossewich (2016) captures an essence of it.

*“...a new generation of mad activists is struggling to assert their right to substantively engage in the conversation around their own identities and self-care. They want to participate in the production of the knowledge that governs their diagnosis and treatment, and they are questioning the very language and narrative frames used to talk about their mental health and wellness. Their argument, embodied in their stories, represents a dramatic shift from the anti-psychiatry, psychiatric survivors, and consumer movements that preceded them. They assert their prerogative to narrate their own identities using their own language, and demand that experts acknowledge their subjective experiences alongside objective measurements. Their struggle echoes the enduring standoff between empiricism and phenomenology, as they strive for their experiences to*

*be recognized as integral to the formation of psychiatric knowledge, and not simply ignored or dismissed as unscientific. They insist that their experiences, captured in their stories, should be admitted as first-class evidence in “evidence-based” research, a claim whose implications extend far beyond the realm of psychiatric knowledge construction and mental health policy”* (Bossewich 2016, pp. 3-4).

Mad Pride brought together those who reclaimed their stories, asserted the centrality of those stories for psychiatry, and took pride in their lived experience (Costa et al. 2012). The Mad movement continues to argue that modern day attitudes to madness are shaped by a calamitous coalition of psychiatry, policy, pharmacy, and power which oppresses and lessens those who are meant to be helped by it. In a passionate preface to key Mad text “Psychiatry Disrupted” (Burstow et al. 2014, p. xvii), Millett wrote about psychiatry “*as means of social control, a kind of voodoo, an invasion of state power upon the individual will struggling with life, with death and debt and unemployment, with the indifference of humanity*”. Chamberlin (1977 p. 5) said “*We envision a system in which this pain would not be labelled illness but would be seen as a consequence of a system that puts wealth, property and power above the basic needs of human beings*”. Borrowing a term from Hanisch writing about radical feminism in 1969, it can be seen that, for the Mad movement “*the personal is political*” (Hanisch 2006).

The Mad model is now acknowledged as an emerging field of international scholarship which includes seminal texts, from Church and Reville’s paper arguing for the inclusion of ‘mental health consumers’ in service provision in 1988, to Mad Matters, a book bringing together many key names and introductory discussions about the origins, key themes, and diversity of this growing field (LeFrancois et al. 2013). The field includes key scholars including, but certainly not restricted to, many named in this chapter, its own publication (Asylum 2021), and further educational training now in Scotland, and inspired by early examples first run in Ryerson and York universities in Canada in the early 2000s (LeFrancois et al. 2013, Queen Margaret University 2021). Mad Studies is not necessarily anti-psychiatry but is often critical of it (Huda 2020, Moncrieff and Double 2020). Mad Studies is sometimes but not always aligned with Disability Studies and activism (Spandler et al. 2015). At its core, Mad Studies remains an evolving activist community

which seeks change, recognition and reprioritisation of Mad perspectives (Spandler et al. 2015, Spandler and Poursanidou 2019). Citing Costa and LeFrancois, Ballantyne (2019 p.30) noted, *“It is not owned by anyone, it is evolving and no one defines its borders or has authority over the direction it may go in”*. In a similar vein, Beresford (2015, p. 257) said *“they did not want to replace one orthodoxy with another, one monolithic theory with another”*. It is still considered countercultural. When considering why, we might read the words of key Mad ally Church (1995, p. 12) who said in the preface to her book that signs of rebellion against medical orthodoxy throw the entire stage into disarray: *“the knowledge/power relations of community mental health are significantly disrupted by processes which bring forward survivor knowledge repertoires. When this happens, mental health professionals and bureaucrats become unsettled; their personal as well as professional identities are called into question”* and *‘it makes professionals angry to think that people would label themselves as ‘survivors’ of a system which they think is helpful’*. It is this which might underpin ongoing challenges to the Mad model (Chapter 2.2.1).

### *2.2.3 A bit of this and a bit of that*

Over time the models described above have ‘bled into’ each other. Compound models make it possible to create a bespoke way of understanding the nature of mental illness. Few contemporary key mental health nursing texts promote an entirely biological model of understanding (Chambers 2017). More in evidence is the biopsychosocial model which blends three models in one (Engel 1977, Wade and Halligan 2017). Those using compound models to understand their experiences are more likely to believe that they can influence their lives. Baart and Widdershoven (2013) found that people who believed in the susceptibility model of mental illness were inclined to believe that they were able to influence their expression of illness by managing aspects of their lives. This model believes in a genetic predisposition to expressions of illness, which social factors might ‘trip’ into action. Yet self-management through compound models is challenging because the biopsychosocial model gives no indication of the ratio or relationship of one aspect to another. It is not entirely inconsistent that the biological model can accept the contextual aspects favoured by the sociological model whereby contextual factors such as poverty and exclusion affect the biology, causing internal changes which affect mental health. The challenge is to know whether the sociological factors are distal, and biological causes are proximal or vice versa, whether there is causality rather than correlation and

if so, the direction of it. Compound models arguably muddy the water of understanding and the nature of mental illness is exposed as complex (Farre and Rapley 2017). This means that any self-management solutions are equally challenging. Furthermore, with healthcare professionals at the forefront, medical language and processes predominating, scant resources for psychological support, and little beyond anti-stigma messaging in the way of social change, the biological appears to dominate the model. This imbalance is noted by many critics of current mental health provision and calls for a 'paradigm shift' which incorporates meaningfully the role of society into approaches to mental health care come from many quarters, including the United Nations (UN Human Rights Council 2017, Cosgrove et al. 2019).

### 2.3 Self-managing in a contested landscape

My intention in this chapter was to argue that shared understanding of mental illness cannot be presumed. I have illustrated that the nature of mental illness is a contested landscape and that it is possible to adopt numerous positions about it (Rogers and Pilgrim 2005, Read and Dillon 2013). I have also shown that the way mental illness is understood might be linked to how a person understands self-management should be done, i.e., who should be involved in doing it, what resources are needed, and which outcomes are sought? Whether or not one of the many options is *right*, or *more right* than any other, is less important than the fact that there are many options. The complexity of understandings makes it challenging to know how to care for others and oneself. In the main, models present an individual with a sense of helplessness and produce difficulty performing self-management, albeit for different reasons.

Table 2.1 Thinking about mental health and the consequences for self-management

<p>John</p> <p>Mental illness has biological origins and affects 'normal' people, making them 'ill'. Symptoms are signs that a person has an illness and should be resolved so that the individual can return to normal function. The experts in illness are health care professionals and they are the solution to the problem. Government should support the medical system to optimise treatment and encourage individuals to seek support. The individual self-management role is to seek/comply with treatment. Self-management is a way to be involved in the decisions that are made.</p>
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Joe

All people experience life differently and, for some, it is more challenging than others. What society describes as normal is neither possible nor desirable. Some describe their difference as madness, and not all perceive it to be an entirely negative experience. Sometimes this experience of life results in crisis. Crisis is exacerbated by factors external to the individual such as trauma, poverty, and isolation, all of which are more likely due to societal rejection of their difference. Individuals that are mentally different can be supported by others who have similar experiences in order to learn how to live with their difference in a way that causes them less distress. Individuals are the expert in their own experience of the world. Healthcare professionals are not part of the solution because the experience is not perceived as illness. Government and other agencies should support external factors such as poverty and discrimination that contribute to crisis. Peers with lived experience can be allies in finding a way to live with less distress. The individual self-management role is to learn how to live with least distress. Self-management is a way to maintain control of their lives.

Jane

Mental illness is a term applied to people who are responding to factors external to them including trauma, poverty, and isolation. This may or may not cause or be caused by a biological change in their body. Individuals can reduce the effects of their distress by seeking support to moderate the effect of the factors involved. This may include help to manage their response to their situation (e.g., counselling,) and/or living situation (e.g., housing/finances). Medicine may help to manage the biological effects. A return to function may never be possible, but the goal is to live to a life as close as possible to social acceptability. Healthcare professionals are sometimes part of the solution depending on level of belief in the biological causes/consequences but need to work with other agencies who can support a range of non-medical factors. Government should support the medical system and a range of wider factors. Individuals should work with others on a progressively reducing basis and avoid situations which make their condition worse. The role of self-management depends on the factors considered to be the cause of their situation.

To summarise this, Table 2.1 gives examples of how the fictitious people in this chapter might describe their view of mental health, illness, and self-management, with *John* taking a more biological approach, *Joe* a more social one, and *Jane* a pragmatic stance more akin to compound models. For *John*, self-management is following the lead of their doctor, for *Joe*, finding support from their peers and society, and for *Jane*, a portmanteau approach. Their views appear to be organised around several key questions including, but not restricted to; a) does mental illness exist as a biological entity which is resolved predominantly by medical science b) is mental illness a way to define 'normal' people and identify those who are 'abnormal'; c) is mental illness a social ill determined and affected by factors such as poverty and exclusion?; d) is mental illness all or some of the



above; e) does mental illness exist at all? As I work my way through the stages of this study, I will unpick these questions a little further, and try to establish the headings across which people construct their ways of understanding.

## 2.4 Summary

I started this chapter by asking if it was possible to have different ways of understanding mental illness and self-management of it. By its conclusion I have demonstrated that the landscape of understanding is broad and contested. It is reasonable to conclude that, although people may say they agree about self-management and mental illness there is no shared understanding regarding what they are agreeing about. When meaning is vague people can say they agree at a superficial level but fine-tuning abstract agreement into the exacting processes demanded by practice requires that ideas are made concrete and vagueness eradicated. At the level of practice, differences of understanding are exposed and become problematic. For instance, in cases where two or more people in a room hold different views about the nature of mental illness, whose view should be most important in determining a course of self-management action, and how will any difficulties be resolved? In the chapters that follow I want to explore what happens in current policy and practice when they are shaped by medical models of understanding mental illness and self-management.

## Chapter 3. Methodology

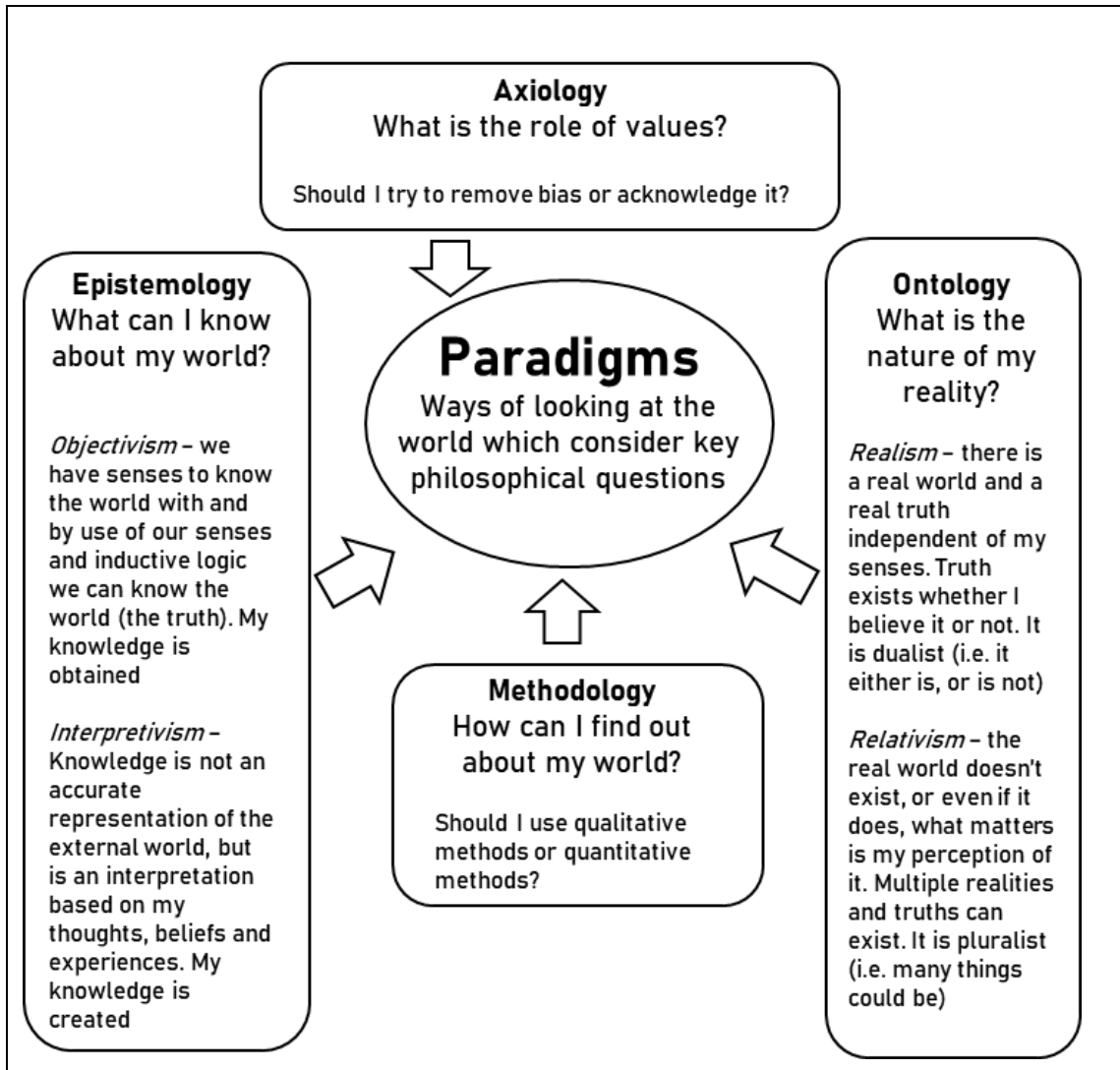
### 3.1 Introduction

By the conclusion of Chapter 2, I had argued that the way a person might do self-management is linked to how they understand the mental illness to which self-management refers. This suggests that what self-management means *to you* is important. Accordingly, it was important to design a study which helped to explore those potential ways that the world is understood. In this chapter this is done by first aligning my own view of the world i.e., meaning is important, with established ways of thinking about how people build knowledge i.e., how they understand and interact with their worlds. This alignment gives some pointers about the theories and methods which might be used to find out how people understand self-management. The latter sections of the chapter explain how I decided to choose particular theories and methods in an effort to expose any disagreement about the meaning of self-management; a topic which is generally presented as agreed. I note that it is sometimes challenging to decide upon a theory which is best suited to explore a particular aspect of a question without some reflection about one's world view and the questions being asked in the study. In summary, this chapter explains *why* I did what I did, explaining first how theory helps to frame questions, and then describing the decision process for the study design chosen to answer the questions.

### 3.2 Using theory and paradigms

Paradigms are theories about the way we build our knowledge (Howell 2012, Polit and Beck 2010, Kelly et al. 2018, Fryer 2020). They represent a set of related ideas which ask fundamental philosophical questions about how people make sense of the world (Graphic 3.1). In this study I took a particular stance on each of these aspects and in this section, I examine and describe my own worldview.

Graphic 3.1 Paradigms and ways of thinking about the world around us



**Ontology.** Ontology considers the nature of existence (Horner and Westacott 2000). The research questions posed in Chapter 1 asked whether there might be differences of understanding which hamper the success of self-management and Chapter 2 has already argued that mental illness could be understood differently by different people. Chapter 2 introduced models which consider the problem of mental illness to be situated within an individual and other models which consider that the wider social context is important, and in some cases central. In that chapter I also showed that there were nuanced understandings which straddled more than one model. This positioning of the study indicates that from its outset, I have taken a view which says that our worlds can be understood in different ways i.e., that our understanding is subjective or relative. I

came to this study with a worldview which believes that there is no single truth about mental illness, and that even if there were, what matters is the way it is understood. This line of argument follows a well-established view which says that our worlds are socially constructed. Social constructionism is based on a key text first published in 1966 by Berger and Luckman (1991) which asserted that what is perceived as reality, is in fact a series of collective social agreements that the world is organised in a particular way. Constructivism, a related concept, views reality as constructed by the individual, while constructionism sees reality as it is constructed through interaction and language (Sommer-Flanagan 2015). Using this constructionist lens to view the research questions posed in this study about self-management, they might be articulated as *how is self-management constructed among those people who experience it, and does everybody construct it in a similar way?* Using this perspective, I arrive at my study question. Rather than asking *what 'is' self-management* I ask, *does self-management mean different things to different people?*

**Epistemology.** Epistemology considers the nature of knowledge, and what it is to know something (Horner and Westacott 2000). In a constructed world of many possible realities, the nature of the world is interpreted by the people who live in it. Consequently, knowledge is constructed by the people who acquire it rather than obtained through acquisition of a knowable truth (Gibbs 2010). Their process of acquiring knowledge is iterative, going back and forth, thinking and rethinking, interpreting, and re-interpreting their worlds. Iteration is a feature of my own qualitative work and in Chapter 4 I note how I have often found myself moving back and forth throughout the three stages of my study, refining and reconsidering. This practice aligns with Srivastava and Hopwood (2009, p. 76) who said that *“the role of iteration in qualitative data analysis, not as a repetitive mechanical task but as a reflexive process, is key to sparking insight and developing meaning”*. A researcher holding this worldview does not test a theory, rather they develop it based on what they observe. Put more simply, rather than asking *is 'this' what is going on in the world of self-management*, I ask *what 'is' going on in the world of self-management?*

**Axiology.** Axiology considers the role of the researcher's values in research (Dudovskiy 2021). The sum of a person's values, experiences and place in the world, their

*positionality*, is always present, whether they be participant, researcher, policymaker, or layperson. In Chapter 1.6, it was asserted that positionality matters. This study has been built around a belief that I am an intrinsic part of the process of constructing knowledge about the world. This means that it is important for me as a qualitative researcher, to be reflexive and curious about my impact on the process of knowledge exploration. Rather than asking, *has the research been biased as a result of the researcher and their decisions*, I ask *how has this research been interpreted by me as a result of who I am and the decisions I make?*

**Methodology.** The stance taken regarding these key questions about the world suggests the ways that the researcher explores it. I have shown how I operate in a constructionist world where what matters is not *what is*, but *what is understood*. The stated task of this study is to gain access to the world of self-management to see how it is constructed by different groups of people. That is best accomplished by accessing their world. This is done in the knowledge that I cannot possibly ask everybody, that one person is not necessarily representative of a whole group, and that whatever I find out will be my own subjective perspective on the limited perspectives I access. Richards captured this notion in her 2015 book.

*“If we are trying to understand people’s socially constructed understanding of their worlds, we can’t know in advance what to ask – or what to expect. We need methods which will access their accounts of their lives, in their words, not ours”* (Richards 2015, p27).

The qualitative methodology offers a toolkit of methods through which to inspect this uncertain world in a robust, credible way. They include, but are not restricted to, in-depth interviews, focus groups, and ethnography, whereby the researcher examines people in context, in the field.

Table 3.1 A figurative review of paradigms and methodologies

	Quantitative methodology	Qualitative methodology
<b>Ontology</b>	<p>Reality is objective, and there is one reality. Researchers think that reality can be described as it is, independent of human perceptions</p> <p>To do this, researchers often collect data through surveys and observations, using numbers and statistics to reveal what is really going on</p>	<p>There are multiple realities, and each reality is subjective. Researchers think there is no access to reality independent of our minds</p> <p>To do this, researchers often use the words of participants in quotes and themes to indicate differing perspectives</p>
<b>Epistemology</b>	<p>There is one truth and it is objective. Truth exists whether or not we believe it or interact with it, and it can be studied</p> <p>Researchers sometimes collect and analyse data without spending a lot of time with participants</p>	<p>There are multiple realities and truths and each is subjective to each person. Researchers want to understand the truth from the perspective of each person</p> <p>Researchers lessen the distance between themselves and the person, getting into the field and participating to gain an understanding of the participants view on their realities</p>
<b>Axiology</b>	<p>Facts can be separated from values</p> <p>Researchers try to remove bias and show statistically that the research is valid and reliable</p>	<p>Facts cannot be separated from values. We cannot describe things as they really are, but only as we perceive them. There is no such thing as an absolute objectivity. Researchers acknowledge their values and biases because they are part of the research and cannot be separated from it</p>

The inclusion of Table 3.1 is figurative, portraying an archetype of methodology which in practice I have found problematic. My own worldview suggests this study is aligned with a qualitative methodology but, in the end, method and theory decisions have sometimes had to be pragmatic. As will be seen in the next section where the decision processes are outlined, sometimes the best tool for the job, i.e., the best theory or method to answer the question, needs a little work. Kara (2018) acknowledged this tension when she outlined the difference between methodology and methods, with methodology the

worldview and method the tool or process which is used to examine the world. She noted that methods are not necessarily methodologically pure i.e., a method often is but does not have to be consistent with a worldview.

*“Methods are the tools researchers use to practice our craft: to gather and analyse information, write and present findings. We have methods for searching literature and sources, gathering and analysing data, reporting, presenting, and disseminating findings. Methodologies are the frameworks within which we do all of this work, and are built from opinions, beliefs, and values. These frameworks guide us in selecting the tools we use, though they are not entirely prescriptive. Therefore, one method, such as interviewing, may be used for research within different methodologies, such as realist evaluation or feminist research”* (Kara 2018).

Richards (2015 p, 27) agreed, noting that *“there are not two types of people, those who are qualitative researchers and those who are not. All good researchers can create data records and analyse them by a range of methods, as appropriate. But all good researchers are also aware of the nature of the reality that they are trying to explore”*.

### 3.3 Convincing an audience

An important aspect of the research process is to ensure that the people who are intended to engage with the work can have confidence in the conclusions it reaches. As understood in quantitative research, credibility is measured through validity and reliability which Polit and Beck (2010, p. 571) describe as *“the degree to which inferences made in a study are accurate and well-founded in measurement. The degree to which an instrument measures what it is intended to measure”*. In a qualitative world this notion of exposing a consistent truth about the world is problematic (Anfara 2002, Connelly 2016). In his 2015 (p. 326) paper Leung noted that, *“in quantitative research, reliability refers to exact replicability of the processes and the results. In qualitative research with diverse paradigms, such definition of reliability is challenging and epistemologically counter-intuitive. Hence, the essence of reliability for qualitative research lies with consistency”*. Golafshani (2003) discussed these challenges and

concluded that, for qualitative work, reliability and validity be reconceptualised as trustworthiness, rigour and quality. Citing Cresswell and Miller (2000), Golafshani promoted triangulation as a “*validity procedure where researchers search for convergence among multiple and different sources of information to form themes or categories in a study*” (2003, p. 604). This explains why it has been important to demonstrate Golafshani’s notion of trustworthiness, rigour and quality, and triangulation across three stages of the study in order to enhance confidence in the conclusions reached.

Interdisciplinarity introduced challenges relating to credibility and defensibility. The findings of this study will need to have relevance for a wider range of groups including policymakers and policy theorists, healthcare professionals and scholars, sociologists, and people with lived experience, and all will need to have confidence in the conclusions that pertains to their own area of expertise. This is challenging when each audience and discipline has its own conventions, theories, practices and languages. These can result in different ways of having confidence in the findings of research, and different expectations of how knowledge is created and understood. Not all readers of this study would be comfortable with qualitative methods, yet the questions I ask about meaning warrant the use of them. The methods and theories I chose therefore, represented a balance between those which answered the questions, satisfied the audience, and accorded with my worldview. That balance was sometimes uneasy.

### **3.4 Stage 1. Asking questions about policy and self-management**

The policy stage of the study was important. Under consideration was the option of using standard qualitative measures such as a series of interviews to explore self-management and promote the findings to policymakers as a way to advocate policy change. I recognised however, that this approach was unlikely to produce the outcome I sought in terms of policy change. As this section will explain, policy theory indicated that policy change is not so straightforward. It suggested that Stages 2 and 3 alone would not be sufficient to make a case for change without an understanding of how policy was made. Policy theory taught me that policymakers make policy on the basis of more than evidence, and sometimes in spite of it. Reviewing policy using policy theory was important as a means to explore why evidence sometimes did not result in meaningful

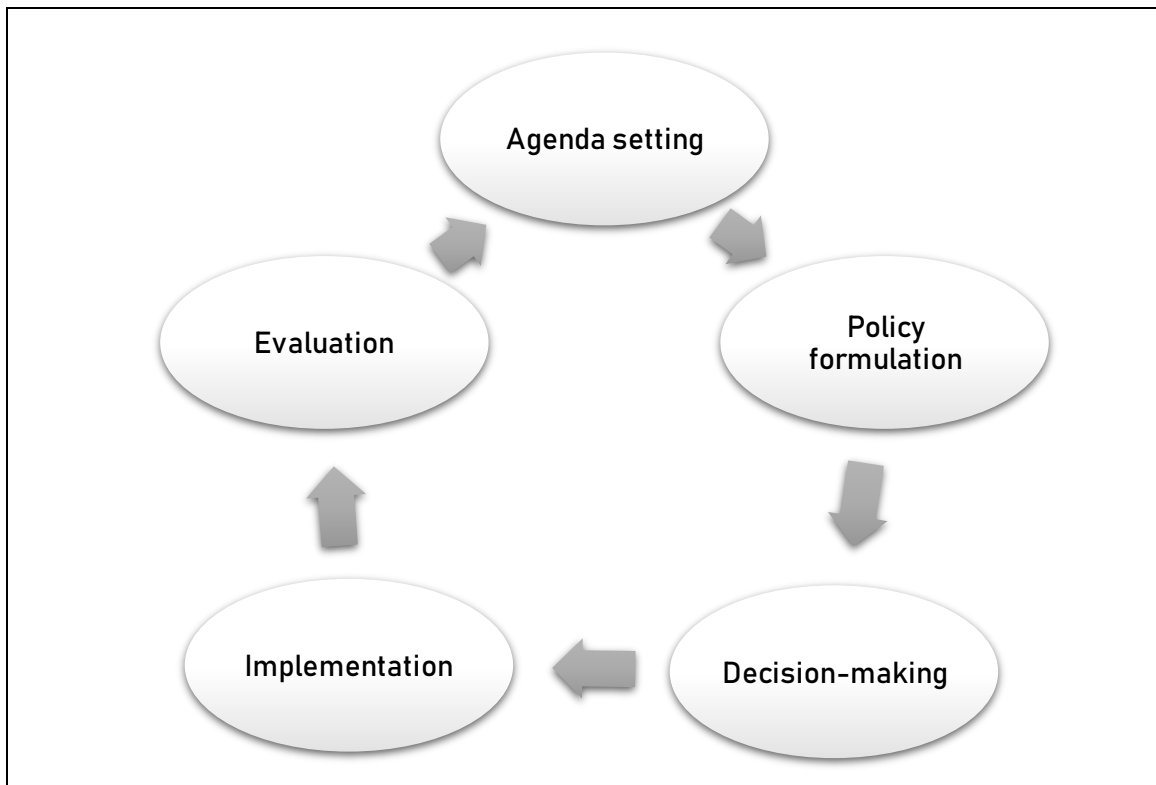


change. Finding out how policymakers construct mental health and self-management was vital because policy theory argues that policymaker understanding impacts the policy that they make (Cairney and St Denny 2020). In summary, this stage focussed on how policy is made and considered what the barriers to change might be.

#### *3.4.1 Making policy in an ideal world*

In the guidance given on the landing webpage of the Journal of Healthcare Communications (2021) potential readers and contributors are advised that *“health policy refers to decisions, plans, and actions which were undertaken to achieve specific health care goals within a society. An explicit health policy could achieve several things that include defining a vision for the future which in turn helps to establish targets and points of reference for the short and medium term. It outlines priorities and the expected roles of different groups and also builds consensus and informs people”*. This definition makes assumptions about how and why policymakers make policy. It requires that everybody involved in making and implementing policy agrees what the problem is, how important it is, how it should be tackled, and what will happen as a result. This assumes that governments know which health needs are important because they have sought and responded to the correct information from the people that are best positioned to give it, and that they know who to work with and what to do to achieve the results that it is assumed that everybody wants. It assumes that the resources assigned are sufficient and directed appropriately, and that the people responsible for translating policy into practice agree and will do their best to conduct their work in accordance with policy.

Graphic 3.2 The idealised policy cycle



This cycle of action represents a generic, idealised view (Cairney 2012), suggesting that policy is made in a rational process (Graphic 3.2). In this ideal-type scenario policymakers have unlimited attention and time to consider equally all topics, and that on the basis, make decisions according to logic and best available evidence. The decisions are then implemented in practice then evaluated. Should evaluation suggest changes are necessary, the process repeats.

#### *3.4.2 Making policy in a complex world*

Rather than the idealised view represented in Graphic 3.2, contemporary policy theories suggest that policy is made in an environment characterised by what Simon described in 1976 as “*bounded rationality*” (Mintrom 2015), where consensus and evaluation is disrupted by limited time, information, resources, energy, and willingness to consider the many pressing issues of the day. This results in the need for cognitive shortcuts to decision-making which may mean that policies are framed in a way that perpetuates the beliefs of those who make them. In this complex world of policymaking, access to influence the policymaking process is limited, meaning that decisions are made based

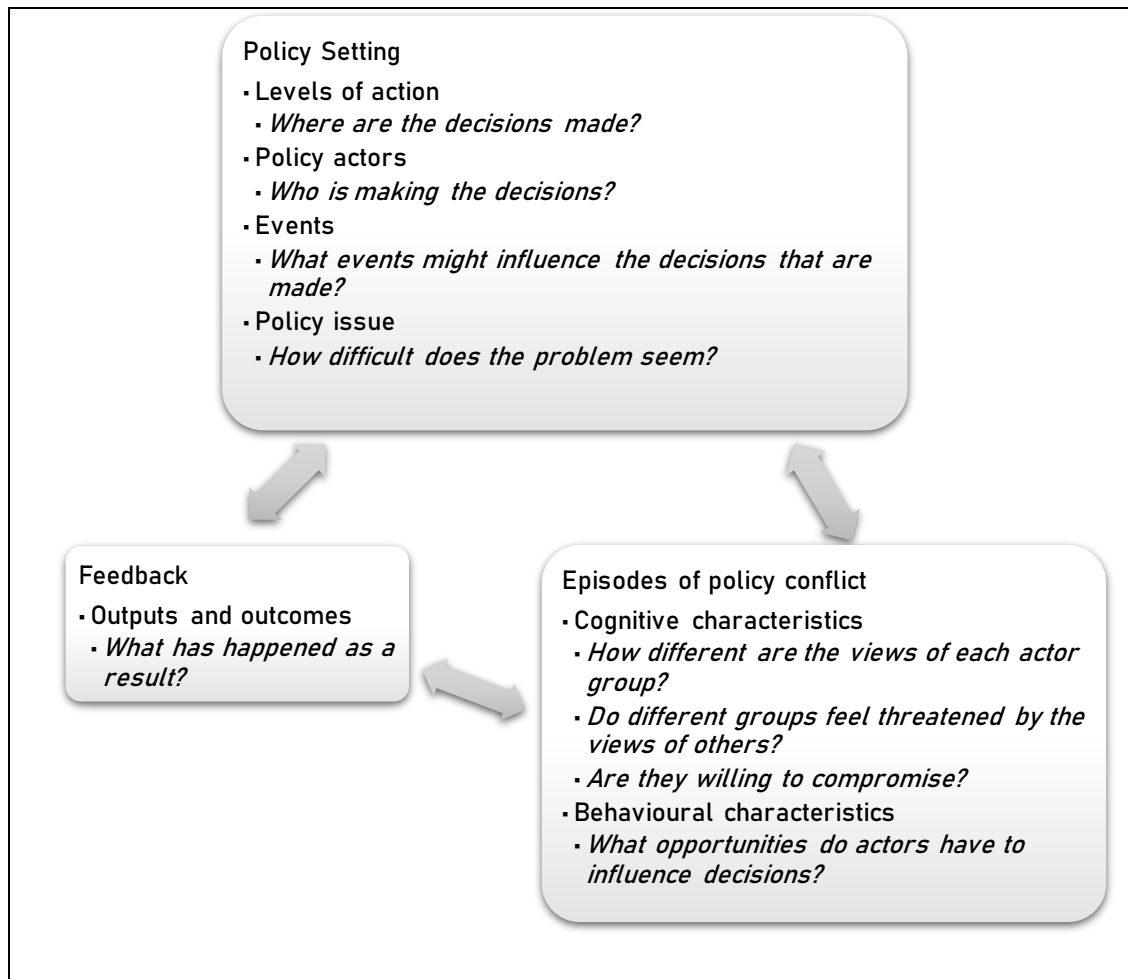
on only some voices. Self-management policy is part of what is understood as a complex policymaking world (Carey and Crammond 2015).

Policy theory offered a way to interrogate the complex world of self-management policymaking, but the abundance of policymaking theories initially presented a problem. The eventual decision about which policymaking theory to use was the result of a series of questions I asked myself about policymaking for self-management. For instance, if policymakers have limited time and attention to consider the many pressing issues of the day, under what circumstances might self-management become a pressing issue? If policymakers use cognitive shortcuts to make policy which is based on their beliefs, what are the beliefs they are using? If there is disagreement, or conflict, among policy actors about self-management, how are they aired and managed? If self-management can be understood in many different ways as has been described in Chapter 2, which of those different ways make their way to the policymakers' ears? What do policymakers do when presented with views which do not accord with their own? The questions centred around how policy theory considered not just how policy is made, but what happens when differences of understanding are encountered. While many theories consider policy conflict, few consider it in detail. Alone among them is the Policy Conflict Framework (Weible and Heikkila 2017).

### *3.4.3 The Policy Conflict Framework*

The Policy Conflict Framework (Weible and Heikkila 2017) was co-authored by Weible who was one of the key names associated with the well-developed Advocacy Coalition Framework on which the Policy Conflict Framework was based. The Policy Conflict Framework uses similar ideas and terminology to the Advocacy Coalition Framework, describing a policymaking world populated by coalitions/groups of different people, each defined by their shared beliefs and ideologies, and with different levels of agency to affect the policymaking process (Weible et al. 2011, Weible and Sabatier 2018, Jenkins-Smith et al. 2018). The advantage of using the Policy Conflict Framework to explore this topic rather than any other, is that it builds upon the ideas of the Advocacy Coalition Framework. It gives prominence to understanding what happens when different groups of people do not share beliefs and understandings and what happens when there is conflict, i.e., the Framework encourages me to explore how disagreements are resolved.

Graphic 3.3 The Policy Conflict Framework and the questions it asks. Adapted from Weible and Heikkila (2017)



This particular framework allowed me to consider the policy topic according to three key headings as noted in Graphic 3.3. It encouraged a review of where and how self-management policies are made (the policy setting), the characteristics of those involved in making them (episodes of policy conflict), and the results of their efforts (feedback). It enabled me to explore the research questions in terms of whether different groups of people involved with self-management agree on policy, believe that the policy positions of others will harm them, are willing to change their policy position to help produce consensus in practice, and are willing and able to engage in politics to influence policy.

#### *3.4.4 Using discourse analysis within the Policy Conflict Framework*

The Policy Conflict Framework is consistent with a constructionist worldview because it prompted a consideration of the context and effects of different ways of understanding self-management. Use of it required an examination of the beliefs, knowledge, and risk/benefit perceptions of individual policy actors. When the original authors of the Policy Conflict Framework first used it in their companion paper of the same year (Heikkila and Weible 2017), their questions relating to *episodes of policy conflict* were quantified using a Likert-based survey methods which measured the beliefs of policy actors in terms of the amount of divergence, perceived threat, and willingness to compromise between different groups. In their original 2017 paper however, Weible and Heikkila were not prescriptive about the tool of measurement.

*“In advancing empirical methods, data may be collected through any source including, but not limited to, surveys, interviews, and automated and manual document coding. While data collection often starts with observations of individuals, the data can be aggregated to organizations, and aggregated to different levels of action. Researchers may also observe the attributes of individuals, other aspects of a policy setting, and outputs and outcomes, through data sources such as laws, policies, news media, or existing data” (Weible and Heikkila 2017, p. 36).*

This quote indicates their openness to experimenting with the Framework using whatever means were deemed necessary to collect data. I appreciated the opportunity to use the structure of the Framework, albeit in a way that was best suited to ask my questions. I determined that for my own use of the Framework qualitative measurements were better suited to drill into the deeper beliefs and understandings I found in the policies I chose. This was particularly the case in this study, where conflict might not be overt, or where some of the contradictions and confusions may not be visible, or when there are drivers which encouraged obfuscation. A qualitative tool of measurement useful in this situation was discourse analysis.

Discourse analysis is an umbrella term for a variety of methods, based around a view that language is performative, i.e., language is an expression of understanding (Gee and Handford 2012, Jaworski and Coupland 2014, and as described in Chapter 1.6). This view is presented in the work of Sayce (2010), who suggested that the ways in which policymakers described and defined a situation as a problem determined the policies they create. Similarly, Bacchi (2016) considered that policy, by its very nature, *defined* a problem which policy is designed to address and said that policymakers' construction of the problem becomes enshrined in the policies they write, and is evident in the language of those policies. This being the case, interrogating the language of the policies and the wider policy setting as indicated in the questions asked by the policy conflict framework presented an opportunity to inspect understanding. Using discourse analysis in conjunction with the Policy Conflict Framework was a way to understand not only the policymaker's constructions, but whether other actors agreed with them, and to consider whether they were inclined or able to act upon any disagreement. Accordingly, in a departure from Weible and Heikkila's first use of the framework, Bacchi's discourse analysis method was chosen to underpin this particular application (Bacchi 2009, 2016).

Table 3.2 What's the problem represented to be? (Bacchi 2016 p. 20)

<p>1: What's the problem (e.g. of "gender inequality", "drug use/abuse", "economic development", "global warming", "childhood obesity", "irregular migration", etc.) represented to be in a specific policy or policies?</p> <p>2: What deep-seated presuppositions or assumptions (conceptual logics) underlie this representation of the "problem" (problem representation)?</p> <p>3: How has this representation of the "problem" come about?</p> <p>4: What is left unproblematic in this problem representation? Where are the silences? Can the "problem" be conceptualized differently?</p> <p>5: What effects (discursive, subjectification, lived) are produced by this representation of the "problem"?</p> <p>6: How and where has this representation of the "problem" been produced, disseminated, and defended? How has it been and/or how can it be disrupted and replaced?</p>
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Of all discourse analysis methods, Bacchi's (2009, 2016) *What's the problem represented to be?* offered the unique opportunity to ask, *if self-management is a solution, what do the policies suggest that the policymakers understood as the problem?* To explore this, Bacchi suggested that researchers work backwards from concrete policies and consider critically a series of six questions (Table 3.2). Thus, through analysis of the way in which policy is worded, discourse analysis made it possible to inspect how policymakers understood the problem they were trying to resolve by enshrining self-management in policy as a solution. As an alternative of the understanding which Heikkila and Weible had sought through quantitative surveys, discourse analysis offered a way to explore deeper understanding embedded within the language of policy documents. In this way, policies become the lens through which to examine the understanding of those who make policy and/or have the power to influence the policymaking process.

### 3.5 Stage 2. Asking questions about practice and self-management

The second stage of the study was designed to find out how self-management was understood by people who work with it on a day-to-day basis. It was important to understand what those who use self-management in their everyday lives think because it is they who make it work – or not. During this stage I wanted to find out *what* people understood when they talked about self-management. Preliminary literature searching had indicated that front-line practice views about self-management for mental health had already been the focus of research attention. It was noted, however, that studies sometimes considered mental illness alongside other conditions, rather than as the focus of enquiry (for example Slomka 2012). There were studies which reviewed the creation or effectiveness of the tools and interventions which had been created to support self-management activities, presupposing what self-management was and what was needed (for example Nicholas et al. 2017). Studies regarding effectiveness were often quantitative, and measured outcomes (for example Kilbourne et al. 2019). Studies which asked specifically *why* people self-managed and explored the meaning it had for them, were fewer in number. A decision was taken therefore, to inspect the existing literature about meaning of self-management using evidence synthesis methods. Looking at pre-existing studies through the lens of the questions of this study offered the potential to extract new knowledge from work that had already been done.

The method through which quantitative evidence syntheses are conducted is well-established (Lau 1997, Akher et al. 2019) but this study's constructivist focus on meaning and understanding suggested that a synthesis should examine the qualitative rather than quantitative evidence base. Several approaches to qualitative synthesis exist (Flemming et al. 2019) Some are reviewed in Barnett-Page and Thomas' 2009 paper including the deductive approach of a framework synthesis and content analysis which distils the content of findings into overarching categories. The decision in favour of meta-ethnography (Noblit and Hare 1988) was taken because it was specifically suited to the questions, type of research data and intentions of this study which included the development of a new model.

**Table 3.3 The seven phases of ethnography (Noblit and Hare 1988) and the 18 reporting criteria of the eMERGe reporting guidance (France et al. 2019a)**

<p><b>PHASE 1 - Getting started</b>  Reporting criterion 1—Rationale and context for the meta-ethnography  Reporting criterion 2—Aim(s) of the meta-ethnography  Reporting criterion 3—Focus of the meta-ethnography  Reporting criterion 4—Rationale for using meta-ethnography</p>
<p><b>PHASE 2—Deciding what is relevant</b>  Reporting criterion 5 - Search strategy  Reporting criterion 6—Search processes  Reporting criterion 7—Selecting primary studies  Reporting criterion 8—Outcome of study selection</p>
<p><b>PHASE 3—Reading included studies</b>  Reporting criterion 9—Reading and data extraction approach  Reporting criterion 10—Presenting characteristics of included studies</p>
<p><b>PHASE 4—Determining how studies are related</b>  Reporting criterion 11—Process for determining how studies are related  Reporting criterion 12—Outcome of relating studies</p>
<p><b>PHASE 5—Translating studies into one another</b>  Reporting criterion 13—Process of translating studies  Reporting criterion 14—Outcome of translation</p>
<p><b>PHASE 6—Synthesizing translations</b>  Reporting criterion 15—Synthesis process  Reporting criterion 16—Outcome of synthesis process</p>
<p><b>PHASE 7—Expressing the synthesis</b>  Reporting criterion 17—Summary of findings  Reporting criterion 18—Strengths, limitations, and reflexivity</p>



Meta-ethnography is a 7-phase synthesis approach (Table 3.3), used to synthesise qualitative evidence across a variety of fields, particularly health (Ring et al. 2011). Its value for this study is manifold in terms of its ability to note how people construct/understand their worlds, to pay particular attention to agreement and disagreement. Meta-ethnography has constructionism at its core. Phase 5 translation specifically required that I looked at how the original study participants understood the topic (first order constructs) and how the authors constructed their understanding of those understandings (second order constructs) (Noblit and Hare 1988). This process created a nested level of construction in which the researcher is required to describe how *they* understood how the *authors* understood how *participants* understood their experiences (third order constructs). Having wondered whether any synthesis which generated *an interpretation of an interpretation of an interpretation* could be considered to produce findings which were valid, Toye et al. (2014) concluded that it could, saying “*we agreed that qualitative synthesis is compatible with idiographic research if the interpretations remain firmly grounded in the primary qualitative studies*”. Meta-ethnography *does* demand that the researcher remains grounded in the original context, and this ensures the validity of findings. Meta-ethnography is well-positioned to examine how different people construct their worlds. It encourages a particular focus on agreements and disagreements, using an assessment of what Noblit and Hare (1988) described as reciprocal and refutational cases. Meta-ethnography is well-positioned to examine whether and under what circumstances views about self-management agree or disagree. A criticism of meta-ethnography was that the method lacked clarity of process for those researchers seeking to apply it. In 2014 France et al. noted that the lack of clarity in Noblit and Hare’s original text regarding how to conduct and report metaethnographies had led to inconsistency in subsequent applications of it. As noted in Chapter 3.3 this lack of rigour impacts the credibility of qualitative research. In response, France et al. created the eMERge guidelines for researchers using the method (France et al. 2019a). Table 3.3 shows those reporting guidelines alongside Noblit and Hare’s original phases. Through their use, France et al. intended to maximise transparency and facilitate trustworthiness in studies using the method. This robust approach to credibility afforded by France et al.’s (ibid.) supplementary advice was another positive factor in the decision to use this method.

An additional guiding force in this second stage was the need to discover *how* people constructed their understanding i.e., what do people consider when they think about what self-management means to them? In their paper reviewing how researchers had used the method, France et al. (2019a) noted that the value of meta-ethnography lay in its ability to produce a product that was more than the sum of its parts.

*“Meta-ethnography aims to produce novel interpretations that transcend individual study findings, rather than aggregate findings (Thorne, 2015). Meta-ethnography involves systematically comparing conceptual data from primary qualitative studies to identify and develop new overarching concepts, theories, and models”* (France et al. 2019a, pp. 2-3).

In another paper published the same year, France et al. (2019b) also said that *“if adequately conducted and reported, meta-ethnography has the potential to generate new evidence on how patients experience their own health condition, disease, or treatments and how this may influence their adherence to treatments”*. When making recommendations for future research to inform practice it would be important to understand how people experience self-management (Chapter 9). Meta-ethnography was, therefore, well-positioned to identify the questions people ask themselves in order to construct their understanding of self-management.

### **3.6 Stage 3. Asking questions through fieldwork**

In the final stage of my study, I intended to explore my research questions in a small primary study. Stage 2 had generated information from a selection of studies where the research questions outlined in this study were not necessarily the focus of attention, and which focused specifically on bipolar disorder. This final piece of work took the specific questions of this study back to people who were experienced in mental illness, which may or may not include the specific diagnosis of bipolar. This allowed me to complete the circle and test the thinking developed in the first two stages. It reinforced confidence in the robustness of the findings (Chapter 3.3). Again, this stage of the study was qualitative because it was intended to generate rich, deep attitudinal information from a range of different people, asking what self-management meant to them. Completing a

small primary study of this scale was a way to find out whether the questions people posed about self-management identified in Stage 2 were useful as a way of structuring my enquiries. As a small-scale study, it could pave the way to more substantive research in the future (Chapter 9). Input from a small group of people involved in the process of self-management based on the model would act as a triangulation tool i.e., if I found a similar range of views to those in Stage 2, it would provide evidence to support a view that the questions used were useful as a way of structuring conversations about self-management.

Consequently, this part of the study could not begin until Stage 2 was complete. Options considered at the outset included a participatory action research approach. Examples of this type of approach include filming, art or workshops (Pain et al. 2012). This type of research is done for the people, by the people, rather than *on* the people. Proponents of action research say that these methods are valuable because they consider “*the location of power in the research process*” (Cornwall and Jewkes 1995, p. 1667), though for Rose (2018), power remains a problem, and Cornwall and Jewkes (ibid.) themselves, were not unequivocal in their support of this type of research. As an option for this study, this attention to power in the research process became particularly salient (Chapter 8). With unlimited time such an approach would have been ideal, but methods of this kind were not feasible within the time constraints of the study. As a result, the primary choices were interviews or focus groups. Focus groups are valued because they are considered an efficient way of accessing large amounts of rich information about the views of a group of people (Lopez and Whitehead 2013). Acocella (2011, p. 1135), however, advised cautious use of the method. She pointed out that, “*the presence of other people can inhibit an individual and influence the way a judgment is formulated or an answer is given, thus pushing participants to express more socially desirable and stereotypical answers*”. By the time that Stage 3 was being developed, findings from stages 1 and 2 had demonstrated that different groups had differences of understanding, and that power imbalances acted to silence less powerful groups. In this way, I had shown already that focus groups were unsuitable. To allow each person to fully express their view, it was important that their view be foremost and unmediated. As a result, a decision was taken to conduct a small number of targeted interviews using semi-structured topic guide questions designed around the model. Braun and Clarke’s reflexive thematic analysis method was a pragmatic choice for analysing interview data, answering the research

questions and verifying the model with sufficient depth and qualitative coherence in the time available (Braun and Clarke, 2006, 2019; Clarke 2017). Although Byrne (2021) noted his concern that the method was often poorly conducted, he did note that it was an “*easily accessible and theoretically flexible interpretative approach to qualitative data analysis that facilitates the identification and analysis of patterns or themes in a given data set*”.

### 3.7 Summary

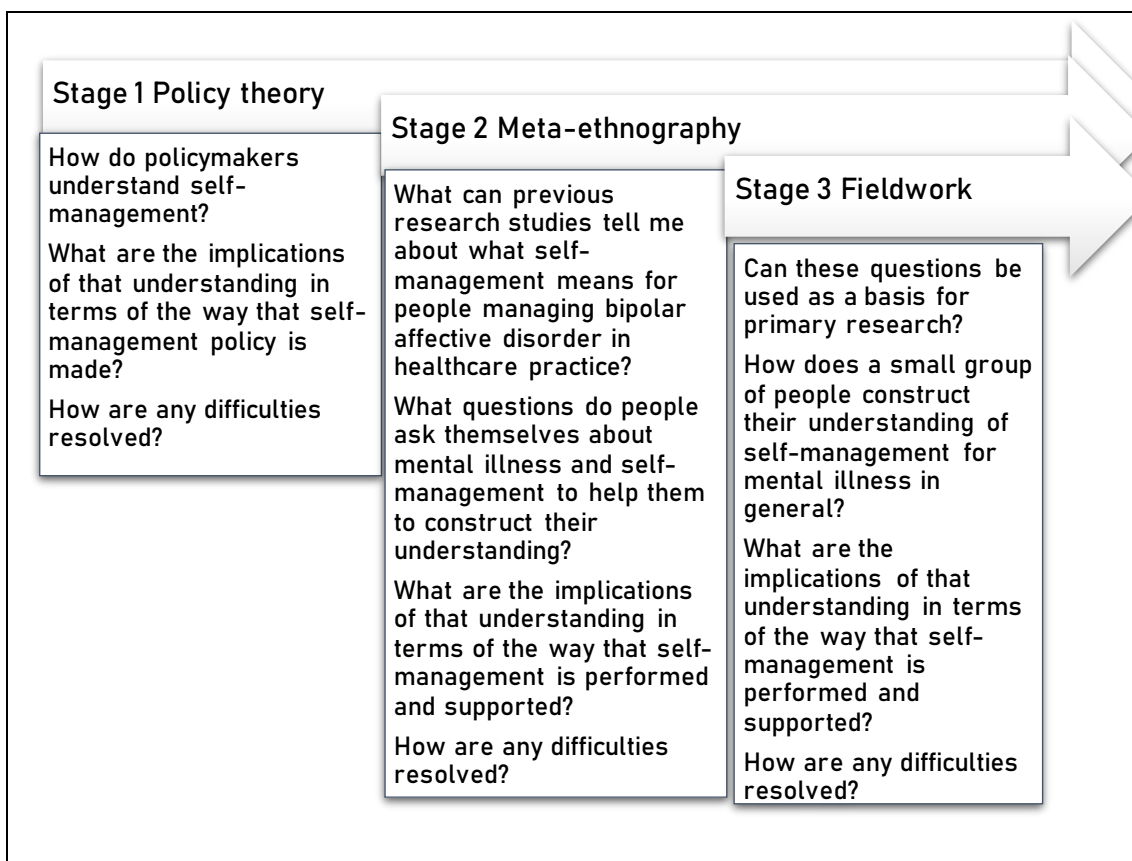
In this chapter I have explained that this study is grounded philosophically in a world where reality is uncertain and open to interpretation. Having determined that I wanted to explore how self-management is understood in healthcare settings, my constructionist viewpoint led me to wonder whether people understand self-management in different ways, and to ask what might happen as a result. The three stages of my study were designed to build on one another to illuminate different aspects of my research questions. The use of policy theory allowed me to understand how self-management policy is made. Using it provided an opportunity to explore how policymakers understand self-management and examine how disagreements are managed. Through the metaethnography process, I was able to explore how participants understood self-management in bipolar affective disorder. Metaethnography helped me to determine how people managed challenges and how they arrived at that understanding. I used the questions people used to construct their understanding in a small Stage 3 primary study which asked how a small selection of individuals understood self-management for mental illness more generally. In all, the three stages worked in qualitative harmony, allowing me to explore self-management thoroughly and robustly at a policy and practice level, and to do so in a way that facilitated articulation of my findings in a clear and engaging way.

## Chapter 4. Methods

### 4.1 Introduction

In Chapter 3 I described my worldview and explained why that led to me choosing a qualitative methodology to explore self-management for mental wellbeing. The three stages of the study were intended to complement each other in order to explore different aspects of the research question and reach a fuller view of the topic when pulled together (Chapter 8).

Graphic 4.1 Stages which are designed to complement each other



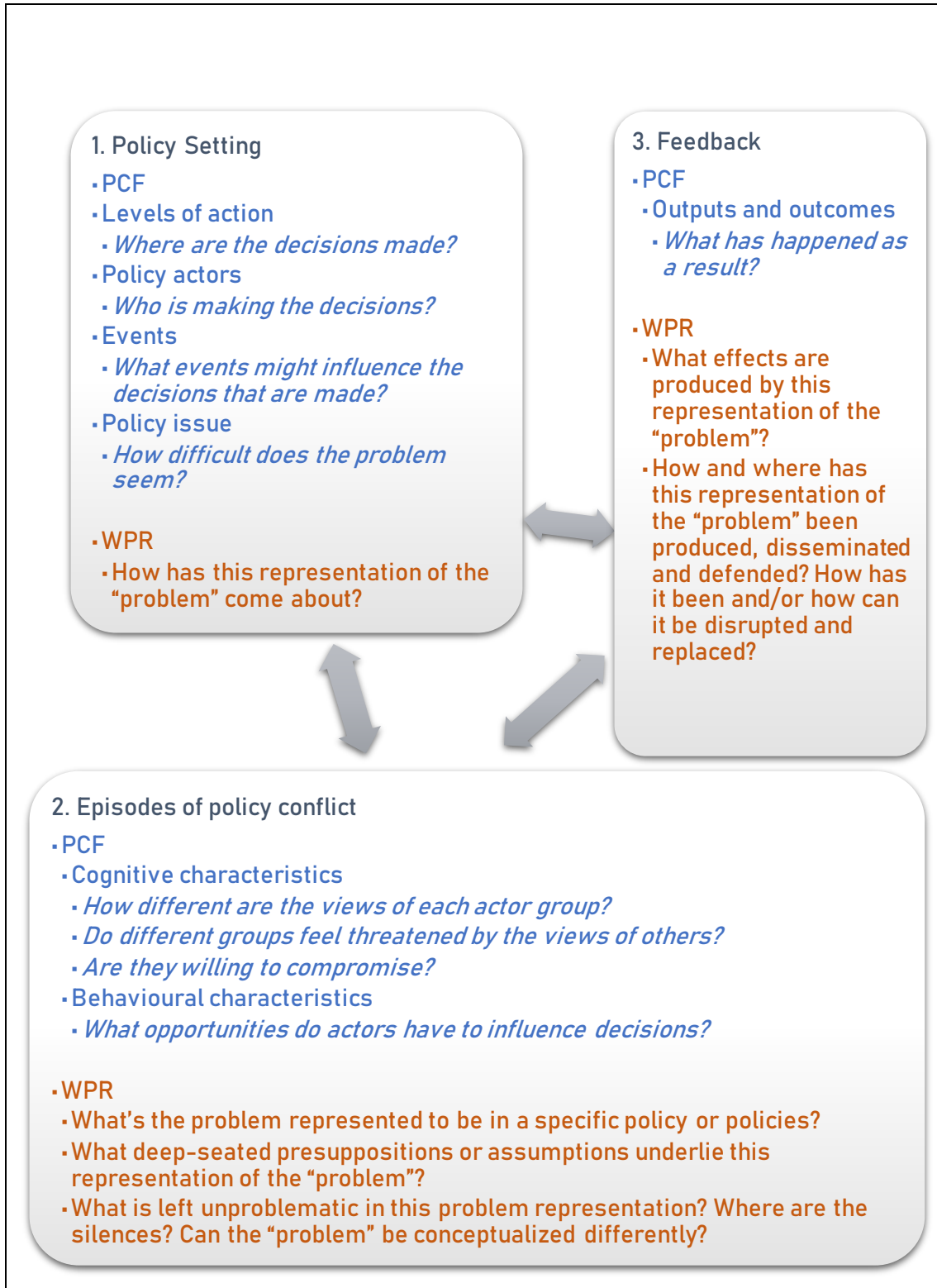
Graphic 4.1 shows that Stage 1 was designed to explore the policymaking environment. It would explore how policymakers understand self-management and consider what might happen when they encounter disagreement. Importantly, use of policy theory allowed me to consider how I might be able to frame my findings in a way that would promote engagement with my work. Stage 2 was designed to look at the evidence which

already existed. I used this to understand what was already known about self-management in practice relating to bipolar affective disorder. More than that, I wanted to ascertain the questions people used to construct their understanding of self-management. Those questions were presented to a small group of participants in Stage 3, where they were used within interviews in a small primary study as a way to explore the ways that self-management was understood in mental illness more generally with a variety of people, including policymakers, healthcare practitioners and people with lived experience. In summary, this chapter describes how I put each of the three stages into practice i.e., *how* I did what I did.

#### 4.2 Stage 1. Policy

Chapter 3.4 explained why I chose Weible and Heikkila's (2017) Policy Conflict Framework (PCF) as a way to structure an exploration of self-management in policy, and discourse analysis as a way to examine how policymaker understanding of self-management was represented in policy language. It meant that completion of Stage 1 combined two different frameworks; the PCF and Bacchi's (2009) *What's the Problem Represented to be* (WPR) framework. When it came to applying the approaches in practice, it was clear that although the WPR was primarily chosen to inform a particular aspect of the PCF i.e., to consider episodes of policy conflict, the range of questions it asked were helpful across this stage of the study. The two approaches worked well together because they each asked similar questions in a slightly different way. This helped to reconsider the topic with a slightly different emphasis each time and thereby conduct a more thorough review. Graphic 4.2 shows how the two approaches were combined.

Graphic 4.2 Combining the PCF and the WPR



The first task as described in Box 1 of Graphic 4.2 was a review of the policy setting. This was in essence, a contextual review of the mental health landscape in Scotland. This was accomplished by reviewing a wide range of government documents and secondary literature such as books and articles. It involved looking for the sorts of information that would help to answer the questions in Graphic 4.2. such that it was possible to understand where policies are made, who makes them, why, and what circumstances bring self-management into the sights of policymakers such that they feel policy decisions are necessary. The WPR's focus involved a consideration about how the representation of the problem had come about; a similar question asking about context.

Next came Box 2 of Graphic 4.2, *episodes of policy conflict*. It was important to review how self-management was understood, consider whether there was evidence to suggest differences of understanding, and if so, how those differences were handled. Having already determined that this could be achieved by considering how policymakers had articulated their understanding in policy documents (Chapter 3.4), I had first to choose policies to analyse. This choice of policy was challenging because there is no policy document currently in place which deals only with self-management for mental health. "Gaur Yersell" (Long Term Conditions Alliance and Scottish Government 2008) is however, a policy which deals with self-management of both physical and mental health and was chosen for analysis as an example of policy which deals with self-management. In terms of providing an example of policymaker views about mental health more generally, the current mental health strategy (Scottish Government 2017b) details the Scottish Government's overarching view on these matters. The current strategy replaces an older mental health strategy established in 2012 (Scottish Government 2012b). I felt that comparing the language of both would offer the chance to see whether policymaker views had changed over time.

With three policies chosen as representative, they were uploaded into NVivo. This was the way I chose to structure my process of close reading. NVivo is a piece of software designed with qualitative analysis in mind (QSR international 2021). While often recommended (Wiltshier 2011, Hilal and Alabri 2013), NVivo is not intended to replace the analytical skills of the researcher. Researchers still need to generate ideas and consider the order and structure of their data, but software makes it easier to organise.



This was the first of three times that NVivo was used with different data sets during this study (Chapters 4.3.5 and 4.4.4). As words, sentences, and paragraphs from the policy text were sorted into groups of codes best described them, I was thinking about the questions asked by the PCF and the WPR. An important question from the WPR was to consider language used to describe the problem the policies were meant to be addressing. It was also important to review what the policies did not say, and the concepts, terms and/or situations they presented as self-evident and unproblematic. The policies were compared with each other to understand how they were different or the same. Although this part of the PCF encouraged a review of the perceived threat and compromise between different groups of people, and the means they had to influence it, this had already been done when considering the policy context during the Box 1 process. Accordingly, I note that my use of the PCF was not strictly sequential but more a 'back and forth' through the data, considering and reconsidering each question.

Answering the questions in Box 3 of Graphic 4.2 meant a return to the mental health context, this time with a different set of questions. These questions required a review of the policies that were made and how they had been received. This time I considered the outcomes of the policy process, rather than the setting in which it was made. The findings of this process are in Chapter 5.

### **4.3 Stage 2. Meta-ethnography**

In Stage 2 qualitative evidence synthesis was used to think about what was already known about self-management in practice. Subsequently that process made it possible to determine the questions a person uses to construct their understanding of self-management, in this case, as they related to bipolar affective disorder. The meta-ethnography method is long-established (Noblit and Hare 1988), but in their 2014 paper France et al. noted variability in the way that meta-ethnographies were reported. Lack of reporting consistency, they argued, had the potential to negatively impact transparency of studies using this method. Their 2019 paper detailed an optimal method for reporting future meta-ethnographical studies, and it is these eMERGe guidelines which have informed the structure of the meta-ethnography reported in this thesis (France et al. 2019a).

### *4.3.1 Phase 1. Getting started*

Phase 1 of France et al.'s (2019a) guidelines require researchers to describe fully the context of their work, articulate their questions, and state their rationale for choosing Noblit and Hare's (1988) meta-ethnography method. This information can be found in Chapters 1 and 3.

### *4.3.2 Phase 2. Deciding what is relevant*

At a high level, the process by which papers are selected for a meta-ethnography is straightforward. In practice, a series of decisions are necessary (Table 4.1).

Table 4.1 Selecting papers for the meta-ethnography

Task	Points to consider
Devise a search strategy which identifies the scope of the search i.e., clearly defines the topic of interest. Identify which databases to use to find papers	How to specify all aspects of the topic of interest such that the papers found are likely to yield information directly relevant to the research questions  How to choose search engines most likely to find papers which are relevant  Considering how the specificity of the scope might limit subsequent findings
Conduct the searches and remove any duplicate papers	How to manage the large amount of information arising from searches which are likely to yield many papers  How to record the process of searching and selecting so that it can be accurately reported
Review the remaining papers and retain for consideration those which are directly relevant to the topic of interest. Exclude the remainder	How to decide which papers to include or exclude such that the papers chosen are those most likely to yield information directly relevant to the research questions
Review the shortlisted papers more closely to ensure that the final selected papers are directly relevant to the topic	How to decide in those cases when it is not clear whether a paper should be included or excluded

A search strategy is a plan constructed by the researcher which helps them to decide which papers to search for. SPIDER (**S**ample, **P**henomenon of Interest, **D**esign, **E**valuation, **R**esearch type) was developed by Cooke et al. (2012) as a useful tool to ensure that the scope of the search is well defined, and this is what was used for this study.

Table 4.2 The search strategy according to SPIDER

Databases	CINAHL Complete, MEDLINE, APA PsycInfo, APA PsycArticles, SocINDEX with Full Text, Health Source: Nursing/Academic Edition
Date range	1980 to April 2019
Language	English
Sample Phenomenon of Interest Design Evaluation Research Type	Adult (18+ years old) self-management of bipolar disorder bipolar or manic depression experience or attitudes qualitative or mixed method

- The academic databases used were CINAHL Complete, MEDLINE, APA PsycInfo, APA PsycArticles, SocINDEX with Full Text, and Health Source: Nursing/Academic Edition. Databases were chosen on the basis that they were most likely to lead to papers dealing with self-management of mental wellbeing. For example, self-management is likely to be promoted in practice by healthcare professionals, and CINAHL Complete, Health Source: Nursing/Academic Edition and MEDLINE typically publish nursing and medical research, but the topic of mental health often involves other disciplines such as psychology and sociology. This suggested the use of APA PsycArticles, APA PsycInfo and SocINDEX with Full Text.
- In order to capture papers written from the beginning of the self-management movement the date range of the search was broad, covering all papers published since 1980 to April 2019, when the searches were conducted.
- The papers needed to be in English, since there was no translation facility available.
- Deciding upon search terms was challenging. There are numerous terms for mental health and self-management, and preliminary searches using boolean searches combined with “AND”, based on as many synonyms for both as could

be identified, yielded an overwhelming number of papers, far beyond the means of this study to synthesise in the time available. I took a decision to focus on self-management alone as a descriptor, and one diagnostic label, “bipolar affective disorder”. Preliminary literature searches had shown that there were disparate mental illness diagnoses. Using a single diagnostic label meant that the synthesis acted as a case study within the broader phenomenon. Bipolar disorder was used as a context-specific example of self-management relating to severe and enduring mental illness diagnosis. The final search strategy is detailed in Table 4.2 and was developed with support and guidance from experienced senior staff including thesis supervisors and information specialists in the university library. The effect of making such a decision had implications for the findings and is discussed in Chapter 8.

Following a search based on the criteria detailed above, the title, date, author(s) and abstract details were uploaded into an Excel spreadsheet. There is little guidance in Noblit and Hare’s text (1988) about how to manage the administrative aspects of search record keeping. It is important to note, however, that meta-ethnography preceded electronic searching and data management tools. Comprehensive electronic data searches in the contemporary era can result in vast amounts of material; a prospect less likely to be encountered by researchers in 1988. Managing this task using Excel was a personal choice, based on experience, confidence with the software, and the ability to store all of the search process in one, at-a-glance place. This use of software made it easy to identify and exclude duplicates and provided an ongoing record of the process which could be used for reporting.

The de-duplicated records had to be reviewed in order to decide which were directly relevant for the meta-ethnography. This is generally accomplished through the use of inclusion and exclusion criteria, which define clearly the attributes of a paper which warrant further examination. For this study the criteria were as described in Table 4.3.

Table 4.3 Inclusion and exclusion criteria

Include if:	Exclude if:
<p>Reports primary qualitative data and is written in English</p> <p>Has as a focus the self-management of bipolar affective disorder by individuals with lived experience from any perspective</p> <p>Population includes adults 18+ self-managing in the community</p>	<p>Data is derived from quantitative studies, or it is not primary research e.g., it is an editorial</p> <p>Population is inpatient, young people, learning disabled, forensic</p> <p>Reports on other aspects of bipolar disorder e.g., the development or assessment of a tool to support self-management, reports living with conditions other than bipolar disorder</p> <p>Are first-person accounts</p>

- The included papers needed to report sufficient primary data. The meta-ethnography method is best suited to syntheses of primary studies, so literature reviews, guidelines, reports, books, and discussion papers were excluded.
- Chapter 3 said that this study was intended to focus on meaning and explained why qualitative methods were best suited to this sort of examination. It justified the use of meta-ethnography as a method of qualitative evidence synthesis. Accordingly, quantitative papers were discounted even when they were primary studies because they did not focus on meaning. Mixed method designs were included, but there needed to be sufficient qualitative data. Whether a paper had *sufficient* qualitative data was a challenging subjective judgement, made on a case-by-case basis. For some, the qualitative portion was sourced solely from a free-text field on a longer survey, and there was insufficient time to contact authors to ask if they could provide additional information. These papers were excluded on the basis that this information was considered too superficial to be of use.
- The included papers also needed to have as a focus the self-management of bipolar disorder by those with a diagnosis and those who supported them. Papers with a focus on co-morbid mental or physical conditions were excluded. As mentioned in Chapter 3.5, fewer papers had a focus on how self-management was understood.
- The included papers needed to feature adults aged 18 years and over living in the community. Papers featuring young people under 18 living in the community

were excluded because self-management, for them, is more complex involving a wider range of factors (Nightingale et al. 2019, Lozano and Houtrow 2018). Forensic, learning disabled and inpatient populations were similarly excluded in discussion with thesis supervisors.

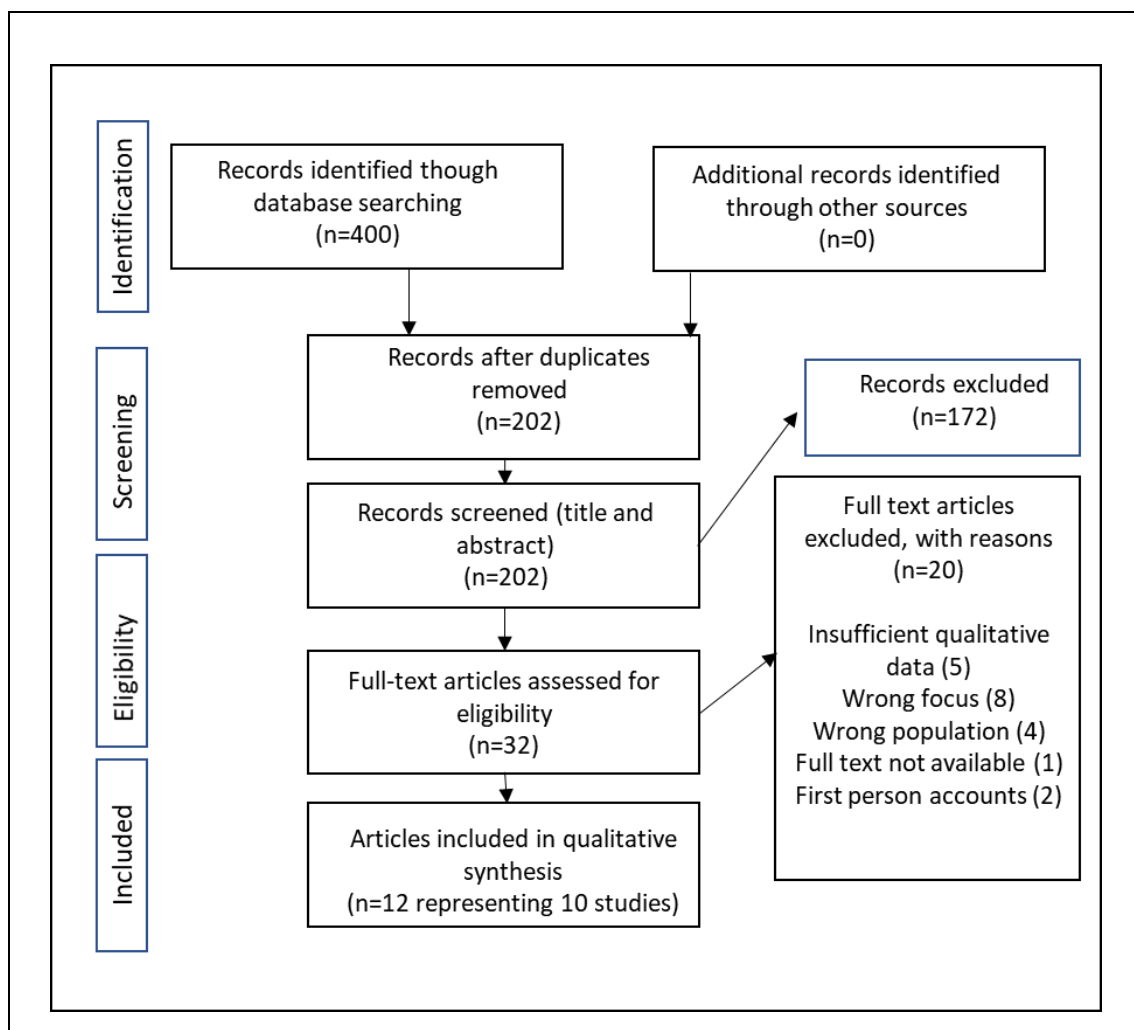
Title and abstract screening identified those papers which met the inclusion criteria at a high-level. An unexpected extra step was the need to briefly scan the full text of the papers which remained after the title and abstract search because titles and abstracts often did not give sufficient information on which to assess their suitability for this study. For the next refinement stage, the shortlisted papers were read more fully to ensure that the final selected papers were directly relevant. This process was facilitated using a quality appraisal tool i.e., the Critical Skills Appraisal Programme (CASP) (CASP 2021). Questions arising from CASP include asking whether the relationship between the researcher and participants was adequately considered, and whether the recruitment strategy was appropriate to the aims of the research. In much research CASP is a process through which low-quality studies are excluded from the final sample but exclusion on this basis is contentious in the qualitative worldview (Noblit and Hare 1988, Garside 2013, Toye et al. 2013). In this case I excluded no papers on the basis of CASP, but it proved a useful way to critically engage with their content.

The shortlist included several borderline papers. In accordance with good practice (Lombard 2010), a second opinion process was undertaken through consultation with a 2<sup>nd</sup> reviewer who was a research student peer. Where this did not result in agreement, this was discussed during supervision. As a key author in the France et al. (2019a) paper, one of the thesis supervisors, Professor Ring, was well-placed to advise and acted as a third reviewer. Some difficult inclusion and exclusion choices were discussed in this forum, and this led to refinement of the inclusion criteria which, it was realised, was insufficiently detailed. For example, one study was excluded on the basis of wrong focus, because it asked people how they *might* self-manage had they been given a diagnosis. A common focus was the development and assessment of tools intended to support self-management. Papers with this focus were excluded because the existence of a tool necessarily presupposes that the nature of self-management is already known. Paper 9 (Chapter 6) was included because although it concerned creation of a tool, the study

was focused on the preliminary stages of development, asking how self-management was understood so a tool could be built. Two papers were excluded because they were first person accounts and in discussion, it was felt that their inclusion would give undue prominence to a single account within a small group of papers.

The full selection process was captured using the PRISMA diagram shown in Graphic 4.3. Commonly used in quantitative systematic reviews, PRISMA was developed to standardise reporting and aid transparency of systematic reviews following concerns about quantitative synthesis reporting (Moher et al. 2009). My use of it reflects PRISMA's wider applicability for evidence syntheses and is recommended by France et al. (2019a) but has necessitated amendment to reflect a qualitative process.

Graphic 4.3 PRISMA (adapted from Moher et al. 2009)



The PRISMA summarises the outcome of each stage of the selection process. It shows that a search using the strategy detailed above yielded 400 papers, and once duplicates were removed, 202 remained. Inclusion on the basis of the criteria in Table 4.3 left 32 shortlisted papers which were read in full according to the process described. From this shortlist, twelve papers were finally selected for inclusion in the review.

### *4.3.3 Phase 3. Reading included studies*

Noblit and Hare (1988) suggested that repeated reading of the selected papers should be purposeful and critical. Through it, they proposed that the researcher could be entirely immersed in the papers, generating a deep curiosity, ultimately resulting in detailed attention. However, they provide little clarity about how this may be accomplished and recorded.

Table 4.4 Attributes to report as characteristics (adapted from France et al. 2019a)

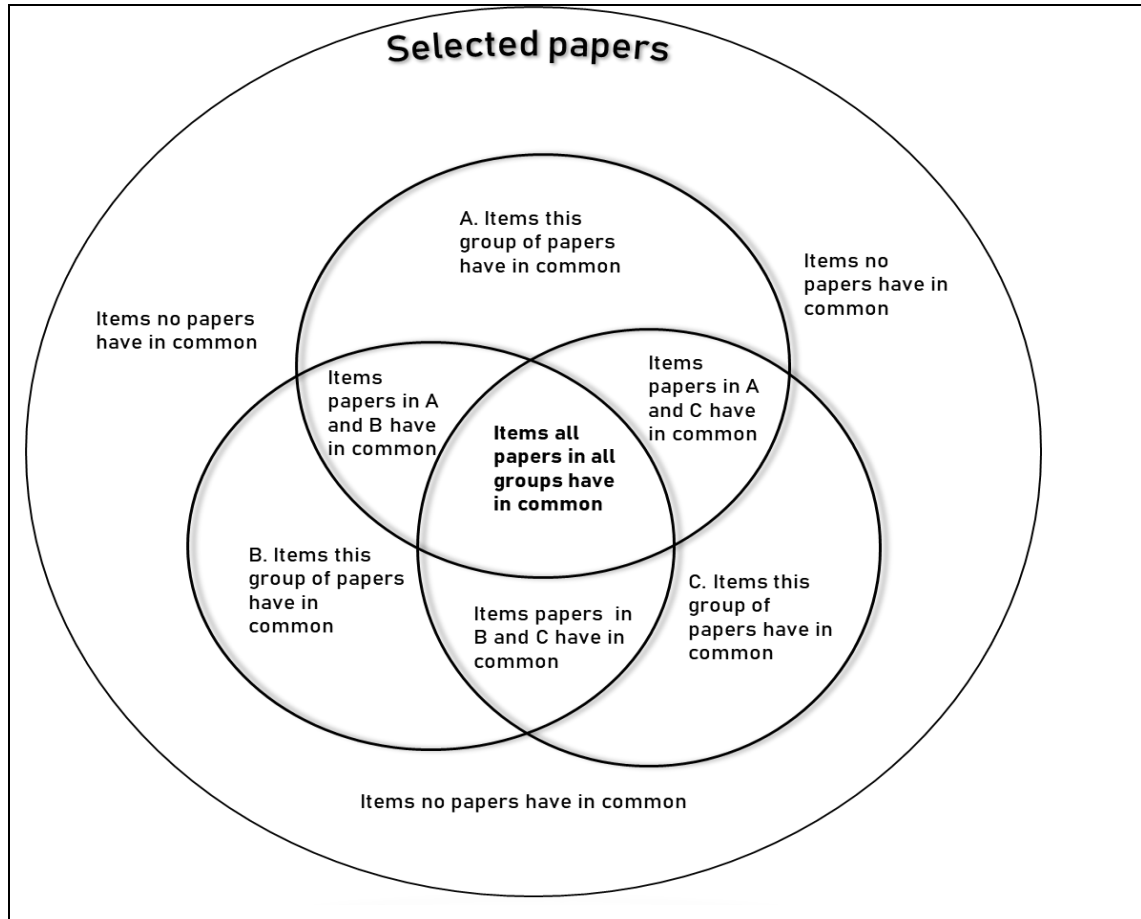
- Study characteristics (such as year of publication, population, number of participants, data collection, methodology, analysis, research questions, study funder)
- Key contextual information about the primary studies and comment on their relevance to the context(s) specified in the meta-ethnography review question. Context of included primary studies can influence the analysis process, for example, primary study accounts published after a certain date may reflect a change in health policy/practice such as the introduction of a smoking ban in enclosed public places
- If two or more included primary study accounts, for example, papers, were derived from the same primary study, this should be made explicit
- Contextual information should include details about the primary study participants (such as their gender, age, socio-economic status, ethnicity, and so on)
- The setting such as a geographical setting (a country, region, city) or organization (hospital, school, company, community)
- Key political, historical, and cultural factors of relevance, for instance, the introduction of a major international guideline, which affected clinical care, preceded publication of included studies. If such contextual information is not available in the primary study accounts, reviewers should make this clear to readers



France et al. (2019a) offered more detailed guidance concerning the features of the papers that the reviewer should be looking for (Table 4.4). These included study characteristics such as year of publication, population, number of participants, data collection, methodology, analysis, research questions, study funder. Describing what the paper reports is centrally important i.e., what did the study find, how did the study authors talk about and organise their findings, and how did the authors of the paper interpret the findings. Undertaking this process helped to develop an understanding about the concepts and/or metaphors that the authors used in each paper. At this stage it was necessary to resist the urge to re-interpret concepts/metaphors: the language and structure of the papers needed to be preserved so that connection to the authors' original meaning was not lost (Campbell et al. 2011). Once complete this process resulted in a table detailing the key characteristics of each study, which is presented and described in Chapter 6.2.

#### 4.3.4 Phase 4. Determining how studies are related

Graphic 4.4 Grouping papers



Moving to Phase 4, I considered how papers related to the review questions and each other. The key question in this phase was to ask myself in what ways papers were the same (*reciprocally related*), and/or different (*refutationally related*) (Graphic 4.4).

Table 4.5 Aspects which could be related (adapted from France et al. 2019a)

<p>Aspects could include research design such as:</p> <ul style="list-style-type: none"><li>• The study aims, contexts, type of studies, theoretical approach/paradigm</li><li>• Participant characteristics, for example, their gender, ethnicity, culture, or age</li><li>• Study focus, for example, a health or social issue, long-term conditions, other diseases, or care settings</li><li>• Findings</li><li>• The meaning of the concepts, metaphors, and/or themes</li><li>• The overarching storyline or explanation of a phenomenon from the primary study accounts</li><li>• Other contextual factors, such as the time-period, i.e., whether findings of primary study accounts differed because they were conducted in different time contexts</li></ul>
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Guidance from France et al. (2019a) suggested aspects of each paper to consider when determining the similarities and differences (Table 4.5). In some metaethnographies, there may be few differences in the way findings are described and interpreted, with all the selected papers largely agreeing. Others may reveal some differences between or within papers, possibly in terms of what the participants said, how the authors interpreted it, or general conflicts of ideas. Refutational papers or sections of papers such as these act as *disconfirming cases*. The research questions I had posed to guide this review asked whether there was an agreed understanding of self-management. This meant that identification of disconfirming cases was vital. Campbell et al. (2011, p. 10) note that in this phase translation/interpreting the papers is not the goal. They say it is important to “[retain], as far as possible, the terminology used by the authors in order to remain faithful to the original meanings”. Use of computer software meant that interpretation and

paraphrasing of the texts was minimised, since it was possible to maintain the integrity and context of the original text. The selected papers were loaded into NVivo. The merits and demerits of NVivo have already been discussed in Chapter 4.2. According to the eMERGe reporting guidelines (France et al. 2019a), researchers should present the outcome of relating the studies and these are detailed in Chapter 6.3.

#### *4.3.5 Phase 5. Translating studies into one another*

Translation is a process of deconstructing, then reconstructing, the meaning of the selected papers, by taking; 1) the interpretation that the participant made of their own experiences (first order interpretation), 2) the way the authors of the papers interpreted participant interpretations (second order interpretation), so that the meta-ethnography researcher can 3) re-interpret those interpretations (third order interpretation). The metaphors and concepts identified in the earlier stages of the meta-ethnography process were translated from the very specific language that the original participants and authors used, into a universal tongue which made it possible to lay the studies next to each other. Through this process it was easier to see where there was agreement/disagreement and take a view about how self-management was talked about in the papers. The context of the original concepts had to be retained, particularly in terms of whose interpretation was being presented. I coded the papers paper-by-paper, line-by-line, and in alphabetical order according to first author surname. NVivo memos and comments were used to capture thoughts and personal reflections as they emerged. Coding frequently resulted in moving back and forth through the papers to capture new ideas/codes, expand old ones, and being open and curious as new thinking occurred. In practice the NVivo codes that were created represented a universal language where concepts which covered the same notion were grouped, while retaining 'who said what' and 'where' in the original text. In this way, reviewer interpretations of the concepts were never disconnected from the way that the paper authors interpreted the interpretations of their participants. According to the reporting guidelines (France et al. 2019a), researchers should present the outcome of translating the studies, and this can be found in Chapter 6.4.

#### *4.3.6 Phase 6. Synthesising translations*

By this stage, use of the meta-ethnography method had offered a way to describe, interpret and consider a number of studies which originally used different ways to look

at, describe, and interpret their work. By collecting the key attributes and distilling the core ideas found in each study into a universal language, it had been possible to identify and consider the differences and similarities within and between each study. Importantly it had offered a way to achieve this without losing the connectedness to the original context, or to the participants. The culmination of this process is synthesis whereby the reviewer creates a sum which is greater than the parts. The purpose of the meta-ethnography is to develop a new way of thinking about the topic as a whole, by creating a new line of argument synthesis. As France et al. (2019a, p. 10) said “*A line of argument synthesis aims to provide a fresh interpretation; it goes further than translation and puts any similarities and dissimilarities into a new interpretive context*”. Noblit and Hare (1988, p. 63) said that “*the goal of lines-of-argument synthesis is to discover a ‘whole’ among a set of parts*”.

In practice, the codes were arranged into a hierarchy of similar ideas. A high-level code was a key concept or theme, with related concepts or subthemes feeding into it. The codes were reviewed in conjunction with the memos and comments, producing an early model. This was adapted and reconfigured through several iterations to ensure that it was an accurate representation of the headings that people used to construct their understanding of self-management as detailed in the selected papers. Through the supervision process, an experienced researcher was able to offer valued suggestions about coding and how best to use the software. They offered their view regarding emerging thinking and the model, and through this process the synthesis was finalised. According to the reporting guidelines (France et al. 2019a), researchers should report the outcome of synthesising the studies, and this can be found in Chapter 6.5.

#### *4.3.7 Phase 7. Expressing the synthesis*

According to the reporting guidelines (France et al. 2019a), researchers should report a summary of the findings. I have provided a narrative description of the findings and provided a summary model of how self-management is understood in Chapter 6. In Chapter 8 I offer further discussion when I consider the findings of all three stages as a whole. The guidelines also say that researchers should consider the strengths and limitations, together with a reflexive account of the process. This can also be found in Chapter 8.

#### 4.4 Stage 3. Fieldwork

Chapter 3.6 showed why I chose fieldwork using one-to-one interviews as the final stage of this study. As described, the metaethnography was intended to identify the questions people used to construct their understanding of *self-management of bipolar disorder*. I believed that these questions would be a useful foundation as a way to explore how different participants constructed their understanding about self-management of *mental illness more generally*.

##### 4.4.1 Ethics, confidentiality and data storage

As indicated, Stage 3 necessarily followed Stage 2. This meant that ethical approval had to be sought late into the study. Approval requires that the researcher details how, who, what and why they propose to conduct a study in the field and this level of detail was not sufficiently clear until Stage 2 was largely complete. In advance of Stage 3 fieldwork, ethical approval was sought from Stirling University's General University Ethics Panel (GUEP) (Appendix 1) (Stirling University 2021).

Table 4.6 Suite of documents required for ethical approval

Document	Intended for	Purpose
Ethics request form	Researcher	Overarching document seeking approval from the ethics panel which details the proposed research fieldwork and the measures taken to ensure ethical integrity
Contact document	Participant	Sent to potential participants asking them if they might take part in the research. Provides information about what to do if interested
Participant information sheet	Participant	Given to participants in advance of taking part. Provides information about the research so that a decision to take part is fully informed. Provides information about who to contact if further information is required
Topic guide	Researcher	Used in interviews by the researcher to guide the questions that they ask
Consent form	Participant	Used to record informed consent

Participant debriefing sheet	Participant	Given to participants at the conclusion of the interview. Provides information about the research for future reference and details who to contact in the event of further questions
Data security form	Researcher	Used by the researcher to record how anonymity and confidentiality will be secured
Researcher risk assessment	Researcher	Used by the researcher to record how researcher safety will be ensured
Ethical approval form	Researcher	Confirmation document detailing that ethical approval has been awarded

Ethical approval is an important aspect of research, and is intended to protect participants, especially those who would be considered more vulnerable such as those living with a mental health diagnosis (UK Research and Innovation 2021). The participant-facing documentation submitted for approval included the wording of an initial email intended to promote recruitment, a participant information sheet sent with the recruitment email to detail what would be involved, a consent form which would be signed by participant and researcher to indicate that consent was fully informed, and a post-interview document which interviewees could retain for future reference. The participant information sheet covered:

- the aims and questions of the study and details about what would happen during the interview;
- the participants' right to withdraw at any time and to have their data removed from the study;
- measures taken to ensure the confidentiality and anonymity of the participants;
- measures taken to ensure the physical and mental safety of the participants. This explained how to access support if it was needed and the right to decline questions or stop the interview at any time;
- the secure storage of research artefacts.

Participant-facing information was written in accessible, jargon-free language, using a clear font and spacing. In addition to feedback about the documents from supervision, the ethics committee scrutinised the acceptability, accessibility and comprehensiveness

of the documentation intended for use by the researcher and participants (Table 4.6). It also considered the measures taken to ensure the physical and mental safety of the researcher. All documents were version controlled. The participant information sheet, and the consent form approved for participant use is reproduced in Appendix 1. Data security and storage is discussed in Chapter 4.4.5.

#### *4.4.2 Sample and recruitment*

Sampling is a process through which participants are chosen, and accomplishing it is dependent on the aim of the fieldwork (Koerber and McMichael 2008). The aim was to understand whether the questions people used to construct their understanding of self-management *in bipolar* were a useful way to understand self-management in mental illness *more generally*. Due to inevitable time and resource constraints resulting from being in the final year of PhD funding, a pragmatic choice was made to undertake targeted, purposive sampling of a small number of individuals who occupied different self-management roles. Campbell et al. (2020, p. 654) defended the choice of purposive sampling, and said that “*the reasons for adopting a purposive strategy are based on the assumption that, given the aims and objectives of the study, specific kinds of people may hold different and important views about the ideas and issues at question and therefore need to be included in the sample*”. When making this decision I was aware of the wider debates about sampling. Fusch and Ness (2015) argued that researchers should attempt to achieve saturation i.e., there is sufficient interview information such that analysis offers no new codes, themes or ideas. The intention of this stage of the study was to access a representative sample, rather than an exhaustive one. No attempt was made to achieve a saturated study sample accessing a full range of potential views in this study, not least of all because of the pragmatic issues mentioned above. Also, with a constructionist worldview, the notion of saturation is challenging. If everybody constructs their experience of life in different ways, how can we ever hope to access them all? Although new themes were not emerging after six participants, it is acknowledged that the sample was small. There would be advantage in using the questions with a wider number of participants than sought in this small qualitative study, and I discuss the opportunity of building on this work at post-doctoral level in Chapter 9.2.4 An alternative to purposive sampling is convenience sampling, where the researchers opportunistically recruit from the population that is easily available to them (Campbell et al. 2020). By the time the fieldwork stage was planned in detail, earlier stages of the study had shown that

understanding tended to differ depending on how the person engaged with the day-to-day practice of self-management i.e., whether they were a policymaker, a healthcare professional or person with lived experience. Given the aim to establish whether the new model was useful as a way of exploring understanding across a range of people involved with self-management, convenience sampling within the small field study described here was unlikely to be able to target the different groups of people/vantage points desired (Lopez and Whitehead 2013).

**Table 4.7 Categories of participants recruited to Stage 3 as approved by the ethics panel**

<ul style="list-style-type: none"><li>• Policymaker with experience of mental health policymaking (past or present)</li><li>• Healthcare worker (psychiatrist) with experience of mental health care (past or present)</li><li>• Healthcare worker (MHN) with experience of mental health care (past or present)</li><li>• Currently self-managing (within medical model)</li><li>• Currently self-managing (not within medical model)</li><li>• Third sector with experience of supporting individuals who identify as having poor mental wellbeing (past or present)</li></ul>
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I constructed a list detailing the desirable attributes of each participant (Table 4.7). Interviews with six participants were approved by the ethics panel. Also approved was the recruitment of up to two additional participants on an iterative basis, in the event that earlier interviews suggested a key perspective was not represented within the initially identified groups. Individuals were approached on the basis of existing networks known to the interviewer and the supervisory team, providing they met one or more of the criteria given in Table 4.7. Approaches to specific individuals were prioritised based on whether they met the criteria, and whether knowledge within networks indicated their inclination to take part in research. Initial contact was by email using the wording agreed by the ethics panel and with an attached participant information sheet (Appendix 1). This document included contact details so that a participant could ask questions before deciding to participate. Potential participants were encouraged to reply if they were



interested in taking part, giving an indication of location, dates and times which suited. In the event of no reply, follow-up email contact was made on one occasion only. If there was no response to the second contact after two weeks, the next potential participant was contacted. Participants were recruited on a first-to-agree basis.

#### *4.4.3 Data collection*

Interviews were planned and conducted in accordance with evidence regarding best practice preparation and interviewing style so that good quality in-depth information could be gathered (Rowley 2012, O'Doody and Noonan 2013, McGrath et al. 2018). Such evidence suggested that power imbalance must be considered in a research interview situation (Anyan 2013). Accordingly, participants were encouraged to state their preference for interview date, time, and location with reference to the guidance in the participant information sheet (Appendix 1). This document suggested that the interview location chosen be private and uninterrupted. Allowing this flexibility meant that it was more likely that participants were able to commit according to their schedules and would be interviewed in a location where they felt comfortable and which was convenient, whether at their place of work, on university premises, or via secure online meeting platform. The intention here was to improve access to research participation and reduce the impact of the research on participants by ensuring they felt at ease in their environment.

Interviews lasted between 30 and 90 minutes. As a first task in the interviews, consent was sought through use of signatures on the consent form approved for use by the ethics panel (Appendix 1). It was important that consent to participate was fully informed, and in addition to the participant information sheet being sent prior to the interview which gave the opportunity to ask questions, a further opportunity was given during the signing of the consent form. Part of that consent included participant agreement for the interview to be recorded. Although ethical approval allowed for interviews to be conducted by videocall, the call was to be audio-recorded only. Permission to conduct online interviews proved useful as the COVID-19 pandemic occurred. Where the interview was conducted online, the consent form was sent in advance of the meeting and repeated verbatim in the first part of the interview so that consent was verbally recorded. Consent forms were stored securely in accordance with ethical approval. During the interview, a semi-

structured guide helped me to stay on topic regarding the questions I asked and reduced the risk of bias and the imbalance of power posed by my positionality (Chapter 1.6). Appendix 1 gives an example of the topic guide. Questions were aligned with findings from Stage 2 Stage 2. Examples included: *Who might be involved in self-management? What sorts of things should they be doing? What are they responsible for? How can you tell that self-management is working?* As they progressed, and following a reflexive process captured in my research diary which resulted in adaptations to the interview guide, prior interviews informed the next. This allowed me to explore developing thoughts with subsequent interviewees. During the interview awareness of best practice guidance noted above resulted in the use of open questions, asking for clarification, and paraphrasing and summarising techniques, which allowed me to check that I had properly understood what had been said. Effective use of silence meant that participants had time to think before responding and felt comfortable. My role was to listen more than talk.

While aware of some concerns regarding the ethical appropriateness of research incentives (Grant and Sugarman 2004), I offered a nominal £20 voucher to cover any expenses incurred through participation. Despite being offered, no participant accepted one. All were offered a document detailing the study for them to refer to after the interview and which had been approved through the ethics process: none accepted a copy. All interviewees asked to be updated regarding the findings of the study.

#### *4.4.4 Analysis*

There are advantages to interview transcription by the interviewer in terms of the deep immersion in the detail of the interviews that results, however, as Bird (2005) notes the process takes time and rigour, especially for the untrained transcriber. Time pressures by this stage of the study meant that this was not feasible, so the audio of each interview was sent for transcription through a secure, password-protected process in accordance with ethical approval and costs were covered by studentship funds. Time pressures also meant the transcriptions were not returned to participants for checking but checking of the transcriptions against the audio recordings was conducted by the researcher. NVivo was the tool used to conduct the process of analysis of the fieldwork transcriptions. Anonymised transcriptions were uploaded into the software package. The model which

had been developed in the Stage 2 meta-ethnography and which had been used to develop the topic guide was used as an initial coding framework with new codes added to capture nuances the model did not include. The process of the analysis was similar to that described for the meta-ethnography (Chapter 4.3.5): interviews were coded in the order that the interviews took place, line-by-line. Once again, memo and comment facilities were used to capture thoughts and personal reflections as they occurred. Again, coding resulted in moving back and forth between the interviews and codes and resulted in a series of themes and subthemes which are described in Chapter 7, where I consider the utility of the questions as a way to explore self-management understanding and the additional understanding those interviews provided in relation to the questions of this study.

#### *4.4.5 Data security and storage*

During recruitment my record-keeping ensured that named individuals were contacted in an efficient way. Participants were assigned a number as soon as they agreed to take part, but thereafter their name was not used. By the conclusion of the study, the contact record was the only connection from the participant numbers to names. These sensitive records were stored securely. During data collection and analysis, interviews were sent through secure online channels to a transcriber that had signed a non-disclosure agreement. Upon return, the resulting transcriptions were anonymised and inaudible sections clarified. At this point, the audio files and the non-anonymised transcriptions were deleted. Hard copy consent forms were stored safely and for the required duration as in accordance with ethical approval.

### **4.5 Summary**

In this chapter I have explained how three complementary research methods were used to consider the questions about self-management given in Chapter 1.4. Each method is useful in a specific way, but when put together, they allow me to examine the questions from different angles. The next three chapters present and discuss the findings of each stage. Chapter 5 will cover self-management in policy, exploring how policymakers understood self-management when they made policy about it. It considers how policymakers manage the policymaking process and how people might seek to influence it. Chapter 6 reviews how participants and authors in previous studies understood self-

management, specifically in bipolar disorder. Chapter 7 presents and discusses the findings from the interview component of the study, which used the findings from Chapter 6 to ask participants how they understood self-management in mental illness more generally. In Chapter 8, the findings are reviewed as a whole, guided by the key question, *if I combine the findings of all three stages, what does it tell me about the questions I have asked about self-management?* Chapter 9 considers the implications of the research findings and articulates limitations.

## Chapter 5. Findings - self-management in policy

### 5.1 Introduction

I have suggested that there is a general view that self-management is a good thing and, in this chapter, will show that this is a view held by the policymakers involved in developing the policies reviewed here. I have also indicated that there is nonetheless a perception that self-management is not working in practice. Having argued that this may be the result of the medical interpretation of self-management, I wanted first to explore how the problem of mental health and self-management was understood at a policy level. Using the Policy Conflict Framework (PCF) (Weible and Heikkila 2017) and Bacchi's 'What's the Problem represented to be' (WPR) (Bacchi 2009, 2016; Bletsas and Beasley 2012) in tandem encouraged me to consider how policy action is impacted by the beliefs and values of key policy actors, how it is influenced by key events, constrained by perceptions of threat, and how boundaries limit access to the policymaking table. The review of self-management policy in this chapter gives insight into the challenges of creating and influencing self-management policy and illustrates why policy does not always result in meaningful or timely change which satisfies the needs of everybody.

### 5.2 The policy setting

The political landscape in Scotland was altered in 1999, when many key policy areas were devolved to the newly established Scottish Executive under the enactment of the first Scotland Act (Scotland Act 1998). Funding was allocated from central UK funds to ensure that the devolved functions could take place. While some matters were reserved to be determined at UK level under the Westminster government, devolution gave the Executive control of the budget and policy relating to health (Scottish Parliament 2016). However, while the new Scottish Government inherited new responsibilities it retained old ways of making sense of mental health. The Scottish Government uncritically adopted a long-standing policy position that mental wellbeing and self-management was a health concern. Accordingly, the government established a Mental Health Division/Directorate which was headed by government ministers and the Chief Executive of the NHS in Scotland. The government went on to produce a series of mental health strategies and policies (Chapter 5.7) including in 2003, the Mental Health (Care and Treatment) (Scotland) Act. The Act did not feature self-management as a concept, focusing predominantly on critical care with a strong focus on risk management and

safety. In terms of wider representation in mental health matters the Scottish Government established the Cross-Party Group (Scottish Parliament 2021) which included a variety of government ministers, lived experience representatives and third sector organisations. Following the creation of the Public Bodies (Joint working) (Scotland) Act in 2014 the government sought to join-up health and social care services by initiating the Health and Social Care Integration agenda (Scottish Government 2021a).

*“The Public Bodies (Joint Working) (Scotland) Act, 2014 (the Act) is intended to ensure that health and social care services are well integrated, so that people receive the care they need at the right time and in the right setting, with a focus on community-based, preventative care” (Audit Scotland 2018).*

The Scottish Government also instigated a period of public consultation relating to the proposed 2017 mental health strategy. As a health matter, the Scottish Government assigned much of the lower-level policymaking and implementation to NHS partners. HEAT targets, later called Local Delivery Plans, set parameters through which NHS Board level performance was measured (Scottish Government 2013). The NHS in Scotland continues to be arranged around fourteen geographically defined Boards which determine budgets and policy at a local level (NHS Scotland 2020, 2021). The proportion of budget allocated to mental health services and subcontracts is Board specific (Public Health Scotland 2021a).

Self-management is an activity which takes place in a community setting outside acute care. Acute care is typically delivered in hospitals, with community support delivered through outpatient clinics and GP services. GP services are currently funded under government contract using a workload formula which allocates budget based on an estimation of patient demographics (Scottish Government 2017c). Further support is provided by a variety of third sector agencies who bid for funding from government and/or NHS Boards to be able to provide subcontracted support services for a fixed number of years. Some but not all third sector agencies are involved in policy discussions. The third sector landscape is populated by a variety of organisations, large and small, national, and local. The Mental Welfare Commission is a non-departmental

public body with lived experience representation at a board level. It is funded by and answerable to government ministers. Among its duties is advocating for the rights of individuals diagnosed as mentally unwell (Mental Welfare Commission for Scotland 2021).

### **5.3 What events influence the decisions that are made?**

There are several contemporary events which contribute to the perceived need to create a policy response, and these are discussed below. What is unclear is the relative priority of these events in the view of those with the power to make or influence policy.

#### ***5.3.1 Socio-economic and policy drivers***

Government is charged with many responsibilities including fiscal governance. Audit Scotland (2021) reported that Scottish health spending accounts for over 40% of the public purse and the effects of ill-health cascade through associated budgets including housing, justice, and social care. Allied with a global financial crisis which resulted in austerity measures across the UK (Cummins 2018) which in turn, impacted the spending power of the devolved Scottish Government, chronic ill-health is sometimes described in terms of a burden, not just for the individual, but on state resources and society (Scottish Public Health Observatory 2020). As a result, initiatives which seek to reduce that burden are adopted. Self-management provides such an opportunity. It shifts the responsibility for care and support from the state to the individual, optimising their restoration to the production of net benefit rather than net cost (MacKenzie et al. 2020). Despite growing evidence that austerity measures and growing fiscal inequality are implicated in the exacerbation of poor health including poor mental health (Wilkinson and Pickett 2010, Toffolutti and Suhreke 2019), promotion of self-management can arguably be perceived less as empowerment and moral altruism, and more as a government response to a broader budget problem. Budgetary concerns of government are discussed further in Chapter 5.5.1.

#### ***5.3.2 Challenges to the dominance of the medical model***

In Chapter 2 I argued that there were many ways to understand a phenomenon commonly described as mental illness, from a dominant perception of it as a purely

biological problem, to more marginal views that mental illness has significant social influences and consequences. There, it was argued that there is now a growing focus on the role of trauma, stigma, exclusion, social inequality, and deprivation on mental wellbeing (Healy and Thase 2003, Read 2005, Rogers and Pilgrim 2005, Wilkinson and Pickett 2010, Read and Dillon 2013, Allen et al. 2014, Speed, Moncrieff and Rapley 2014, Timimi 2014, Pilgrim 2014, Johnstone et al. 2018). It is important to consider how these dominant and marginalised understandings have an impact on the specific Scottish policy context because within this evolving and nuanced view of mental health, the tasks, resources, and desirable outcomes i.e., the meaning and practice of self-management is altered. As a result, the foundational premise of the current mental healthcare system, and the policymaking process that sustains it, is in question. It creates a need for expanded services about which policymakers and healthcare professionals have varying levels of understanding and conviction, and limited budget and resources to achieve.

### *5.3.3 Human rights agenda, co-production and mental health activism*

Historically mental illness has been subject to the paternalism which dominated health, in which care was delivered by healthcare experts to passive individuals (Porter 2002, Rogers and Pilgrim 2005). The rise of the human rights agenda saw this dominance erode. By the early part of the 21<sup>st</sup> century policy was beginning to reflect this change. Concepts such as collaborative care, person-centred care, partnership working, co-production and shared-care began to appear (Scottish Co-production Network 2018, Todd 2020). The ability to translate these concepts into practice has proved challenging, with healthcare professionals and people with lived experience being charged with responsibility for this kind of working but limited in their ability to achieve it. The challenges faced by healthcare professionals as a result of partnership working is discussed further in Chapter 5.5.2.

### *5.3.4 Anti-stigma, mental health first-aid, and recovery*

As originally conceived within the lived experience community, recovery was described as a personally determined goal, achievable through a variety of biopsychosocial supports. The recovery narrative was embraced by government, healthcare professionals, people with lived experience, and lay-people alike (Brown and Kandirikirira 2007). As a positive view of mental health, it joined a suite of well-funded,



anti-stigma and mental health first-aid campaigns designed to tackle negative perception of mental ill-health as a rare and life-long illness and, through it, mobilise public support and aid-seeking behaviours (See Me 2021, SMHFA 2021). Aligned with this was the rise of the *mental health is the same as physical health* narrative which placed the suggestion that *my depression is a mental broken leg*, alongside evidence showing that poor physical health is correlated with poor mental health (Firth et al. 2019). While demonstrably successful in achieving those aims, none are unproblematic. Critics consider that these initiatives deliver a counter-narrative. All ascribe to the notion of illness and treatment. By normalising and/or trivialising mental distress as something with which all people have personal or close experience, and by suggesting that full recovery to a vague societal norm through treatment and self-management is always possible/desirable, it reduces acceptance of those who cannot recover to a socially defined level. An assumption is perpetuated that an individual who does not recover is *less than* and it fails to question the role of social/financial inequalities, lack of services and social capital (Cain 2018, Tyler and Slater 2018). People with lived experience report that the original aims of recovery and associated concepts have been co-opted and the ideas are facing challenge from the very people they sought to empower (Rose 2014, Woods et al. 2019).

### *5.3.5 The influence of the media*

Guidelines exist which advocate balance and care in reporting, but they are not always followed (National Union of Journalists and The Scottish Government 2014). Nowadays, media coverage extends to the internet where there are fewer controls. Critics argue that media seeks less to report events than to determine opinion toward them. This feeds into core beliefs and offers potential for good and bad outcomes. Media often does not take a consistent position and reporting falls into several key discourses (Everett 2015, Rhydderch et al. 2016). Alternately Mad (deserving of fear and exclusion), bad (worthy of scorn and justice), or sad (worthy of care and compassion), the vast field of mental distress is thus consigned to arbitrary stereotypes with limited regard for context. High profile cases of mistreatment by healthcare professionals which demonise healthcare professionals, and crimes attributed to individuals with lived experience which demonise people with lived experience, co-exist in the media narrative and polarise public opinion (Chen and Lawrie 2016). This perpetuates a sense of moral panic which drives periodic, sometimes contradictory policy action.

#### 5.4 Who is involved in decision-making, and do they agree?

Weible and Heikkila (2017) assert that it is important to assess how the policy topic i.e., self-management is understood among the people involved in decision-making. As discussed in the section above, healthcare policy is a devolved concern therefore it was important to consider policy as it applied in the Scottish context. To accomplish this, I examined three Scottish policies; the Scottish Government's first Mental Health Strategy published in 2012, the 2017 Strategy which replaced it, and "Gaun Yersel!", a policy document developed by the Scottish Government in collaboration with the Long-Term Conditions Alliance in 2008 (Long Term Conditions Alliance Scotland and Scottish Government 2008, Scottish Government 2012b, 2017). The Long-Term Conditions Alliance Scotland (LTCAS) is a third sector group reflecting and involving those with lived experience. Looking at these three policies enabled me to consider how self-management is understood by the people involved in writing them, and to consider whether understanding was shared.

##### *5.4.1 What's the problem represented to be?*

In all three documents, self-management was represented as one of several activities perceived as a solution to the problem of poor health. The two mental health strategies (Scottish Government 2012b, 2017) focused specifically on mental health, while "Gaun Yersel!" (LTCAS and Scottish Government 2008) regarded mental illness as one of several long-term health conditions including those which are physical, such as diabetes. The quotes which follow are illustrative of key themes which were present across all documents.

*"Improving mental health and treating mental illness are two of our major challenges"* (Scottish Government 2012b, p. 1).

*"...we must prevent and treat mental health problems with the same commitment, passion and drive as we do with physical health problems"* (Scottish Government 2017b, p. 2).

*“Self-management is the key to meeting the growing challenge of long-term conditions” (LTCAS and Scottish Government 2008, p. 5).*

All documents were broadly agreed regarding *why* mental illness is a problem stating that it had a negative impact on society, the economy, and the individual, and all stated that those outcomes needed to improve. Indeed, the documents all included reference to the importance of social factors and social consequences of mental ill-health i.e., that poor mental wellbeing was caused by *and* resulted in social inequalities such as poverty, social exclusion, and access to employment (Allen et al. 2014). In this, they reflect a discourse which has been gaining traction since the latter half of the 20<sup>th</sup> century (Rogers and Pilgrim 2005).

*“The impact [of poor health] can extend to social, economic, psychological, physical, cognitive and cultural aspects of a person’s life” (LTCAS and Scottish Government 2008, p. 5).*

*“As there is evidence that psychiatric crisis is often preceded by a social crisis, integrated, responsive health and social care services are vital” (Scottish Government 2012b, p. 40).*

*“Environmental, social and individual factors help to determine mental wellbeing. Genetic and environmental factors affect the prevalence and level of severity of mental illness in a population. These interactions are complex, but they offer different ways to influence mental health at an individual and population level” (Scottish Government 2017b, p. 11).*

All documents stated that services needed ongoing change in order to provide a better environment for mental health to improve.

*“Within services that are led by the NHS we will take forward our plans for investment twinned with reform to help deliver the best mental health outcomes possible” (Scottish Government 2017b, p. 9).*

Across all documents was a sense that resolving the problem, now defined as mental illness, was not a sole responsibility of the person experiencing poor mental wellbeing. Instead, it was a mutual activity which required a sharing of tasks and responsibility between individuals and healthcare professionals.

*“Recognising service users as equal partners in their own healthcare and emphasising expectations of good health and a good life” (Scottish Government 2017b, p.7).*

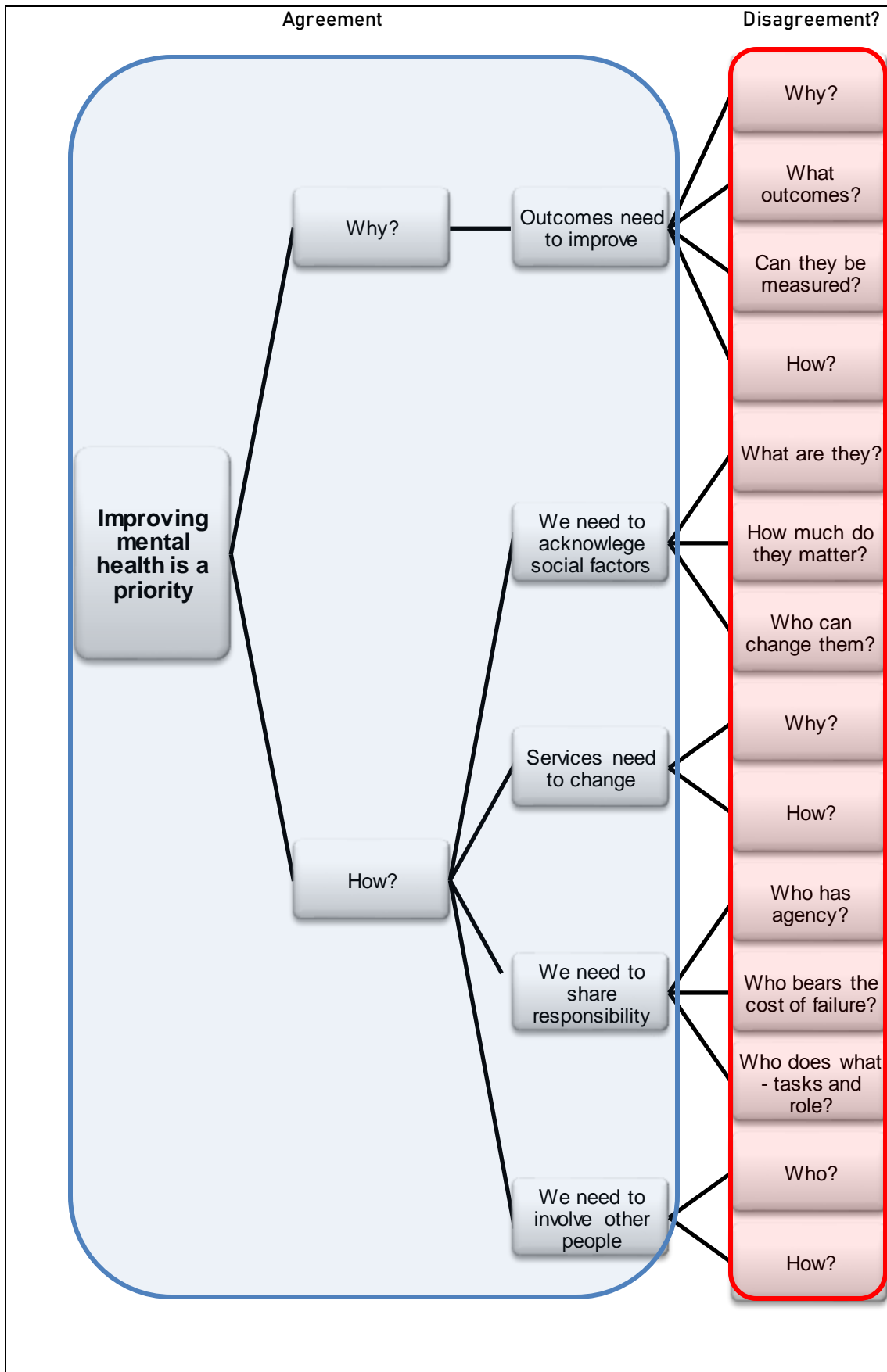
Further, the documents agreed that the solution involved people and agencies beyond the ‘doctor/patient’ relationship.

*“We will target key connections between mental health and other policy areas such as employment, justice and early years services, where mental health has a large contribution to make” (Scottish Government 2012b, p. 1).*

*“Working to improve mental health care is not just the preserve of the NHS or the health portfolio. We will be working not only across the Scottish Government, but also across the wider public services to harness the broadest range of opportunities to improve the population’s mental health. This work is broad and far-reaching” (Scottish Government 2017b, p. 8).*

*“It is a broad church and includes partnership with a wide range of agencies, carers and health professionals” (LTCAS and Scottish Government 2008, p. 10).*

Graphic 5.1 Representing the problem of mental illness according to this study



#### *5.4.2 What are the assumptions?*

The documents assumed that all the people involved with self-management would work together to resolve a health problem with the same energy and priorities, and for the same reasons/rationale. This is a reasonable assumption based on the agreements presented thus far which demonstrate a shared representation of the problem of mental health (Graphic 5.1). In that shared representation there was broad agreement that improving mental health outcomes is a key priority. There was also agreement that to achieve better mental health outcomes, services needed to change, responsibility should be shared, and a wide range of people should be involved. There was an acknowledgement that social factors are important in any effort to improve mental health outcomes.

#### *5.4.3 What is left unproblematic and what effect does this have?*

Closer inspection of the policies showed that, while the high-level ambitions were shared, the detail of those ambitions in terms of making a difference in day-to-day practice was missing. As Graphic 5.1 summarises, there was a lack of clarity regarding what outcomes were important and which/how/if they should be measured, what social factors might be, their relative importance compared to healthcare involvement, who or what should be involved, and what needed to be done to address them.

##### **5.4.3.1 Outcomes need to improve**

There was broad agreement across the policies that outcomes needed to improve but the detail about what outcomes were, and how they should be measured, displayed evidence of difference. Although they mentioned individually defined outcomes, the mental health strategies (Scottish Government 2012b, 2017) placed emphasis on service-driven outcomes. They created targets and commissioned reports which were quantitatively measurable. Meeting targets was intended to reduce reliance on services and create cost benefits in addition to improved care and support.

*“This work will ensure that Scotland remains at the forefront of outcomes measurement in mental health”* (Scottish Government 2012b, p. 17).

*“Over the 10 years of this Strategy, we must see, and be able to measure, the following for mental health...”* (Scottish Government 2017b, p. 7).

“Gaun Yersel!”, a document written with lived experience involvement, offered a different perspective on this detail (LTCAS and Scottish Government 2008). While the document included quantitative measures, it placed emphasis on individual qualitative goals which were less measurable and demonstrable. The language it used was more qualitative and personal. For instance, the outwardly practical task of providing information was labelled *“living for today”* as a way of *“helping people to ‘navigate an often difficult journey’* and *“build bridges back into society and social roles”* (LTCAS and Scottish Government 2008, p. 9). Measures of this kind are less able to quantify improvement, but “Gaun Yersel!” (ibid.) suggested that the outcomes were defined and valued by those with lived experience.

A target-driven culture is a feature of contemporary healthcare in which policymakers are required to prove the effectiveness and economic utility of policy to the broader voting public. For instance, the second mental health strategy said that Scottish Government must be able to *“we must see and be able to measure [...] people’s responses to treatment, and people’s experiences of mental health services, just as in physical health care”* (Scottish Government 2017b, p. 7). Such measures are not always sensitive to the features of the wide range of conditions represented by the term ‘mental health’. For instance, readmission targets are imperfect measures of conditions some of which are relapsing/remitting, and prescribing rates are not an accurate measure of a portfolio of conditions which do not always require medication.

#### **5.4.3.2 We need to acknowledge social factors, reform services and involve other people**

As stated, all documents acknowledged the importance of social factors. Pre-dating the two mental health strategies, the “Gaun Yersel!” authors talked about the importance of social factors and the need for joined up services (LTCAS and Scottish Government 2008). They cited numerous case studies which showed how change might work in practice using existing resources. On the suggestion of “Gaun Yersel!”, a £2 million per annum budget was established to support self-management innovation (ALLIANCE

2016). This sum was intended to provide support for all long-term conditions but represented a fractional investment in terms of NHS budgets.

In the mental health strategies (Scottish Government 2012b, 2017) there was growing acknowledgement of social factors as important antecedents and consequences of mental illness. The first mental health strategy (Scottish Government 2012b) acknowledged social factors, with reference to social prescribing, mention of investigating the creation of crisis houses in collaboration with the third sector (p. 41) and a stated intention to develop “*integrated (cross health and social care) and person-centred planning*” (p. 40). That strategy (Scottish Government 2012b) put a date to this ambitious future; 2020.

*“Our vision is that by 2020 [...] We will have a healthcare system where we have integrated health and social care, a focus on prevention, anticipation and supported self-management”* (Scottish Government 2012b, p. 11).

Five years later, the second mental health policy (Scottish Government 2017b) continued to emphasise the importance of attending to social factors with a similar, arguably increased, impression of aspiration.

*“Working to improve mental health care is not just the preserve of the NHS or the health portfolio. We will be working not only across the Scottish Government, but also across the wider public services to harness the broadest range of opportunities to improve the population’s mental health”* (Scottish Government 2017b, p. 8).

Acknowledging social factors in this way meant that mental health became linked in complex ways with other policy areas which were now recognised as important. The second mental health strategy (Scottish Government 2017b, p. 8) detailed its intention to attend to poverty and health inequalities through its “Fairer Scotland Action Plan” (Scottish Government 2016), education through the “Getting it right for every child”



(GIRFEC) approach (Scottish Government 2017a, 2021b), and justice by working with Police Scotland and the Scottish Prison Service. They mentioned addressing social security and employment as key areas, though gave less detail about how they would address this. The strategy described a desire to work with Local Authorities to address inequalities in communities and tackle in-work poverty (p. 20), and a section (p. 21) which dealt with training housing officers to respond to those with mental health problems (p. 21). Each of these policy areas have their own set of complexities to manage, and progress towards them continues.

Despite the discussion of social factors there was an ongoing assumption that mental illness and self-management were primarily health problems situated within the individual and to which healthcare should direct its efforts. There was a strong sense in the second mental health strategy (Scottish Government 2017b) of the centrality of the healthcare system, i.e., expanding the healthcare workforce by 800 additional mental health workers in hospitals, GP surgeries, prisons and police stations, link workers in primary care (p. 26), improving access to treatment for more individuals, joining up physical and mental healthcare, improving access to psychological therapies (p. 26-7), better infotech (p. 27), early intervention for psychosis (p. 27), transformation in the primary, urgent and child and adolescent care healthcare sectors (p. 9) and a desire to “*break down barriers*” through the integration agenda (pp. 9, 26) (Audit Scotland 2018, Scottish Government 2021a). Self-management was mentioned as a key aspiration (Scottish Government 2017b pp. 11, 18, 35-6). With government focused on other pressing issues, self-management practice was relegated to healthcare to steer through recovery approaches, social prescribing, psychoeducation, and online support. Generally, the 2017 mental health strategy gave some detail about how its ambitions might work in daily practice, but in the main, translation of the high-level policy ambitions was a duty turned over to healthcare to adopt into practice at a day-to-day level.

## 5.5 Change as a threat

In the last section I argued that there was high-level agreement across the policies that improvement of mental wellbeing was a priority. To accomplish this priority, it was agreed across the policies that outcomes needed to improve, responsibility shared, social factors considered, and that service change was necessary. These high-level goals

notwithstanding, in the mental health strategies (Scottish Government 2012b, 2017) there continued to be vagueness in the detail, leaving healthcare charged with finding ways to put policy into front-line practice. “Gaun Yersell!”, a policy written with third sector and lived experience involvement (LTCAS and Scottish Government 2008), made efforts to tackle what change might look like at a practice level and articulated outcomes in person-centred ways, some of which were not measurable. “Gaun Yersell!” was a policy which articulated change and attracted a notional budget, but as Chapter 5.7 will demonstrate it found little traction in policy after it was made. When considering the reasons for the slow progress regarding the laudable intentions of mental health policy, it is important to look at the threat that substantive change represents for key policy actors.

### *5.5.1 Threat for policymakers*

Although I have shown in Chapter 5.3 that policymakers acknowledge the need for change due to the influence of events which focus policy attention, change represents threat. At a high level, change might be said to represent a challenge to core moral values about how society should function. In response to the financial pressures and austerity measures mentioned in Chapter 5.3.1, policymaking has moved towards the neoliberal approach discussed in Chapter 2.2.2. This is a situation which Liebenberg and Ungar (2013) suggest has resulted in responsabilisation. Through it, individuals adopt a moral duty to be the guardians of their own success. Their ability to self-manage and to overcome ‘*illness*’ to re-join society as a functioning member is expected and deemed within their own power to achieve (Cain 2018, Watts, 2018). The ongoing dominance of the medical model fits a responsabilisation morality. To illustrate this, mental health is one of the health areas in which repeat business i.e., relapse is seen as the result of the individual’s actions rather than the consequence of service actions. It may explain *why* government is uncritically inclined to accept the medical model and supports the recovery, and anti-stigma narratives (Chapter 5.3) as a way of mobilising individuals to recover so they are able to contribute to society. Individuals are encouraged by policy to make the choices which will result in return to function, exemplified by the focus in policy on paid work as a treatment goal (Friedli and Stearn 2015). Chapter 3.4 has already illustrated how policymakers must apportion their limited budgets, time, and energies. If responsibility lies with the individual and the healthcare professionals as primary actors to resolve illness, government need not consider the wider complex and costly social

reforms such wide-ranging changes would require. Having done exactly that in the 2017 mental health strategy, the problem seems altogether more complicated to address. However, with the problem predominantly defined as a medical concern, the delegation of government responsibility to the healthcare professional as the illness expert is justified.

### *5.5.2 Threat for healthcare professionals*

With mental healthcare thus delegated, healthcare professionals are thereafter charged with the responsibility to demonstrate that they can treat the illness which causes the individual not to participate in society. The ongoing privilege of healthcare professionals as experts in illness/treatment is embraced, perpetuating a power differential that is hard to unseat. Through training and expertise, healthcare professionals are invested in a predominantly medical model of mental wellbeing and, with significant resources and delegated authority, occupy a powerful position. They are a disparate group with varied skills and reputational power operating within an historically hierarchical and powerful institution (Hugman 1991), with variation in ideologies of care, levels of agency, and access to information. More recently, healthcare professional responsibilities have been extended to include a requirement to accomplish improvement for their patients through partnership with them (Chapter 5.3.3). This is not without its challenges (Stomski and Morrison 2017). Responsibility requires agency and attributes accountability. However, healthcare professional agency is limited by many things including the ability to determine internal patient factors such as engagement and subjective understandings of 'improvement', and the ability to determine external patient factors such as access to social networks, paid work and/or benefits and social care. Healthcare professional agency and attention is also restricted by competing responsibilities including government performance targets (Scottish Government and NHS Scotland 2014), budget pressure (Audit Scotland 2017), increased pressure on acute sector care, complex and shifting routes of referral to other services and increased presentations in general (Mental Health Foundation for Scotland 2016). Sharing power with patients influences the outcomes on which professional reputation and performance are based and leaves the healthcare professional with a challenging conflict of interest; responsible yet without sufficient agency.

### *5.5.3 Threat for people with lived experience*

Within the current healthcare system people with lived experience must share responsibility with healthcare professionals to produce clinically determined outcomes such as absence of symptoms which they may neither value (Voronka et al. 2014), nor have the full internal or external resources to achieve. Within that model of care, the self-management responsibility for people with lived experience is to make best-efforts to accord with treatment and become educated about the illness it treats. Their self-management choice is then limited to which of the treatment options to accept. This model de-responsibilises an individual experiencing mental challenges i.e., *it's not me, it's an illness*, but responsabilises them for doing all they can to *fix* themselves. With the medical model as the primary policy influence, the fixing agents i.e., treatments are provided, and require only policy tweaks to ensure they are optimised.

Yet, for people with lived experience, business as usual is problematic. Among the lived experience community there is a sense that while there has been overt policy shift, the orthodoxy survives covertly (Cain 2018, Recovery in the bin 2018; Watts 2018). Through it, the language of self-management is co-opted, shifting responsibility for self-management to patients without understanding or mobilising the resources toward tackling healthcare professional culture shift and social factors. This implies that people with lived experience can and should self-manage, and through it, achieve measurable recovery despite social factors and scarcity of resources. Those who will not, become the problem rather than the ill-health, the services, or the state. Those with lived experience also face a challenging conflict of interest in which they too are left responsible yet without sufficient agency.

The review of three policies and the differences seen in the policy which was written with lived experience involvement is indicative that change is more desirable for this group. Further evidence of views and understanding of self-management at a practice level is offered in Chapters 6 and 7. For government and healthcare, however, there are strong drivers to maintain business as usual. Though change is indicated by events (Chapter 5.3) and signposted in the policy that is made (Chapter 5.4), it represents threat and makes the problem seem difficult to resolve. In policy, conflict is not expressed, the language of change is evident, but action is limited. To consider why this might be the case, it is important to review the need for compromise as a means to influence policy.

## 5.6 Compromise as a means to influence policy

In the preceding sections I have argued that there is a general desire for change but there are different perceptions of the threats associated with striving towards it. As indicated, challenges to the medical model, the growing appreciation for social and political factors of mental wellbeing, and the increased need to seek and respond to lived experience views, disrupts long-established assumptions. Roles and priorities become ambiguous in this changing landscape. Those involved have seemingly conflicting demands, different risks, and varying power to affect the priorities of others. This section argues that, where ambiguity exists, the power in the setting privileges some voices over others, and the cost of access to the policymaking table is exacted in the need for compromise between *insiders* (Chapter 5.6.1) and *outsiders* (Chapter 5.6.2) in the policymaking setting (Maloney 1994). In this, my line of argument accords in some ways with a recent paper by Cairney (2021) in which he describes outsider status as a position of resistance against the dominant view, saying that people can only be insiders if they ‘*follow the rules of the game*’.

### 5.6.1 *Insiders*

The venue where most policy is made is occupied by two powerful *insiders*: government and healthcare professionals. Problematising mental wellbeing as *medical* has perpetuated this policymaker framing throughout subsequent discussions and has privileged the medical profession whose framing accords. For government their policymaking influence is high, and they view self-management as a collateral benefit: it is a way to resolve other policy concerns of greater perceived importance. Chapter 5.2 suggested that high-level mental health strategy is founded on policymaker belief that mental distress is a predominantly medical problem, albeit with an increasing focus on social factors. Chapter 5.4 indicated that this core belief was enshrined in the policy that was made. The topic has low salience due to the volume of competing policy demands in the policy setting, and power for resolving what is defined as the problem of mental illness is delegated to those with medical expertise. The increasing pressure wrought by the events described in Chapter 5.3 has meant that government needs to be seen to make progress towards change, although Chapter 5.5 suggests that change represents threat. It is argued that this is what is seen in Chapter 5.4, where the language of change is evident in policy, but it is performative because the detail of achieving it is missing and substantive action toward it is slow. Additionally, Chapter 5.5.2 showed how healthcare

professionals are tasked with resolving the problem of mental illness, but that change in their roles and responsibilities in response to the events has created tensions i.e., should healthcare professionals deliver population-level return to function and meet the performance targets set by government OR work to an individually-framed patient-led agenda?

### *5.6.2 Outsiders*

So far, I have indicated that those with lived experience are more supportive of change, but they are outsiders to the policymaking process and must conform to rules of engagement. As is evidenced by their inclusion in writing “Gaun Yersel!” (LTCAS and Scottish Government 2008), and the initiatives outlined in Chapter 5.2, outsiders are sometimes invited into policymaking spaces, but their access is bounded. Here, they are obliged to enter a medical-focused policymaking venue based on the high-level assumption that mental wellbeing is primarily a medical problem and have limited power to assert their position, especially if their message is not framed in medical terms or relates to issues beyond the scope of the medical system and or devolved powers of the Scottish Government to resolve. People with lived experience are required to balance being authentically Mad with being sufficiently professional (Voronka 2016a). Their voice lacks the legitimacy of the research hierarchy which places lived experience as the lowest form of evidence, rather than the quantitative evidence the medical sector most values (Faulkner 2015, Ingham-Brookfield 2016). For them, the topic is of higher salience, but their influence is mediated by their need to conform to agendas and framing set by the insiders. Lived experience positions are considered tokenistically (Stomski and Morrisson 2017). Where conflict with the insider position exists, it is hidden or suppressed by the need for compromise which allows access the policy setting.

As described in Chapter 2.2.2, the need to amplify the patient voice in a care environment dominated by healthcare agendas has created a space occupied by a number of emancipatory lived experience groups. Stating that they have survived mental difference and a harmful healthcare system, and/or rejecting a medical framing of their experiences, Mad activists and survivor communities seek radical social reframing of their lives and advocate for system reform (LeFrancois et al. 2013). In the chapter it was noted that debate and disagreement about core beliefs about the nature of mental illness is

considered a valuable attribute in this community of individuals whose views are historically disregarded. This makes it not only hard to identify a collective position on the key mental health questions but also, to some extent, undesirable to do so (Beresford and Russo 2016). This makes compromise challenging, even within their number. The reframing of the problem as a social problem rather than a medical one positions them as a threat (Church 1995). Their voice is delegitimised, and their access to policymaking venues is restricted. They seek to reclaim the lived experience position as active owners/orchestrators of their own stories and address a perceived lack of social capital, but their lack of access to policymaking spaces and their reluctance to compromise their position in order to achieve access limits their ability to achieve this. Their influence is often restricted to informal spaces online and in the production of grey literature with limited visibility (Bossewitch 2016). For the most part, the potential for people with lived experience to influence policy is confined to informal spaces which have limited amplification. Within these spaces, individuals have negligible funds, loose networks of organisation, and disparate beliefs which align or distance them from the dominant medical discourse (Beresford and Russo 2016, Beresford 2018). People with lived experience are directly impacted by policy but have fewer resources and less power to address any concerns they may have. In the main, they must rely on indirect access to the policymaking venue, often through the advocacy of the third sector.

Many third sector agencies have created innovative working practices and networks which optimise collaboration with people with lived experience, and in some cases includes peer working and representation (Penumbra 2021, Scottish Association for Mental Health 2021a). For some, though not all third sector organisations, there is a willingness to frame experiences in non-medical terms, and to focus on social factors. Mental health policy has high salience for the third sector, but their involvement in formal policymaking spaces continues to be challenging. Reliant for existence on an uneven ebb and flow of government funding and public charity, and in the face of competing pressures for dwindling funds (Bach-Mortenson and Montgomery 2018), third sector organisations are obliged to make key strategic decisions to ensure their survival which compromise their ability to advocate for those with lived experience. Smaller organisations focus on single conditions (Bipolar Scotland 2021), deal with practical issues at a regional level (Mental Health Aberdeen 2021), or both. They often lack the cohesion, power or funds to engage with mental health policymaking at a meaningful

national level. For larger national organisations, funding is often sourced through a tendering process, and the need to compete with other third sector organisations every few years to maintain funding, means that effort is diverted from the front line to bid development. Funding is increasingly reliant on proof of concept which requires standardised empirical measures of recovery. The knowledge that the tender will go to the lowest bidder which offers services which are understood and valued by those awarding it rather than those receiving it, creates a scramble to the bottom. Third sector are structurally primed to create low-cost services which are valued by funders rather than by users, and to be in competition rather than working together. Where organisations do have a policymaking voice, ongoing inclusion in the policymaking process is subject to rules of engagement which have included their controversial involvement in welfare benefits health assessments, receipt of funding from the pharmaceutical industry (Ozieranski et al. 2019), and restriction of overt criticism toward policy decisions (Pring 2018). These constraints combine to impact the third sector's ability to advocate for people with lived experience.

### *5.6.3 Inside-outsiders*

Dwyer and Buckle (2016) have argued that the insider/outsider division is not binary. Instead, they suggest that there is a space where it is plausible for individuals to hold positions in *and* outside. It is occupied by the third sector, researchers and healthcare professionals who declare lived experience. It is the space in which I operate (Chapter 1.6). People like me have opportunity to hold credibility in policymaking spaces, with professional peers, and as representatives of people with lived experience. Their ability to represent the lived experience voice could influence the policymaking process, but their position is also not without threat (LXP Revolution 2021). For academics, their limited ability to deliver credible policy options is common with the more general challenges of translating evidence into policy (Cairney and Rummery 2018, Walker et al. 2018, Zampini 2018). Efforts to promote qualitative research findings within the healthcare evidence hierarchy continue to be challenging (Clark et al. 2018). For researchers and healthcare professionals, overt conflict with the insider voice may be career-limiting (Boyd et al. 2016). They are challenged by delegitimisation resulting from their lived experience and this comes from within their respective professions *and* the policy venue (Blackshaw et al. 2017). This makes a declaration of lived experience an individually risky option and while increasingly common it remains a contested identity



(Brown and Leigh 2018). The need for insider-outsiders to preserve their contested power makes compromise in policy-making spaces more likely. This leads to further delegitimisation from the activist community, who perceive their conciliatory tone and position of insider privilege as untrustworthy, and no longer representative of the community they seek to serve (Voronka 2016b, Carr 2019).

### 5.7 What has happened as a result?

Using the Policy Conflict Framework meant that I needed to consider the *outcomes and outputs of the policy conflict* in the policies that are made. The WPR asks similar questions, asking me to consider *what effects (discursive, subjectification, lived) are produced by this representation of the problem and how and where has this representation of the problem been produced, disseminated, and defended*. Both require an assessment of the context of the topic and a review of what has happened as a result. In this section the outputs and outcomes experienced in Scottish mental health policy since devolution are reviewed.

Table 5.1 Some key events and policies

1998	Health policy was devolved to the newly established Scottish Executive. Enacted in 1999, under these powers, the Executive has control of the budget for health
2001	The National Programme for Improving Mental Health and Wellbeing is launched. By 2003 it produced its first report covering the years 2003-06 in which it advocated the inclusion of people with lived experience in future MH strategy and policy (Scottish Executive 2003)
2003	The Mental Health Act was produced (Mental Health (Care and Treatment) (Scotland) Act 2003). It remains in force and does not feature self-management as a concept, focusing predominantly on critical care with a strong focus on risk management and safety
2005	"Building a health service fit for the future" also known as "the Kerr report" (Scottish Executive 2005) was commissioned and published. It sought to review the state of Scotland's health and care services. Though not mental health focused, it recommended key culture shift to include self-management and patient involvement
2006	The Long-Term Conditions Alliance (LTCA) was formed on the recommendation of the Kerr report. Membership was from third sector agencies and people with lived experience representing a variety of long-term health conditions including mental health. Professional groups were

	<p>included but did not have voting rights. In this inaugural year, the LTCA ran its first conference in Edinburgh</p> <p>"Delivering for mental health" (Scottish Executive 2006a) was published setting out targets and commitments for mental health services</p>
2007	<p>In an unprecedented move, the Scottish Government asked the LTCA to co-produce a self-management strategy and awarded £11M to make it happen</p> <p>"Better health, better care: action plan" (Scottish Government 2007) was published, referencing the Kerr report. It restated a commitment to self-management support. Written with people with lived experience, it expressed a desire to continue to involve them in service design</p>
2008	<p>Guan Yersel! was co-produced with Scottish Government and third sector mental health agencies (LTCAS and Scottish Government 2008). It committed £2m/year for self-management initiatives across all conditions. The document accepted as a core principle the medical model, perpetuating a problematic equivalence for mental and physical self-management. That notwithstanding, it advocated a revolutionary reorganisation of care in Scotland as a result of its focus on the wider factors affecting health. Despite several innovative initiatives arising, few of the mental health policies which followed cited it. It remains well-considered among educators and people with lived experience</p>
2009	<p>"Towards a mentally flourishing Scotland" (Scottish Government 2009b) was published as a policy and action plan for mental health covering 2009-11. It discussed and offered commitments to addressing social factors and self-management</p>
2011	<p>Despite best practice guidance, legislation, and other regulatory measures long established and noted in this table, the Winterbourne View scandal emerged relating to failures in care at a residential home in England. Public faith in healthcare professionals across the UK was compromised. Media attention prompted a serious case review (Flynn 2012) and recommendations included a need to deliver personalised care</p>
2012	<p>Scottish Government produced its first Mental Health Strategy to cover the years 2012-2015 (Scottish Government 2012b). It referenced "Delivering for mental health" (Scottish Government 2006) and "Towards a mentally flourishing Scotland" (Scottish Government 2009b) as the instigating documents, but "Guan Yersel!" was not referenced. The strategy was declared to be consistent with the 2020 Workforce vision (Scottish Government 2012a) which was published in the same year and addressed healthcare service provision, stating high level targets for population level health improvement</p>
2013	<p>Despite the improvement measures taken in the wake of Winterbourne View, a further high-profile care failure emerged in the Mid Staffordshire NHS Trust. UK public faith in healthcare professionals was rocked again. In response, the UK government commissioned the Francis report (Mid Staffordshire NHS Foundation Trust 2013) which was published in 2013. Recommendations included a need to listen to patient feedback</p>

	The austerity programme was implemented by the UK government. The effects of this policy are reported to have a disproportionate effect on individuals experiencing poor mental wellbeing (Cummins 2018)
2014	Scotland held an independence referendum which resulted in Scotland electing to remain part of the UK. A key factor in the debate was the Barnett formula which calculates the budgets allocated to Scotland from the UK Government (Institute for Government 20210. This had implications for the amount of money Scottish Government has to spend on its devolved powers
2016	<p>UK government held a referendum asking whether to leave the EU. A key factor in the debate was £350M which would no longer go to the EU but would instead improve NHS budgets upon exit (Ward 2021). Estimates suggested that an exit from the free-movement policy of the EU would impact NHS care due to uncertainty over the future of the non-UK workforce (Holmes 2021). Brexit drew significant attention and budget over the course of ensuing years, to the detriment of other policy areas</p> <p>Health and Social Care integration legislation was introduced. Through it, budget was allocated with the intention of improving care and support for people who use services, their carers, and their families. It did this by putting a greater emphasis on joining up services and focussing on anticipatory and preventative care (Scottish Government 2021a)</p> <p>The Fairer Scotland Action plan was published aimed at reducing generational poverty despite ongoing welfare cuts from the UK government (Scottish Government 2016)</p>
2017	<p>The second Mental Health Strategy was produced after a protracted consultation period, closing a gap in coverage between 2015 and 2017 (Scottish Government 2017b). Upon delivery its broader focus was broadly welcomed, but concerns were expressed regarding how its wide ambitions could be translated into action (Cardwell 2017)</p> <p>The Special Rapporteur to the UN Human Rights Council presented a report to the 35<sup>th</sup> session of the Human Rights Council regarding mental health across member nations (Puras 2017). Interviewed after the presentation he stated "<i>Mental health policies and services are in crisis - not a crisis of chemical imbalances, but of power imbalances. We need bold political commitments, urgent policy responses and immediate remedial action</i>" (Infante-Cañibano 2017)</p>
2019	The final report of the health and social care integration was published by the ministerial strategic group for health and community care. It stated that " <i>The pace and effectiveness of integration need to increase</i> " (Scottish Government 2019, p. 2)
2020	The COVID-19 global pandemic emerged as a public health emergency. Mental health services erode as community-based practitioners are called to front-line work. At the time of writing, evidence is still being compiled regarding the social and financial consequences related to lockdown and reprioritisation of resources (Shevlin et al. 2021, United for Global Mental Health 2020)

In Table 5.1 a snapshot of Scottish mental health policies is provided across time and events. The National Programme for Improving Mental Health and Wellbeing came into being in 2001 shortly after devolution and the transfer of the responsibility for healthcare to the Scottish Government. It advocated for lived experience inclusion, such that those with lived experience are included in policy decisions about them. The co-produced policy, which was released in 2008, however, did not take a pivotal role in future policy (LTCAS and Scottish Government 2008). Despite this, over time, and in response to key events including the patient abuse scandals emerging from Mid Staffordshire and Winterbourne View which saw public confidence in healthcare erode as they witnessed care failures despite regulatory measures, policymakers have increasingly used the language of change.

Chapter 5.4 argued that, for government, the medical lens predominated, but policy was increasingly permeated by an acknowledgement that self-management, patient consultation and involvement, and social factors were growing as key concepts. While the language and intent of the policy shifted, detail and substantive action at an operational level has lagged. When it was published in response to the second mental health strategy (Scottish Government 2017b), the third sector expressed its concern that the wide-ranging ambitions of the strategy would be challenging to translate into action (Cardwell 2017). Nonetheless the Scottish Government has signalled its desire for change with an increasing focus on social factors over the lifetime of the two mental health strategies (Scottish Government 2012b, 2017). At that time, Scottish Government identified partner agencies they would like to work with, and associated policy areas of relevance, yet despite that intention there has been slow progress towards a tangle of interconnected goals. Acknowledging the complexity of the social factors has meant that any change at a practice level may yet take some time. In general, management of the mental health 'problem' remains driven by health services and aimed at resolving a problem which is situated within an individual. Outcome measures remain a key feature of measuring progress despite acknowledgement that outcomes are subjective and personal. For now, one might argue that what we see is worthy rhetoric and a significant spend, but no real change for the people at the sharp end.

It may be that progress will be hampered following the emergence of COVID-19 in 2020, a global event which has taken focus away from many other policy areas. Evidence is still being compiled regarding the effects, particularly as the pandemic is not yet over. Evidence already suggests that the pandemic has resulted in significant healthcare challenges, in terms of individuals struggling to cope with the huge lifestyle changes it created and the need to reprioritise healthcare professionals to dealing with acute physical health needs. There are indications that due to lockdown, people living with a mental health diagnosis have been increasingly unable to engage in the activities of self-management such as maintaining social relationships and engaging with sport and recreation, and face-to-face healthcare support was moved online, such as routine one to one appointments with services such as psychiatry and psychology (Molodynski et al. 2020, Johnson et al. 2021, Kwong et al. 2020, O'Connor et al. 2021). There have been significant wider social and financial consequences arising from this global threat, especially for a Britain coming to terms with the impact of Brexit (Powdthavee et al. 2019). Quite how this will impact mental health policymaking and practice in the short, mid, and long term remains to be seen. A full progress review of the ambitions of the second mental health strategy is expected in 2022 (Scottish Government 2017b, p. 6). It will be interesting to see how far they have been realised.

Table 5.1 shows that consideration of Scotland's mental wellbeing spurred a complex web of policies, not all of which were directly related to mental health but mentioned it. For the most part, self-management for mental wellbeing was rarely the primary focus of policy, acting as a tool ancillary to policies dealing with the bigger problem of the nation's health. The definition of problem as a health problem is reflected in policy which continues to use policymaker and healthcare professional language, priorities, and metrics. Nonetheless, there are signs that the medical model's predominance is being disrupted. This suggests a will to change, but the added complexity of accommodating social factors means that there is little focus and little clarity about how to make it happen in a way that is meaningful for those engaged with mental health self-management on a day-to-day basis.

## 5.8 Summary

My use of policy theory has resulted in the findings which are summarised in Table 5.2.

Table 5.2 Chapter 5 findings

<ol style="list-style-type: none"><li>1. The Policy Setting is multi-level and hierarchical. Government sets the parameters of the policy topic, assigning power and funding</li><li>2. Events occur which may influence the policies that are made because they indicate that change is necessary</li><li>3. Where there is evidence in the policies that are made, they demonstrate high-level agreement that change is necessary, but limited detail about how it should be achieved at a practice level</li><li>4. Change represents threat for insiders. Views advocating change represent threat</li><li>5. Groups representing desire to change have little choice but to compromise to influence policy</li><li>6. Policy represents limited, compromised views. Threat is managed. Change is limited. Business continues as usual</li></ol>
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In this chapter I have argued that mental health policies are made in an environment which confines how the 'problem' of mental illness is constructed, limits how the 'solution' (self-management) is understood, suppresses any agreement/disagreement that policies encounter and constrains what happens as a result. It is suggested that insiders within the policymaking process appear to agree that mental wellbeing needs to improve, but the seeming consensus masks conflict between groups of people regarding what mental wellbeing is, why it is important, and how it should be improved. Meaning around these key concepts is ambiguous and the space in which interpretation is made is occupied by insiders in the policymaking environment who have the power to assert their interpretation over others. On the basis of a core policy presumption that mental illness is a medical problem situated within an individual, policy agendas are set within a boundary where the medical model, its practitioners and their priorities are privileged. Where conflict exists, that privilege prevents meaningful discussion and compromise is coerced. So profound is the key assumption, and so far-reaching its effects, that events such as responding to social factors which bring it into question have an effect but increases complexity in terms of how they might respond to it. Outsiders to the policymaking process may be in overt conflict with the policy position but have negligible power to influence the status quo.

It is expedient for government to define the problem affecting a proportion of the nation as a health problem and to delegate it mostly to healthcare to resolve. Yet, through its growing acceptance in policy of the wider factors, government finds itself the architect of a new problem where they find themselves squeezed by upstream *and* downstream pressures to respond to what government increasingly appears to agree is widely reframed as a social crisis rather than a medical one. In the absence of detailed change, language seems performative, progress slow, and wider input to the policymaking by lived experience representatives tokenistic. Similarly, it is expedient for healthcare to delegate responsibility for self-management to the individual since it reduces the pressure on healthcare resources even though to do so creates reputational risk as a result of sharing responsibility for goals. Health professionals find themselves squeezed by upstream and downstream pressures to meet goals from government *and* patients which they do not have all the resources to achieve. This complex interplay of ideas and power is suggested as the reason for the lack of substantive change to 'business as usual'. Good intentions are implied in policy but it fails to deliver. Policymakers speak to the need for changes to service delivery which require powershift but do not seek to disrupt the system which sustains it. The topic is saturated with barriers and drivers which prevent significant deviation from a long-established path.

## Chapter 6. Findings - self-management in existing research (meta-ethnography)

### 6.1 Introduction

In the last chapter I showed that, in the policymaking process, using the medical model as a way to create policy about mental illness and self-management is beset by challenges when alternative models of understanding mental illness and self-management are considered. In the main, these challenges are managed through power because a wider range of voices do not have a seat at the policymaking table. My next task was to think about how self-management is understood by those who use self-management in their everyday lives. I wondered whether the same situation happened in practice i.e., whether using the medical model as a way to organise practice produces challenges and, if so, how those challenges were managed. I wanted to understand how, in practice relating to bipolar affective disorder, self-management is understood within and between groups of people, and to consider what happens if and when there are differences of opinion.

To consider this, I used Noblit and Hare's (1988) seven-phase meta-ethnography method, synthesising the existing qualitative literature about self-management at a practice level. In Chapter 4 I described how I applied this method and presented a PRISMA table summarising how 12 papers from 10 studies, ranging in date of publication from 2009 to 2018 were included in the final selection. Papers 3 and 4 reported the findings of one study, and papers 7 and 8 both reported the findings of another. Here, the meta-ethnography process from Phase 3 onward is reported, describing the outcome of the latter of Noblit and Hare's phases in terms of reading, relating, translating, synthesising, and expressing the selected papers. My intention here was to develop understanding that was more than the sum of its parts. By grouping papers together based on common attributes and translating their findings into a common language across several primary studies, I have been able to make sense of them as a whole. The meta-ethnography synthesis allowed me to turn a significant amount of primary information into a coherent narrative of self-management as it was understood across the multiple experiences represented by the selected papers. The process culminated in identification of the questions that individuals use across the many studies represented



in this sample to construct their understanding of self-management as it related to bipolar disorder.

## **6.2 Presenting the characteristics of the selected papers**

In Table 6.1 I present an overview of the characteristics of the included papers. Further information such as age, ethnicity, and clinical features, where collected by authors of the original studies, are detailed in the table at Appendix 2.

Table 6.1 Characteristics of included studies

Paper	Author(s), Country, Year, funder	Title	Research aim (as quoted)	Design and sample Lived experience involvement	Key findings summarised
1	Baart, I. and Widdershoven, G.  Netherlands 2013  The Dutch Centre for Society and the Life Sciences	Bipolar disorder: idioms of susceptibility and disease and the role of 'genes' in illness explanations	Explores (1) how members of the Dutch Association for People with Bipolar Disorder explain the affliction of bipolar disorder; (2) the relationship between genetic, environmental and personal factors in these explanations and (3) the relationship between illness explanations, self-management and identity	7 x focus groups. n=40 (reported as 18 female, 12 male)  <i>Recruited from:</i> The Dutch Association for people with bipolar disorder  <i>Diagnosis:</i> Not verified by the study team, however membership of the Association requires that individuals have a diagnosis  <i>People with lived experience:</i> as object of study only	The authors report that participants explained bipolar across four domains: 1) the role of genes and chemicals 2) the role of non-biological components, 3) self-management 4) identity Position differed depending on whether they favoured a susceptibility or disease explanation for their illness
2	Billsborough, J., Mailey, P., Hicks, A., Sayers, R., Smith, R., Clewett, N., Griffiths, C.A., and Larsen, J.  UK 2014 AstraZeneca	Listen, empower us and take action now!': reflexive-collaborative exploration of support needs in bipolar disorder when 'going up' and 'going down'	To investigate support needed during periods of mania and depression, and when 'going up' or 'going down'	Interviews (n=27). People with lived experience =16 (9 female, 7 male) Supporters =11 (9 female, 2 male)  <i>Recruited from:</i> Third sector organisation connections, previous studies, and word-of-mouth	Support needs differed in periods of depression and mania. They are expressed by the authors across three main themes: 1) being listened to and active engagement 2) empowerment 3) acting early

				<p><i>Diagnosis:</i> Self-report</p> <p><i>People with lived experience:</i> as object of study and 5 x People with lived experience: involvement in design, collection, analysis, and reporting</p>	
3	<p>Blixen, C., Perzynski, P., Bukach, A., Howland, M., and Sajatovic, M.</p> <p>US 2016 National Institute of Mental Health of the National Institutes of Health, Clinical and Translational Science of Cleveland, National Center for Advancing Translational Sciences</p>	<p>Patients' perceptions of barriers to self-managing bipolar disorder: A qualitative study</p>	<p>To assess perceived barriers to disease self-management</p>	<p>Interviews (n=21) 15 female, 6 male</p> <p><i>Recruited from:</i> An RCT to test medication adherence. This study was part of the baseline assessment.</p> <p><i>Diagnosis:</i> Participants were required to be diagnosed and poorly adherent with BD medication as measured by the "tablets routine questionnaire" tool</p> <p><i>People with lived experience:</i> as object of study only</p>	<p>The authors report three domains of barriers to self-management:</p> <ol style="list-style-type: none"> <li>1) personal-level barriers (psychological, knowledge, behavioural, and physical)</li> <li>2) family and community level barriers (limited understanding of bipolar disorder and limited community resources)</li> <li>3) health care system level barriers (patient/provider relationships and access to care)</li> </ol>

4	Blixen, C., Levin, J.B., Cassidy, K.A., Perzynski, A.T., and Sajatovic, M.  US  2016 As paper 3	Coping strategies used by poorly adherent patients for self-managing bipolar disorder	To address the gap between coping theory and the clinical use of coping strategies used to self-manage BD	As paper 3	In the categories identified by the authors, there are two domains of coping strategies: 1) problem-focused (altering eating habits, managing mood stabilising medications, keeping psychiatric appointments, seeking knowledge about BD, socialise, and self-monitoring) 2) emotion-focused (distracting, distancing, helping others and seeking social support)
5	Cappleman, R., Smith, I., and Lobban, F.  UK 2015 Doctoral award	Managing bipolar moods without medication: a qualitative investigation	Understanding the processes involved in managing bipolar moods without medication might indicate which factors help people when they make this choice, and how they might overcome any difficulties faced	Interviews (n=10) 5 female, 5 male  <i>Recruited from:</i> Third sector adverts, adverts on social media etc  <i>Diagnosis:</i> Verified by HCP as inclusion criteria  <i>People with lived experience:</i> involved in design.	The authors found that stopping medication was part of an evaluative process about the effects and side effects of medication, rather than lack of insight. They say that an ongoing decision-making process occurs, with the individual “ <i>evaluating the effects of strategies and deciding whether changes are necessary, given pre-conceived views of themselves, who they want to be, and beliefs about their moods</i> ” (p. 248)
6	Mandla, A., Billings, J., and Moncrieff, J.  UK 2017	“Being Bipolar”: A Qualitative Analysis of the Experience of Bipolar Disorder	The present study uses a qualitative analysis of readily accessible internet blogs to explore how bipolar disorder is	Discourse analysis of 45 internet blogs. Bloggers (n=22) 15 female, 4 male, 3 unknowns.	Bloggers' discussions about BD were reported across four domains: 1) the nature of BD 2) diagnosis 3) causes

	None stated	as Described in Internet Blogs	presented on the internet by people who identify themselves as having the condition	<i>Recruited from: N/A</i> <i>Diagnosis: self-report</i> <i>People with lived experience: as objects of study only</i>	4) treatment The authors say, " <i>there is a public view of [bipolar disorder] as a broad concept that can encompass a wide variety of problems, has fluid boundaries with normality and fulfils a moral function</i> " (p.863)
7	Murray, G., Suto, M., Hole, R., Hale, S., Amari, E., and Michalak, E.E.  Canada 2011 British Columbia Medical Services Foundation	Self-management strategies used by 'high functioning' individuals with bipolar disorder: from research to clinical practice	To provide a description of the self-management strategies identified as effective by this sample of high functioning individuals and 2) to explore these results from a clinical perspective	Focus groups and interviews (participants offered the choice, unclear how many of each were conducted) (n=33) 20 female, 13 male.  <i>Recruited from:</i> Third sector adverts, adverts on social media etc  <i>Diagnosis:</i> Verified by researchers using assessment tools  <i>People with lived experience: as objects of study only</i>	In the order reported by the authors, self-management strategies are grouped into six themes: 1) sleep, rest, diet and exercise 2) ongoing monitoring 3) reflective and meditative practices 4) understanding BD and educating others 5) connecting with others 6) enacting a plan
8	Suto, M., Murray, G., Hale, S., Amari., and Michalak, E.E.  Canada 2010 As paper 7	What works for people with bipolar disorder? Tips from the experts	To synthesize and critically evaluate self-management strategies used by high functioning people with BD	As paper 7	In the order reported by the authors, self-management strategies are grouped into six themes. 1) sleep, rest, exercise, and diet 2) ongoing monitoring 3) enacting a plan 4) reflective and meditative practices

					5) understanding BD and educating others 6) connecting with others.
9	Todd, N.J., Jones, S.H., and Lobban, F.A.  UK 2012 Mersey Care NHS Trust Research and Development Grant	'Recovery' in bipolar disorder: How can service users be supported through a self-management intervention? A qualitative focus group study	To explore how an opportunistically recruited group of service users with BD experience recovery and self-management to understand more about how a service users' recovery may be supported	5 x Focus groups. (n=12) 5 female, 7 male  <i>Recruited from:</i> adverts to self-help groups and online discussion forums  <i>Diagnosis:</i> Verified by researchers using assessment tools  <i>People with lived experience:</i> as objects of study only	The authors identify four key themes: 1) recovery is not about being symptom free 2) recovery requires taking responsibility for your own wellness 3) self-management is built on existing techniques 4) overcoming barriers to recovery: negativity, stigma and taboo.
10	Van den Heuvel, S., Gossens, P.J.J., Terlouw, C., Van Achterberg, T. and Schoonhoven, L.  Netherlands 2015 None stated	Identifying and describing patients' learning experiences towards self-management of bipolar disorders: a phenomenological study	This study describes learning experiences of service users in self-managing BD that provide a possible explanation for this varying effectiveness	Interviews (n=16) 8 female, 8 male  <i>Recruited from:</i> Community care clinics by nurses  <i>Diagnosis:</i> Verified by researchers using assessment tools  <i>People with lived experience:</i> as objects of study only	The authors report five personal learning experiences towards effective self-management of BD: 1) acknowledgment of having BD 2) processing the information load 3) illness management 4) reflecting on living with BD 5) self-management of BD.
11	Wang, G., Tse, S., and Michalak, E.E.  New Zealand	Self-management techniques for bipolar disorder in a sample of	To consider how New Zealand Chinese with bipolar disorder manage their condition, regain and	Interviews (n=9) 5 female, 4 male	The authors identified four self-management themes: 1) viewing the current condition through a more positive framework

	2009 None stated	New Zealand Chinese	maintain wellness through the use of self-management techniques	<p><i>Recruited from:</i> community health centres, identified by case managers</p> <p><i>Diagnosis:</i> inclusion criteria specified diagnosis</p> <p><i>People with lived experience:</i> as objects of study only</p>	<p>2) understanding the importance of taking medications 3) maintaining harmony 4) being vigilant and cautious when disclosing the illness to others. They also say, "<i>the concepts of health and life as part of traditional Chinese culture were found to be the fundamental elements influencing the participants' coping patterns</i>" (p.607)</p>
12	Weiner, T.  US 2011 None stated	The (un)managed self: paradoxical forms of agency in self-management of bipolar disorder	Through an examination of clinical literature as well as the practices and narratives of members of a bipolar support group, this paper explores ethnographically the possibilities for subjectivity and agency that are conditioned or foreclosed by the self-management paradigm, which seems to simultaneously confer and deny rational selfhood to bipolar patients	<p>Ethnography and interviews (n=5) 2 female, 3 male</p> <p><i>Recruited from:</i> a bipolar support group</p> <p><i>Diagnosis:</i> Self-reported</p> <p><i>People with lived experience:</i> as objects of study only</p>	The author reports that, " <i>through their self-management practices, bipolar support group members model provisional and distributed forms of agency based on an elusive, discontinuous, and only partially knowable or controllable self—revealing, perhaps, the limits of the contemporary reification and medicalization of both selfhood and disease</i> " (pp.448-9)

Papers 3, 4 and 12 were written by authors based in the USA, papers 1 and 10 by authors working in the Netherlands, papers 2, 5, 6, and 9 by authors from the UK, paper 11 by an author in New Zealand, and papers 7 and 8 by authors from Canada. Paper 12 was the only sole-authored paper.

Papers 3 and 4 were conducted using the same sample, as part of a larger randomised controlled trial looking at medication adherence in bipolar disorder. Papers 7 and 8 also reported the same study as each other. There was overlap in the written text and quotes between papers 7 and 8, though findings were reported in a different order. Of the ten studies reported by twelve papers, nine sought the views of participants, and one conducted discourse analysis on world-wide blog content (paper 6). Of the participant-based studies, interviews were used by six (papers 2, 3/4, 5, 10, 11, 12) and two used focus groups (papers 1, 9). One study used both focus groups and interviews (papers 7/8). Of the nine participant-based studies, three recruited from medical settings (papers 3/4, 10, and 11), and a further three (papers 5, 7/8 9) recruited more widely but inclusion required that confirmation of clinical diagnosis was made by healthcare professionals or using clinical assessment tools. The three studies associated with papers 1, 2, and 12 recruited more widely and did not verify diagnosis. In total, the studies sought the views of 172 participants, with a further 22 participants included as a result of analysis of their blogs. There were more female participants than males (111:70:3 unknown). Paper 1 reported involving 40 participants but the reported gender split totals only 30, and paper 7 reported 33 participants but the reported gender split totals 32. Participants were aged between 18 and 75+ years.

Appendix 2 presents further detail of the included studies. Ethnicity was only reported in four papers (2, 3, 9, 11). Paper 11 sampled exclusively from Chinese immigrants to New Zealand. Papers 3/4, 5, 7, 9 and 11 reported occupation or employment status, and papers 1, 4 and 10 reported education levels. Marital status was recorded in papers 3, 4 and 10. All papers except 1, 2, 6, and 12 reported additional clinical attributes of their participants. Commonly reported was whether the bipolar diagnosis was type I or II, years since onset/last hospitalisation and whether or how long individuals had taken medication. Except papers 2 and 5, people with lived experience were not included in the research process other than as objects of study. Papers were published in healthcare journals, with impact factors between 0.27 (International Journal of Therapy and Rehabilitation) and 4.084 (Journal of Affective Disorders). To date, citations range between 4 for paper 6 and 92 for paper 7.



### 6.3 Relating the papers

As outlined in Chapter 4, in this phase the researcher should consider how the selected papers could be grouped, asking *in what ways are they the same* (reciprocally related), *or different* (refutationally related)? Findings from this phase determined that papers could be related by study aims and findings, associations with healthcare, and descriptions of bipolar disorder and the goals of self-management.

#### 6.3.1 Grouping according to aims and findings

Table 6.2 Aims and findings across the papers

Paper looks at	Papers											
	1	2	3	4	5	6	7	8	9	10	11	12
Tasks	n	y	y	y	y	n	y	y	n	y	y	n
Understanding of bipolar	y	n	n	n	n	y	n	n	n	n	n	n
Understanding of self-management	n	n	n	n	n	n	n	n	y	n	n	y

Table 6.1 presented each paper's stated aims and summarised key findings. In Table 6.2 it is noted that studies were dominated by task-focused research aims and questions. Papers 3, 4, 5, 8 and 11 focused on what is done i.e., what are the tasks of self-management? Papers 2, 7, and 10 focused on how people might be supported to do those tasks, with paper 10 asking how people learned to do the tasks involved in self-management. Of the twelve papers (ten studies), only papers 1, 6, 9 and 12 specifically asked about understanding. That is, participant understanding of how the diagnosis of bipolar disorder affected self-management (papers 1,6) and how self-management itself was understood (papers 9,12).

#### 6.3.2 Grouping according to association with healthcare

Table 6.3 Healthcare association across the papers

	Papers											
	1	2	3	4	5	6	7	8	9	10	11	12
Authors are healthcare-related	?	n	y	y	y	y	y	y	y	y	y	?
Recruit medically and/or verify diagnosis	n	n	y	y	y	n	y	y	y	y	y	n
Healthcare funded	?	y	y	y	?	?	y	y	y	?	?	?
Total Y (maximum = 3)	0	1	3	3	2	1	3	3	3	2	2	0

Papers could be grouped by their association with healthcare in terms of authorship, funding, and design/recruitment (Table 6.3). Papers were mostly authored by healthcare professionals working in Western healthcare systems, with psychiatrists (papers 3/4, 6, 7/8), psychologists (papers 5, 9, 11), and nursing (paper 10) represented. The professional background of some corresponding authors (papers 1, 12) was unclear. Except paper 5, which asked for lived experience input at design stage, and paper 2 which included lived experience throughout the research process, no other study included lived experience in the authorship or study design.

Chapter 6.3 showed that papers 2, 3/4, 7/8, and 9 were funded by medical or healthcare research institutions. It also recorded that participants in papers 3/4, 5, 7/8, 9, 10 and 11 were recruited from medical settings, and/or had their diagnosis verified by a clinician or clinical tool as a condition of inclusion. Paper 10 (p. 808) considered that their recruitment method using purposive selection of community psychiatric nurse caseloads ensured '*variation of perspectives*'. Participants in paper 5 who had rejected medication, took part in medicalised research which required that their diagnosis be verified. Participants who were non-concordant with medication in papers 3 and 4 had consented to participate in a medically recruited RCT aiming to re-establish adherence. Papers 1, 2, 5, 6, 10, 11, and 12 were less healthcare-associated with each demonstrating at least one aspect which was not clearly healthcare associated. In many cases this was because authorship or funding was not stated/unclear rather than definitively non-healthcare associated. Paper 2 was noteworthy, being the only paper authored by members of the third sector/lived experience. This was one of the two studies to involve people with lived experience in the study design, but it was also one of six declaring medically sourced funding. Two papers suggested no healthcare association, but on closer scrutiny, paper 1 asked participants to debate two medical views of bipolar disorder, strengthening healthcare association in this case. Paper 12 appeared to have no connections with formal healthcare services but since this paper lacked details about its funding and authorship, this conclusion is uncertain.

### *6.3.3 Grouping according to a description of bipolar affective disorder*

Papers can be grouped according to how bipolar disorder was described by participants (first order constructs) and authors (second order constructs) Table 6.4 presents these descriptions as extracted from the original papers.

Table 6.4 Describing bipolar disorder in the words of the original participants and authors

Paper	Bipolar disorder (BD) Participant quotations (first order constructs)	Bipolar disorder Author quotations/citations (second order constructs)	Bipolar disorder Researcher interpretation (third order construct)
1	<p>“In the sixties and seventies, when the cause was not genetic, we were thought to be misfits”</p> <p>“Twenty years ago a psychiatrist explained to me how it works, with these chemicals in the brain etc”</p> <p>“For me it’s a disease”</p> <p>‘they have a craving for doing things right, finding things out, they are doers’</p>	<p>“affliction”</p> <p>“Illness”</p> <p>“A mood disorder defined (by psychiatrists) by the presence of one or more episodes of abnormally elevated energy levels concerning cognition and mood, and one or more depressive episodes (Suominen 2009)”</p>	<p>Disagreement within paper across first and second order</p> <p>Participants do not always define bipolar disorder in medical terms. They do not always talk about the diagnosis as a negative experience</p> <p>Authors define bipolar disorder in medical terms. They talk about the diagnosis as a negative experience</p>
2	<p>“I need a psychiatrist who’s going to spot the early warning signs before things get too bad, because I find that once ... if I go deep into an episode its very, very difficult to get out”</p> <p>“[Bipolar disorder is] like a fix ... you feel much better, it makes you feel in control ... you can do anything you want to do”</p>	<p>“People with bipolar disorder endure extreme changes in mood related to such fluctuations, and some also experience distorted or confused thinking that can lead to actions that are dangerous to self and others”</p> <p>“People with enduring mental health problems often experience periods of relative stability and wellness alternating with episodes of instability and illness (Walsh &amp; Smith, 2012)”</p>	<p>Disagreement within paper across first and second order</p> <p>Participants do not always define bipolar disorder in medical terms. They do not always talk about the diagnosis as a negative experience</p> <p>Authors define bipolar disorder in medical terms. They talk about the diagnosis as a negative experience</p>
3	<p>“It’s basically one of those illnesses, like cancer or AIDS or something like that. So, it’s very serious, like heart attacks or those illnesses that can take your life”</p>	<p>“Bipolar disorder is a chronic mental illness associated with reduced quality of life, decreased functioning, high rates of suicide and high financial costs (Murray &amp; Lopez, 1997; Zaretsky, Rizvi, &amp; Parikh, 2007)”</p>	<p>Agreement within paper across first and second order. Medical perspective used</p> <p>Participants do not always define bipolar disorder in medical terms</p>

	<p>"I feel different from other people. Sometimes I feel God gave me a bad hand. If I can't think like most people, or you know, do stuff like other people, it gets to me"</p>	<p>"All the respondents agreed that BD was a very serious illness"</p>	<p>but talk about the diagnosis as a negative experience</p> <p>Authors define bipolar disorder in medical terms. They talk about the diagnosis as a negative experience</p>
4	<p>"I've done a lot of research on it. Like on the internet. Like I searched what is bipolar disorder, and how does it affects you. I've got tons of research on that and it's helped me understand"</p> <p>"It took me several years to notice my mood swings and identify that I'm having them. Because I have a good support system that actually helps me identify them"</p>	<p>"Bipolar disorder (BD) is a chronic mental illness associated with reduced quality of life, decreased functioning, high rates of suicide and high financial costs (Murray &amp; Lopez, 1997; Zaretsky, Rizvi, &amp; Parikh, 2007)"</p>	<p>Agreement within paper across first and second order. Medical perspective used</p> <p>Participants define bipolar disorder in medical terms. They talk about the diagnosis as a negative experience</p> <p>Authors define bipolar disorder in medical terms. They talk about the diagnosis as a negative experience</p>
5	<p>"...altering the emotional state, so if you're feeling low anything that makes you feel good and if you're feeling high anything that'll calm you down, if you're paranoid anything that'll make you feel safe..."</p> <p>'several participants described their elevated moods as a valued part of their personality'</p>	<p>"Clinical guidelines for professionals working with those who experience bipolar moods have traditionally focussed on medication, and continue to devote more coverage to pharmacological interventions than they do to any other approach"</p>	<p>Disagreement within paper across first and second order</p> <p>Participants do not always define bipolar disorder in medical terms. They do not always talk about the diagnosis as a negative experience</p> <p>Authors define bipolar disorder in medical terms</p>
6	<p>"I had a monster within me that had taken up residence. At times the monster was quiet and I would actually forget that it was "there"... Managing the monster was</p>	<p>"Bipolar disorder (BD) is a mental disorder whose boundaries and characteristics have been contested within the professional literature"</p>	<p>Agreement within paper across first and second order. Less medical perspective used</p>

	<p>exhausting... And my greatest fear was that I WAS the monster”</p> <p>“I feel driven and with purpose. I feel like I’m in a positive vortex and I’m happy and productive for the first time in months”</p>	<p>“The blogs present a “bipolar identity,” which is much broader than traditional definitions, is based on a medicalized model of the disorder, and connected to the moral function of enabling people to externalize unwanted aspects of the self”</p>	<p>Participants do not always define bipolar disorder in medical terms. They do not always talk about the diagnosis as a negative experience</p> <p>Authors question a medical definition of bipolar disorder</p>
7	<p>“Well, I had periods where I was really depressed and, and very dark, and not involved in community, not involved with others”</p> <p>“It’s like a motor slowly turning off in my body”</p>	<p>“Bipolar disorder (BD) is a complex mental illness that results in substantial costs, both at a personal and societal level”</p> <p>“Bipolar disorder (BD) is a chronic psychiatric condition typically characterized by recurring episodes of depression and mania (a distinct period of abnormally elevated, expansive or irritable mood) or hypomania (the subsyndromal counterpart to mania) (Goodwin &amp; Jamison, 2007). Marked variability can occur between individuals with BD in terms of the type, number and length of episodes experienced, the severity and type of symptoms encountered, and the degree of recovery attained between mood episodes</p>	<p>Agreement within paper across first and second order. Medical perspective used</p> <p>Participants do not always define bipolar disorder in medical terms, but they talk about the diagnosis as a negative experience</p> <p>Authors define bipolar disorder in medical terms. They talk about the diagnosis as a negative experience</p>
8	<p>“When you’re not feeling well, that’s one of the things that kind of gets blown out of proportion”</p> <p>“If I have three days in a row where I’ve just kind of felt down and blue, then I pull out my wellness plan and I look and it usually will kind of help me out in that time. If that’s not working and I actually end up into</p>	<p><i>As above</i></p>	<p>Agreement within paper across first and second order. Medical perspective used</p> <p>Participants define bipolar disorder in medical terms. They talk about the diagnosis as a negative experience</p>

	'signs and symptoms,' and those are listed, the little red flags like, 'I don't care'"		Authors define bipolar disorder in medical terms. They talk about the diagnosis as a negative experience
9	<p>"You can't get rid of the illness; you have to acknowledge that it is there and you have to turn it to your advantage".</p> <p>"I think I had about 4 quite severe episodes of being really ill, very distressed, relationships broke up, jobs evaporated, I moved, usual absolute chaos ... but there are huge positives"</p>	"Bipolar disorder (BD) is a highly recurrent affective disorder characterised by periods of extreme mood, including depression and mania or hypomania (Goodwin & Jamison, 1990), and has been identified in 2% of the population (Merikangas et al., 2007). Although BD is ranked by the World Health Organisation as one of the sixth most debilitating conditions (Murray & Lopez, 1997), outcome is highly variable and there are those who experience long periods of stability (Michalak et al., 2006)"	<p>Disagreement within paper across first and second order</p> <p>Participants do not always define bipolar disorder in medical terms. They do not always talk about the diagnosis as a negative experience</p> <p>Authors define bipolar disorder in medical terms. They talk about the diagnosis as a negative experience</p>
10	<p>"It was simply something I could not accept for a long time... This label of being mad – it seemed it came out of nowhere. It opened my eyes to the fact that it is important to do things to prevent a further downfall and a way out of the depression"</p> <p>"Most...remembered their first hypomanic episode as a period wherein they felt great and special"</p>	"Bipolar disorder (BD) is a severe chronic mental illness characterized by fluctuating mood and activity patterns, alternating between euthymic, hypo-manic or manic, major depressive, and mixed-mood episodes"	<p>Disagreement within paper across first and second order</p> <p>Participants do not always define bipolar disorder in medical terms. They do not always talk about the diagnosis as a negative experience</p> <p>Authors define bipolar disorder in medical terms. They talk about the diagnosis as a negative experience</p>
11	<p>"No doctor can cure me. During those years, I had to rely on myself to find a way to deal with my illness"</p> <p>"we don't want people to know our mental illness. This is a problem I had when I was in Hong Kong. I hid from others. I didn't want them to know that I was crazy"</p>	"High rates of relapse and other poor psychosocial outcomes remain for some individuals with bipolar disorder (BD), even after syndromal remission has been achieved (Bauer et al., 2006; Michalak et al., 2006)"	<p>Agreement within paper across first and second order. Medical perspective used</p> <p>Participants define bipolar disorder in medical terms. They talk about the diagnosis as a negative experience</p>

			Authors define bipolar disorder in medical terms. They talk about the diagnosis as a negative experience
12	<p>"I have bipolar disorder, OCD, and anxiety, which are all kind of the same thing! I was thinking this week about how it's funny never to know what you're going to be like the next day. Like, what's it gonna be? Will I be depressed or manic?"</p> <p>"And mood disorders aren't like that. For one thing, there's no blood test. There's no way of absolutely knowing how sick you are at any given point. And there's no way of regulating your diet and regulating your meds to the point where you're gonna be fine"</p>	<p>"Contemporary psychiatric taxonomies and treatment modalities in the United States are increasingly driven by a biomedical model that presumes the isolability of personhood from pathology and focuses on the latter as the object of intervention"</p> <p>"Such a model, humanist anthropologists have long argued, carries consequences for "the way doctors perceive patients, the way society perceives patients, and the way patients perceive themselves" (Luhmann 2000, p. 23), often doing violence to the patient's complex psychological experiences and identity"</p>	<p>Disagreement within paper across first and second order</p> <p>Participants do not always define bipolar disorder in medical terms. They talk about the diagnosis as a negative experience</p> <p>Author questions a medical definition of bipolar disorder</p>

Table 6.5 How participants described bipolar disorder

Bipolar is	Papers											
	1	2	3	4	5	6	7	8	9	10	11	12
More medical Medical terminology and/or negative attitudes towards bipolar												
Participants	n	n	y	y	n	n	y	y	n	n	y	y
Authors	y	y	y	y	y	n	y	y	y	y	y	n
Less medical Non-medical terminology and/or positive attitudes towards bipolar												
Participants	y	y	n	n	y	y	n	n	y	y	n	n
Authors	n	n	n	n	n	y	n	n	n	n	n	y

Table 6.5 summarises how bipolar disorder was described across the selected papers. In papers 8 and 11, participants *and* authors defined bipolar disorder using a predominantly biomedical frame; as an illness, a condition, or by using clinical symptoms. In these papers, bipolar disorder was framed as a negative, undesirable experience. In papers 1, 3, 4 and 7, participants agreed mostly with the authors, sharing a somewhat less medicalised, but nonetheless negative view of bipolar disorder e.g., describing it as difference, unreality, a lack of cohesion, and “*not feeling how you’re supposed to feel*” (paper 4: p1333). These were all papers associated strongly with healthcare services (Chapter 6.3.2).

Six papers showed signs of disagreement between authors and participants in their definitions of bipolar. Authors of papers 1, 2, 5, and 9 used predominantly clinical language and were sometimes negative in what they said, but their participants were less so, describing positive aspects of their experience of the diagnosis, sometimes referring to increased energy, or feeling good. Paper 10’s authors reported that their participants were sometimes positive, but their own description was always negative. Overall, participants were more likely to refer to positive aspects of the diagnosis. In paper 12 however, the author questioned purely medical definitions of bipolar, but the participants disagreed, using less medical but negative terminology. In paper 6 bipolar disorder was defined by participants *and* authors using non-medical terminology and language which was sometimes positive. This was one of the papers described in Chapter 6.3.2 as being less associated with healthcare.

#### 6.3.4 Grouping according to metaphors about the goals of self-management



Table 6.6 Describing the goals of self-management using examples of metaphors used by participants and authors

Metaphors used/Papers	1		2		3		4		5		6		7		8		9		10		11		12		Third order
Participants (P). First order constructs Authors (A). Second order constructs	P	A	P	A	P	A	P	A	P	A	P	A	P	A	P	A	P	A	P	A	P	A	P	A	
Positive. Self-management is a way of getting																									
Wellness/absence of symptoms/illness/ avoiding relapse/engagement/not in services/concordance with medication	n	n	y	y	n	y	n	y	n	y	y	y	y	y	y	y	y	y	n	n	n	y	y	y	Medical outcomes which are measurable
Control/empowerment/ agency/ independence/ perspective/ risk-taking/ autonomy/competence/trusted	y	y	y	y	y	y	n	n	n	y	y	y		y	y	y	y	y	y	y	y	y	n	n	Personal outcomes which are subjective, hard to define and measure
Inclusion/ fitting-in/ normality/ normalcy/not doing the wrong thing/respect/friendships/family/ social connection/understanding or acceptance from others/	n	y	n	n	y	y	y	y	n	y	y	y	y	y	y	y	y	y	n	y	n	y	y	y	Normative, personal and social outcomes which are subjective, sometimes hard to define and measure
A better/good/worthy/valuable/enjoyable/meaningful/fun/fulfilling life	y	y	n	n	y	n	y	n	y	y	n	n	n	n	n	y	n	y	n	n	n	n	n	y	Personal outcomes which are subjective,



Coping with/getting on with/quality of/involved with/acceptance of life	y	y	n	n	n	y		n	n	n	n	n	n	y	n	y	y	y	n	n	y	y	y	y	Personal outcomes which are subjective, hard to define and measure
Negative. Self-management is a way of avoiding																									
Illness/symptoms/relapse/crisis/hospitalisation/side-effects/impairment/institutionalised/suicide	y	y	y	y	y	y	y	y	y	y	y	y	y	y	y	y	y	y	y	y	y	y	y	y	Medical outcomes which are measurable
Isolation/exclusion/absence of friends/family	y	n	n	n	y	y	y	y	y	y	n	n	y	n	y	n	n	y	n	n	y	y	y	n	Personal outcomes which are sometimes normative, subjective, hard to define and measure
Judgement/stigma/lack of understanding from others/being a misfit/discrimination	y	n	y	n	y	y	y	y	n	n	y	n	n	y	y	y	y	y	y	n	y	y	n	n	Personal and social outcomes which are subjective, hard to define and measure
Negative social circumstances e.g. lack of housing/money/career/job/arrest/constraints	y	y	n	n	y	y	y	n	y	y	y	y	n	y	n	y	n	n	y	y	n	n	y	y	Social outcomes which are measurable but hard to



Papers were related in the way they spoke about the purpose or goals of self-management. Table 6.6 reveals that all papers talked about self-management as an endeavour undertaken to avoid illness/symptoms. Participants and authors across papers were also in agreement that self-management was a means to achieve wider outcomes. Wider goals were broad in scope and included “a better life”, “hope”, “happiness”, “calmness”, “fitting-in”, or “not being a misfit”. External and internal stigma featured, in terms of how diagnosed people felt about themselves, and how they felt they were perceived by others. Normative outcomes included “fitting-in” and “having a good life”. Outcomes were talked about as negatives and positives, often within the same paper. i.e., as a means to reach achieve a desired outcome or to avoid its converse, undesirable outcome. Paper 12’s approach was somewhat different in that it talked about intended goals of self-management but questioned how self-management was positioned to achieve them.

Table 6.7 Summary showing how the papers are related

	Papers												Total Y across papers
	1	2	3	4	5	6	7	8	9	10	11	12	
Concerns tasks	n	y	y	y	y	n	y	y	n	y	y	n	8
Healthcare associated (in any aspect)	y	y	y	y	y	y	y	y	y	y	y	n	11
BD=medical perspective													
Participant	n	n	y	y	n	n	y	y	n	n	y	y	6
Author	y	y	y	y	y	n	y	y	y	y	y	n	10
SM=goals are medical only													0
Participant	n	n	n	n	n	n	n	n	n	n	n	n	0
Author	n	n	n	n	n	n	n	n	n	n	n	n	0
Total Y within papers (1=less healthcare associated)	3	3	4	4	3	1	4	4	2	3	4	1	

In summary, completion of Phase 4 of the meta-ethnography highlighted that the included papers were more alike than different (Table 6.7). Overall, papers tended to relate with task focused aims and findings (Chapter 6.3.1). Included papers also tended to show a strong association with healthcare services (Chapter 6.3.2). Papers were more likely to define bipolar disorder medically and have a negative view of the diagnosis from the perspective of authors, though participants were often less negative than authors (Chapter 6.3.3). Participants and authors across all papers described self-management in terms of tasks undertaken towards a

broad range of outcomes including but not confined to those which are medically valued (Chapter 6.3.4).

Papers 1, 2, 5, 6, 9, 10, and 12 had a less medical stance. There remained, however, at least some element of medicalisation whether through funding, design and/or medical stance of the participants and/or authors. The less medicalised view of papers 2 and 5 suggested that inclusion of the lived experience voice was important, but that without attention to other attributes of the study, inclusion alone was insufficient as way of broadening fully the views which were represented. The least medicalised was paper 6, whose only connection to healthcare was the occupation of the corresponding author. The paper was in all other aspects, less medical. No paper was entirely free of the biomedical gaze.

## **6.4 Translating the papers**

The participants and authors in the papers spoke about self-management in terms of tasks (Chapter 6.4.1) outcomes (Chapter 6.4.2) and knowledge (Chapter 6.4.3).

### ***6.4.1 Tasks***

Original participant and author data translated into four self-management task categories, 1) activities, 2) information-gathering, 3) medication, and 4) monitoring. Table 6.8 shows papers where topics were mentioned.

Table 6.8 Tasks of self-management in papers

	Papers											
	1	2	3	4	5	6	7	8	9	10	11	12
Activities												
Sleep	n	y	y	y	y	y	y	y	n	y	n	n
Nutrition	n	n	y	y	n	y	y	y	n	n	n	y
Exercise	n	y	y	y	y	y	y	y	y	y	n	n
Stress management/relaxation	n	y	y	y	y	y	y	y	y	y	y	n
Reduction illicit drugs/alcohol	n	y	n	n	y	y	y	y	n	n	n	y
Support networks	n	y	y	y	n	y	y	y	y	y	y	n
Socialisation	n	y	n	y	y	y	y	y	y	y	n	y
Information gathering/learning	y	y	y	y	y	y	y	y	y	y	y	n
Medication	y	y	y	y	y	y	y	y	y	y	y	y
Self-monitoring	y	y	y	y	y	y	y	y	y	y	n	y
Outcomes	y	y	y	y	y	y	y	y	y	y	y	y
Self-knowledge	y	y	y	y	y	y	y	y	y	y	y	y

#### 6.4.1.1 Activities

Across all papers except paper 1 which concerned itself with understanding of the diagnosis, people with lived experience were described as responsible for undertaking specific activities and routines.

Activities and routines most commonly translated as tasks were managing sleep, exercise, nutrition, including sugar and caffeine use, stress, use of alcohol/illicit drugs, and socialisation. Paper 2 concerned itself with a view that activities and needs were different at different phases of the diagnosis. Paper 12 offered a disconfirming case in which a participant said “...*there’s no way of regulating your diet and regulating your meds to the point where you’re gonna be fine*” (p. 469).

#### 6.4.1.2 Information-gathering

Paper 12 did not discuss information-gathering, but papers 3, 7, 8, 9, 10, 11 reported that healthcare professionals were considered responsible for teaching individuals about the diagnosis and the tasks necessary to self-manage it. In all but papers 5, 6, and 9 it was reported that the responsibility to learn rested with the patient.

*“Although, pharmaceuticals are considered the primary choice of treatment, evidence shows the effectiveness of psychosocial support... and additional psychological*

*therapy ... where service users are taught to identify and react on prodromal signs and symptoms to promote self-management” (Authors. Paper 10: p. 802).*

In this quote from one of the papers less associated with healthcare, one participant said that healthcare input into information-seeking was unwelcome.

*“I’d like a resource that I can go to that excludes them altogether” (Participant. Paper 9: p. 119).*

Participants described a process of “*trial and error*” (paper 10: p. 806) establishing which tasks or activities had relevance in their lives. The authors in paper 1 acknowledged this.

*“Studies in medical sociology (and psychology) reveal the complexity of how patients... appropriate scientific knowledge. They do not appropriate it as such, but link it to their personal lives and blend information into personal constructs” (Authors. Paper 1: p. 642).*

Accordingly, participants in papers 4, 6, 7, 8, and 9 expressed the need to find alternative sources of information from a variety of sources including the internet and peers with lived experience.

*“There’s chat rooms, and people in there blogging about their experiences that they have with it. And how they manage to cope with it. It was all types of stuff. It is helpful, because it makes me feel like I’m not alone, you know” (Participant. Paper 4: p. 1331).*

*“I went out and looked it up on the web, I bought books, I found things that help myself and thought I am a strong person and I can get through this and I will do whatever it takes” (Participant. Paper 9: pp. 118-9).*

In the following quote from paper 10, the participant described it as their responsibility to adapt information about signs and symptoms to their own experiences.



*“You have to learn to recognise your signs... you have to learn to recognise it and ‘play’ with it... You have to experience it for yourself, just to know what your boundaries are and how to cope with it... If you can master it in that way, for me, that is self-management”* (Participant. Paper 10: p. 806).

In this way, individuals assumed responsibility for becoming an expert in their lived experience of a bipolar diagnosis. This was noted by one participant in paper 9.

*“I am an expert because I have had it for years erm and when I go on to Bipolar sites and it gives me a list of the DSM, it is giving me nothing, I don't even look at it”* (Paper 9: p. 119).

Patients not informing themselves was described as a factor in the ineffectiveness of self-management in papers 3, 4, 7, 8, 10 and 11, all medium-to-strongly medically associated. It resulted in the responsibility of the healthcare professional to ensure the person understood the diagnosis according to the medical model.

#### 6.4.13 Medication

Findings translated from papers 1, 3, 4, 7, 8, 10, 11, all medium-to-strongly associated with healthcare (Table 6.7), presented a view that medicine-taking was *“a cornerstone of treatment for individuals with BD”* (Paper 3: p. 635). For them, healthcare professionals were responsible for giving information about medication, prescribing it appropriately, and responding to side-effects experienced.

*“I was given Anafranil at that time, and that's very stimulating [...] I think that was to blame [...] maybe if I'd been given different medication, it might not have happened [...] the psychiatrist said I should have taken Luthimil”* (Participant. Paper 1: p. 646).

Paper 11 authors also reported consensus between healthcare professionals and patients about the importance of the role of healthcare professionals regarding medication, and they supported their assertion using evidence from their participants.

*“Other individuals who reported taking their medication reliably expressed a deep feeling of trust and respect towards their treating doctors. In their view, taking medication was not a bad thing, and the doctor would help them manage the side effects of medication and reduce the dosage as necessary: “Taking medication for the rest of your life is not a bad thing. Medication definitely has side effects but the doctor will gradually reduce the amount you intake” (Authors then participant. Paper 11: p. 604).*

Papers 2, 3, 4, 6, 7, 8, 10 and 12 presented examples of participants that said it was their responsibility to take medication as prescribed and to inform their doctor when medication appeared to be ineffective.

*“I try to think happy thoughts and just try to force myself not to get upset or angry at things. But a lot of times that don’t work. So, that’s why I try to take my medicine, when I’m supposed to” (Participant. Paper 4: p. 1332).*

*“Most bloggers emphasized the importance of drug treatment, along with self-management techniques” (Authors. Paper 6: p. 858).*

*“It felt like a real gamble when I restarted working, due to the irregular hours and decreasing Lithium at the same time. . . but my psychiatrist and partner supported me by putting faith in me. Because of this confidence I was given, I was careful not to break our mutual trust” (Participant. Paper 10: p. 806).*

*“Oh yeah, if I stop taking my medicine I’ll become manic within like a week” (Participant. Paper 12: p. 465).*

A participant in paper 4 described this as a challenge, lacking a reference point about what *effective* looked like.

*“Trying me on different medications and giving me some information that would explain how you’re supposed to feel so I can understand if it’s working for me”.* (Participant. Paper 4: p. 1333)

In strongly medically associated papers 3, 4, 7 8 and 11, not taking medication was described as not doing self-management. This was a view held by the authors in paper 3.

*“However, negative or ambivalent attitudes about medications prescribed for their BD posed barriers to self-management”* (Authors. Paper 3: p. 638).

A participant in paper 3 agreed, saying they knew their reticence regarding medication was “messed-up” (p. 638).

Authors and/or participants in the less medically associated papers 2, 5, 6 and 12 presented less conviction about the role of medication. Within these papers was expressed a concern that medication was unsuitable or ineffective, and may be rejected periodically, or entirely in the case of participants in paper 5.

*“For example, Lisa stated that when she used medication “I still had an episode”, and concluded “what’s the point in taking meds if you’re still gonna have [an episode] probably?”* (Participant. Paper 5: p. 244).

*“Other bloggers expressed their disappointment that the effects of medication did not live up to what they felt they had been promised. Hence one blogger compares her doctors to a “medical Cheshire cat promising the world and pointing me in completely the wrong direction”* (Authors and participant. Paper 6: p. 862).

*“Over the years, members lost track of why particular changes in their treatment regimes had been made, and sometimes questioned during group discussions whether their current cocktails were redundant or suboptimal. Furthermore, at times the drugs seemed to have agencies of their own that defied a relationship of rational management by the somatic individual... many of the group members had experienced or worried*

*that a medication they relied upon might suddenly lose its effects. Others...had to weigh the benefits of a medication against risky or debilitating side effects, either all too perceptible or dangerously invisible to them” (Author. Paper 12: p. 467).*

Paper 5’s authors (p. 241) cited LeClerc et al. (2013), saying that *“it is estimated that up to 64% of people diagnosed with [bipolar disorder] will stop taking medication prescribed for their moods at some point”*. Strongly medically associated papers 3, 4, 7, 8 and 11 said it was the responsibility of the healthcare professional to find ways to address these barriers and impress on the patient the need for adherence. This was noted in paper 4.

*“It has been amply demonstrated that simply telling a person to take their medication is not likely to result in long-term and consistent adherence. To begin to address medication-taking and consistent adherence, which is known to be foundational to good outcomes in [bipolar disorder], it is important to understand how individuals conceptualize their role in health behaviors and use this as a starting point in partnering with patients to optimal engagement in care” (Authors. Paper 4: p. 1333).*

Less medically associated paper 5 offered an alternative view because it looked specifically at how people with a diagnosis managed without medication. It concluded that their choice not to take medication *“may be the result of a deliberate evaluative process rather than a “lack of insight” (p. 248).*

#### **6.4.1.4 Self-monitoring**

In all papers except paper 11 which did not discuss monitoring, participants described assuming responsibility for monitoring behaviour and feelings in order to identify whether they were experiencing the signs and symptoms of illness. This was evident in participants in papers 8 and 1.

*“What really allowed me to move and carry on from my episode was doing a lot of reflection and insight into myself... Insight and reflection I think were huge. And in maintaining, because that's the way that, you know if you are feeling high or something like that, you can say ‘OK maybe I should hold back on talking for a bit” (Participant. Paper 8: p. 79).*

*“For me this was the beginning of realizing ... wow ... you really have to get to know yourself very well!”* (Participant. Paper 1: p. 650).

The authors in paper 7 pointed out that failure to monitor should be addressed by healthcare professionals.

*“It may therefore be advisable to have a discussion with patients to discuss how the benefits outweigh the demands”* (Authors. Paper 7: p.104).

In papers 1, 2, 4, 5, 7, 8, 9, 10 and 12 it was noted that participants had limited responsibility for monitoring themselves. The task of monitoring was usually shared with others.

*“My partner’s a medical writer, so she’s... very good at spotting if I’m going a bit funny”* (Participant. Paper 5: p. 246).

From findings in these studies, monitoring is a task for which responsibility shifts. There is an element of ambiguity about why and when this responsibility is assumed and when it is removed, the circumstances of which are linked to the perceived ability of the individual to understand/know themselves (Chapter 6.4.3).

#### **6.4.2 Outcomes**

Table 6.6 notes that the goals of self-management were discussed across all papers in wide terms. Some of the outcomes were clinical i.e., self-management as a way of creating clinically measurable improvements in illness or symptoms.

*“Help me learn ways to cope with the symptoms, try to help find a way to keep me on a schedule”* (Participant. Paper 4: p. 1333).

*“You have to overcome your fear – that fear of a recurrence – by trusting your medication, yourself”* (Participant. Paper 10: p. 806).

Some of the outcomes noted across the papers, however, were wider, ill-defined, and subjective. Authors in paper 7 say their findings also serve “to remind the clinician of significant individual differences in the person meaning and concrete application of superficially similar strategies”. A participant in paper 9 agreed.

*“It’s an individual’s opinion about themselves really, despite what the medical profession might say” (Participant. Paper 9: p. 118).*

Table 6.6 shows that participants evidenced a desire to avoid negative personal and social outcomes such as arrest, stigma, or social isolation which occurred as a result of their diagnosis, seen in these quotes from papers 3 and 11.

*“Bipolar is a serious disease because I make irrational, crazy decisions, mainly when I’m manic. Then I have to face the consequences. I got arrested because I had warrants on me from 2012 for being argumentative and irritable in public places. And when the cops approached me, I would be yelling and screaming. And then I got jail for eight days and lost my job” (Participant. Paper 3: p. 637).*

*“It is difficult to have a girlfriend. I can’t talk about my illness to others. If I tell them, they may be afraid of me and think I become violent when I am sick (Participant. Paper 11: p. 605).*

*“It took a long time for me to take the medicine because I didn’t want to be classified as having a mental illness because I thought I’d be ostracized ... If my friends knew that I was taking medicine because I was bipolar, they’ll say I am crazy” (Participant. Paper 3: p. 637).*

Allied with this, Table 6.6 also indicates that participants were seeking “normalcy”, “a good life” fitting-in”, and “not doing the wrong thing”. This supports paper 1’s statement which said that the desire to accord with culturally accepted norms is one which is self-imposed.

*“moral concerns (in the sense of what for them constitutes a good and valuable life and good and valuable ways of doing) appeared to be critical elements.... To be a misfit, and to be out of control, are elements of a morally undesirable identity that should be avoided”* (Authors. Paper 1: p. 646).

Paper 6’s authors said that a diagnosis was used by those with lived experience as a way to explain why they did not fit in.

*“A striking feature of several blogs was the way that BD was invoked to explain moral issues or perceived failure”* (Authors. Paper 6: p. 862).

Paper 10 offered an alternative view from other papers saying that *“dormant fear of a recurrent episode is a hampering factor in [self-management]”* due to *“being too prepared”* and over-vigilance from others (p808). Paper 12 noted a patient is expected to manage the unmanageable and be able to take control of their lives.

*“The bipolar patient came to be envisioned as an ideal neoliberal subject in potentia who, through suffering from a disease that threatens to destroy the basis of rational thought, has the capacity to fully manage the disease and determine his or her own destiny through rational choice”* (Author. Paper 12: p. 458).

#### **6.4.3 Self-knowledge**

All papers said that individuals were encouraged to know themselves as a bipolar patient in terms of acknowledging, accepting, and educating themselves about the diagnosis.

*“Since I accepted my illness though, what was driving my personality and behaviors became obvious. Now I knew. What controlled my life became front and center”* (Participant. Paper 6: p. 860).

In this presented understanding of the self, ill-me is the person who exhibits the signs and symptoms of a diagnosis, and well-me is the person who does not exhibit those symptoms. In Chapter 6.4.1, quotes were given which described monitoring behaviour for deviations from well-me. Papers 1, 2, 5, 7, 8, 9, 10 and 12 explored the challenges that self-monitoring

presented in terms of identifying when a diagnostic boundary had been crossed. Paper 2's authors say this is a result of the illness itself.

*“Many participants had learned to identify early warning signs, but some were less aware of their mood changes, particularly when becoming manic”* (Authors. Paper 2: p. 12).

A participant in paper 2 however, noted that it was challenging for the individual to determine whether an experience such as sleeplessness/sleepiness, hunger/lack of hunger, fatigue/energy was a normal experience, a personality trait or a symptomatic one, especially in the knowledge that signs and symptoms are considered to be person-specific.

*“How do you know what is really your illness and what is your “self” or your personality (your habits, attitudes, and styles of relating to others; the way you are most of the time)? How do you train yourself to know the difference between you when you’re well and you when you’re ill, and not fool yourself into thinking that changes in mood, energy, or activity are just “how I’ve always been?”* (Participant. Paper 2: p. 12).

Participants in papers 1, 2, 5, 9 and 10, talked about positive aspects of living with a bipolar diagnosis, and paper 6 notes a tendency for participants to ascribe positive aspects of their personality to who I am, and negative to bipolar. As one of their participants said, *“I wasn’t bad, I was just unwell”* (Participant. Paper 6: p. 861).

Without sufficient self-knowledge the ability to know was shared. In papers 1, 2, 5, 6, 7, 8, 10, 11, and 12, family, friends and carers were described as knowing the individual better than they knew themselves. This was exemplified in the following quote.

*“How to let your boyfriend know what he should look for” If you stay in your pajamas one day, it’s nothing to worry about; you’re having a bad day. If you stay in your pajamas two days, it’s time to ask “honey, are you okay?” If you stay in your pajamas for three days, then you ask “maybe you should call your therapist?” Four days, you call the therapist for her”* (Participant. Paper 12: p. 477).



In papers 2, 7, and 8 participants considered that healthcare professionals best knew the boundaries between ill and well.

*“I need a psychiatrist who’s going to spot the early warning signs before things get too bad, because I find that once ... if I go deep into an episode its very, very difficult to get out”* (Participant. Paper 2: p. 12).

Paper 12 said this is the paradox of self-management, in which the self-manager must have enough rationality to know when they are unwell enough not to have rationality.

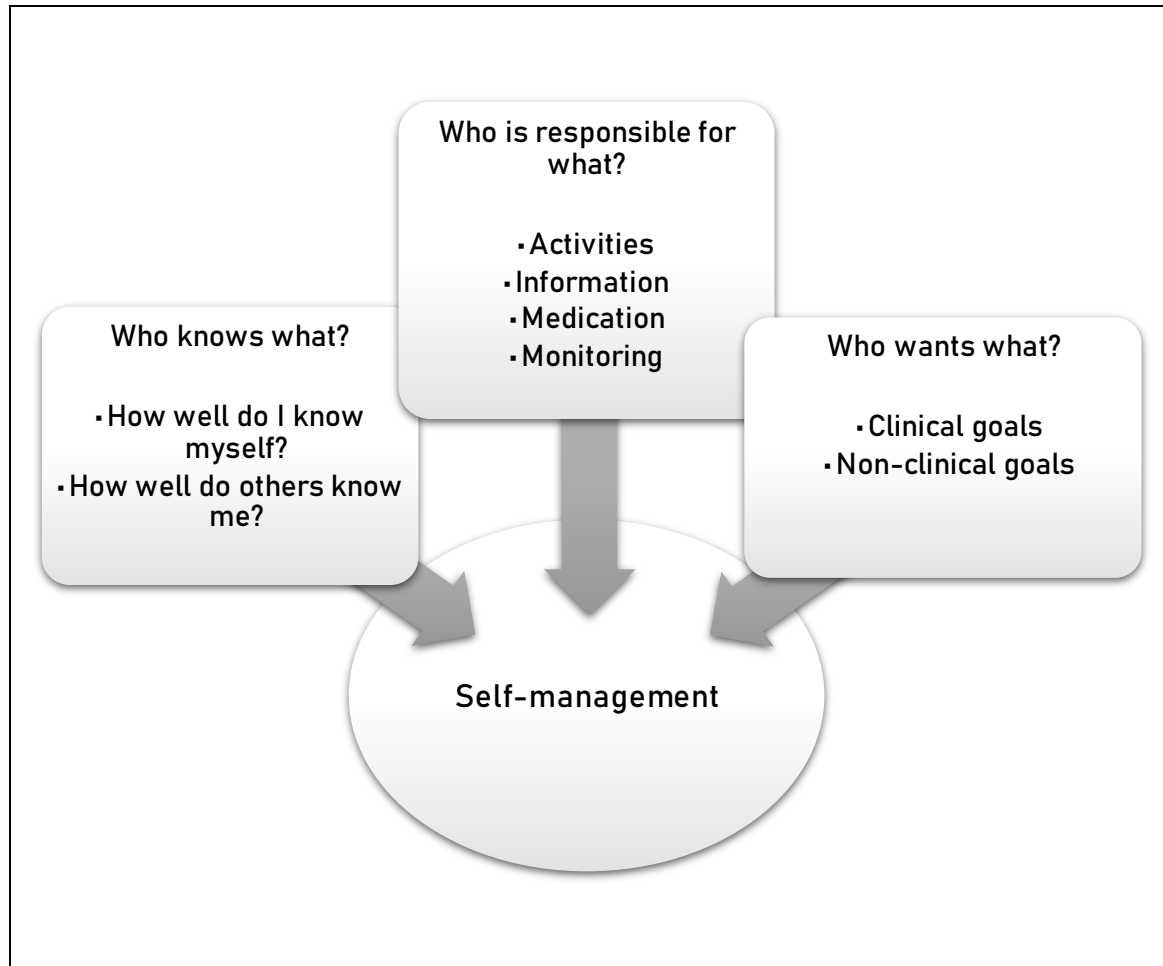
*“The managing self of biomedical discourse is predicated on a distinct notion of authentic selfhood as something that is and must be delineated and distanced from the disease. According to this logic, there exists a subtle but actual boundary between the real person—who is characterized by coherence and stability, or continuity across time—and disease manifestations that may take the appearance of personhood and “fool” the untrained patient. Thus, when the Guide describes learning to know “the difference between you when you’re well and you when you’re ill,” as in the example of Maureen, the implication is that in fact even when ill, the real self retains the ability to rationally assess and act upon the disease”* (Author. Paper 12: p. 461).

*“To express their expertise as rational self-managers, patients/consumers must, paradoxically, articulate constant suspicion toward their present thoughts and emotions, and distrust of an imagined future self”* (Author. Paper 12: p. 466).

The author said that sharing responsibility for this task created, a sense of *“distributed agency”* (paper 12: p. 473) i.e., the individual must forfeit aspects of their autonomy because they do not have consistent self-knowledge to know whether they are well or ill. Paper 9 (p. 123) and 10 (p. 806) noted that the subsequent oversight by others and loss of agency can be counter-productive for self-management efforts, though paper 10 (p. 807) referred to the sharing of agency as a *“higher form of autonomy”*.

## 6.5 Synthesising the papers

Graphic 6.1 How understanding of self-management is constructed by participants in the papers of the meta-ethnography.



Translation of findings across the studies had enabled me to identify papers where similar findings were reported albeit using different terminology. Through the translation process I had determined that the included papers talked about self-management in terms of tasks, outcomes, and knowledge. With the meta-ethnography process almost at a close, it was possible to form a line of argument about self-management for bipolar disorder as it related to the selected papers. A graphic was created representing the learning about self-management from these papers. The image describes the headings across which self-management understanding is formed (Graphic 6.1). In it, tasks map to who is responsible for what, outcomes map to who wants what and self-knowledge maps to who knows what. The headings are presented in more detail in the following sections.

### 6.5.1 Who is responsible for what?

Table 6.9 Summary of responsibilities for effective self-management in the medical model

The healthcare professional should	The person living with diagnosis should
Give person information about the diagnosis	Learn about the diagnosis from healthcare professional, possibly supplemented with other information
Give the person information about the signs and symptoms associated with the diagnosis	Learn about the signs and symptoms, and identify which are most salient in their lives through trial and error
Monitor for signs and symptoms, take action when threshold is reached	Monitor for signs and symptoms, check with others when unsure whether threshold has been reached. Request action when warranted
Give the person information about medication and prescribe it	Take the medication as prescribed
Monitor effectiveness of medication, adjust medication, respond to uncertainty with information	Monitor effectiveness of medication, ask for adjustments if ineffective, ask for clarification if uncertain
Give person information about self-care activities which may be useful	Learn about the self-care activities which are most salient in their lives and do them

Chapter 6.4.1 showed that self-management involves a set of tasks. When summarised in Table 6.9 above, the synthesis of papers suggested that responsibility for those tasks is shared, albeit not equally. Activities were advised then adapted to the lived experience, information was given then adapted to lived experience, medication was prescribed then taken as advised, and self-monitoring was important but only to a point. In a medical construction of self-management, responsibility was led by the healthcare professional, and delegated in part to the person living with the diagnosis. Healthcare professionals were *defining and instructing*, and patients were *doing and monitoring*. Lived experience input was an optional adjunct to the primacy of the healthcare professional's expertise. While the less medical papers in the sample introduced uncertainty about the role of medication and self-monitoring, under the medical gaze, ineffectiveness of self-management was constructed as failure of the individual to assume the responsibilities which were delegated to them by the healthcare professional.

### 6.5.2 Who wants what?

In Chapter 6.4.2 I showed that self-management can be described medically as a journey towards clinically defined and measured outcomes. Were this the only measure, healthcare professionals could be acknowledged as the experts of wellness. I noted however, that wider, non-clinical outcomes were widely acknowledged among participants *and* authors. In some cases, the wider outcome was to avoid the negative personal and social consequences of the diagnosis, or conversely to reach towards normativity i.e., to fit in and avoid stigma. This suggests that the person sometimes self-managed because of extrinsic, normative factors; once diagnosed the consequences of exhibiting what were perceived to be symptomatic behaviours and/or bearing the diagnostic label were undesirable.

Clinical outcomes such as reduction in symptoms, medication adherence, and reduced acute presentations, are clearly defined, measurable and achievable. Many wider outcomes, however, are more nuanced and ill-defined. According with cultural norms is challenging when cultural norms are inclined to shift across time and geography, as indicated in paper 11 which considered migrants from Chinese to New Zealand cultures. Outcomes can be interpretative, subjective, and less measurable and achievable. The resolution of some social outcomes including work, occupation, and stigma, is socially and/or politically determined and lies beyond the sole control of either healthcare professional or patient. This suggests that self-management may be impacted as a result of failing to fully understand and accommodate the breadth of outcomes as understood by the person living with the diagnosis, particularly when those outcomes are subjectively hard to define/measure and/or outside of the remit of either party to achieve.

### 6.5.3 Who knows what?

In Chapter 6.4.3 I established that for the individual living within the medical model, acceptance of a diagnosis was constructed as a lens through which to know themselves. Thereafter everything an individual knew about themselves was seen through this lens. Individuals were encouraged and accepting of the challenge of becoming experts in the lens, so that they could better understand themselves through it. Failure to achieve normative behavioural standards and outcomes was assigned to illness. Some individuals ascribed the negative parts of themselves to illness and the positive to who they actually are. Self-management was used as a tool of normativity, co-opting the willingness of the individual to fit-in and avoid the negative consequences and stigma of living with a diagnosis. Self-monitoring allowed the individual to

notice the nuances between *myself* and *illness*, though this is a judgement they were not able to know consistently. Paper 12 referred to a paradox wherein a person with a diagnosis was required to know themselves well... until they could not. Diagnosed individuals agreed that they were considered to be unreliable experts in themselves or the lens, and in face of uncertainty, deferred that knowledge to others. Diagnosis resulted in oversight by others, including healthcare professionals, family, and wider society. This determined the finite reach of knowing for the diagnosed individual, because only somebody else could make the final decision about whether an individual was themselves or an ill self. The healthcare professional was thereby co-constructed as the arbiter of wellness. Family, carers, and the individual themselves were complicit in this *who knows me best* role. This revealed a second paradox; that self-management is often constructed as empowerment, but was revealed as inherently disempowering, wherein the individual must exist with what the author of paper 12 (p. 473) termed “*distributed agency*”.

## 6.6 Summary (Expressing the synthesis)

In this chapter I have demonstrated an understanding about self-management as it is understood in healthcare practice relating to bipolar disorder. There are many who conceptualise their experiences medically, and the nuanced understanding I have presented may help to organise more effective services under that system. Nonetheless, under the predominantly medical construction of mental illness represented in the papers of this review, I have found evidence of difference. Where the less-medical voice is heard, it indicates that the role of medication and monitoring is problematic, and questions were raised as to whether self-management assigns responsibility without attaching empowerment. I argue that, in the main, self-management support within the healthcare system is based on a presupposition that the individual's primary responsibility is to cleave to the medical model as a way to understand their lives, albeit to attain goals which are ill-defined and questionably achievable within the clinical model.

A positive outcome of the meta-ethnography is that I was able to produce a graphic which described the way that self-management is constructed for bipolar disorder. This meant that in the next stage of my study I would be able to see if the questions represented in the graphic were a useful way of structuring conversations about self-management understanding with a small group of people regarding self-management of diagnoses (which may or may not be bipolar disorder).

## Chapter 7. Findings - self-management in fieldwork

### 7.1 Introduction

In Chapter 5 I argued that in the policymaking process, conflicts of understanding between policy actors are hidden by issues of power, resulting in an outward sense of consensus and policy stasis. In the meta-ethnography reported in Chapter 6, I concluded that, at a healthcare practice level, self-management support for bipolar disorder is based on a presupposition that an individual will use the medical model to understand their lives, despite a view that the goals sought are ill-defined and possibly unachievable within the clinical model. So far, this study has presented information to show that policy and healthcare practice predominantly uses a medical way of understanding self-management for mental illness. I have described the implications of that understanding in terms of who does what, who knows what, and who wants what. While differences of understanding do exist, the need to receive support and care limits the extent to which they are articulated. For example, in Chapter 5, I argued that, in the policymaking process, conflicts of understanding between policy actors are hidden by issues of power, resulting in an outward sense of consensus and policy stasis. In the meta-ethnography reported in Chapter 6, I concluded that, at a healthcare practice level, self-management support for bipolar disorder is based on a presupposition that an individual will use the medical model to understand their lives, despite a view that the goals sought are ill-defined and possibly unachievable within the clinical model.

In this final stage I wanted to explore understanding among a contemporary group of individuals regarding self-management for mental illness more generally. This stage involved a series of interviews loosely structured around questions developed in Stage 2. Participants represented a range of roles, in and out of the healthcare setting.

### 7.2 Characteristics of participants

Ethical approval permitted interviews with six participants, with the option to add two additional participants. At my progress annual review at the end of year 2, my two academic reviewers advised me to keep my participant numbers small to ensure the study was feasible in the thesis time remaining. Nine people were approached. One of the people

approached declined because they felt their experience was not sufficiently current, and another had retired. A request for participation from a current policymaker in the Scottish Government failed to elicit a response, though it is likely this was due to the growing workload due to the COVID-19 pandemic which was taking centre-stage at this time (Chapter 8.8.1).

Ultimately, six participants were recruited and interviewed between January and April 2020. Earlier interviews were conducted in person at various locations including the University and participant places of work but, due to lockdown measures in response to the COVID-19 pandemic, the latter two interviews were conducted by videocall, one by Teams and one using the NHS videocall system. The medium of the interview did not appear to have an effect because the longest (90 minutes) and shortest (30 minutes) interviews were both conducted in person. Implications of this necessary adjustment to planned data collection are discussed in Chapter 8.1. Participants were chosen to be representative of the range of people involved with self-management. The characteristics of the interviewees are detailed in Table 7.1.

Table 7.1 Participants in Stage 3

Participant	Role	Gender	Interview
1	Psychiatrist	Female	In person
2	Community mental health nurse	Female	In person
3	Lived experience peer worker in the third sector	Male	In person
4	Individual with lived experience	Female	In person
5	Consultant psychiatrist	Male	Video call
6	Former mental health policymaker	Male	Video call

For the remainder of this chapter, recipients of healthcare services are referred to as patients as is commonplace in the medical setting, but participants 3 and 4 did not identify as patients and are described as participants with lived experience of a mental health diagnosis.

### 7.3 Themes

Once analysed according to the method described in Chapter 4, coding of participant responses was grouped around the three main headings identified in Stage 2 i.e., *who does*

*what, who wants what and who knows what.* A fourth theme was identified; self-management barriers and opportunities for change.

### 7.3.1 Theme 1. Who does what?

All participants said that the practice of self-management was not management of the self solely by the self. A wide range of people and agencies beyond healthcare professionals and the patient were involved in the process, many on an ongoing basis (Table 7.2).

Table 7.2 The range of people that may be involved with self-management

Participant	1	2	3	4	5	6
People involved with self-management						
Patient	y	y	y	y	y	y
Healthcare professionals	y	y	y	y	y	y
Third sector	y	y	y	y	y	
Family, friends, peers	y	y	y	y	y	y
Social workers, social care	y	y		y	y	y
Criminal justice	y				y	y
Policymakers/politicians		y	y		y	y
Schools		y				
Welfare commission						y
Support groups				y		
Housing	y					

The third sector was considered an important resource by all except participant 6 who did not mention them. All participants felt that family, friends, and peers with lived experience provided valuable support. Also involved were social workers and social care workers (1,2,4,5), housing departments (1), schools (2), and the criminal justice system (1,5). Policymakers and/or politicians were involved as a result of their involvement in policy which affected self-management according to participants 2,3,5,6. The involvement of the mental welfare commission in terms of patient advocacy was discussed by participant 6 and participant 4 spoke positively about support groups. Many of these groups were affected by barriers and some presented opportunities (Chapter 7.3.4).

All participants said that patients and healthcare professionals were involved in self-management, and each had self-management tasks (Table 7.3).



Table 7.3 Tasks of self-management

Tasks	Participant	1	2	3	4	5	6
<b>Healthcare professional tasks are</b>							
Diagnosing, prescribing, planning treatment		y	y	y		y	y
Monitoring and making decisions relating to wellness/ capacity/ risk/autonomy		y	y			y	y
Giving information/signposting		y	y		y	y	y
Pastoral tasks: Supporting/ reassuring/ helping them find their true self/ being a safety net/ support patient to make decisions		y	y			y	y
<b>Patient tasks are</b>							
Asking for and accepting help, expressing needs and preferences		y	y	y	y	y	y
Learning from HCP and/or others about how the illness impacts them/gaining insight/adapting learning to their own life/ becoming an expert, gaining autonomy.		y	y	y	y	y	y
Demonstrating commitment to treatment and self-management/engaging		y	y			y	
Taking medication and reporting effects		y	y			y	y
Dealing with life past, present and future, coping			y	y	y		y
Managing condition/symptoms through diet, exercise, social connection and/or monitoring		y	y	y	y		
Making supported decisions about their lives		y					y

Healthcare and policymaking participants (1,2,5,6) shared their view that, for healthcare professionals, a key part of their role was diagnosing and planning treatment and outcomes in collaboration with patients, and monitoring/assessing/managing risk and patient capacity to make decisions. For participant 5, healthcare professionals dealt with the “*severe end*”, while patients were best positioned to take control when symptoms were “*mild to moderate*”. Participant 6 was alone in their view that psychiatrists helped patients to manage their internal thought processes. All healthcare and policymaking participants said that it was important to demonstrate pastoral attitudes, with three (1,5,6) describing healthcare professionals as supportive, three as respectful (1,2,5), and one (2) as reassuring and comforting.

All participants talked about understanding the patient role as seeking help and expressing their needs and preferences for treatment and learning from others how to become an expert in living their lives. Participants 1, 2 and 5 said that patients should demonstrate commitment by engaging with treatment, and participants 1, 2, 3 and 4 said patients should manage themselves through activities which included routines and monitoring. For participants 2, 3, 4 and 6 there was a view that patients should be coping with their lives.

Participants 1 and 6 talked about patients making decisions with the support of healthcare professionals.

Lived experience participants 3 and 4 said that the involvement of healthcare professionals was not optional. Participant 4 pointed out that accepting a diagnosis was because, *“pragmatically, for me to get help, I need one”*. Participant 3 said *“I had no option, had this meeting, I was diagnosed, and this was a doctor saying these things, so I believed it”*. In contradiction of the pastoral attributes noted above, these participants said that poor attitudes impacted their desire to engage (Chapter 7.3.4). They felt that healthcare professionals should be involved, but in a more limited way.

*“It’s far healthier that people are having networks of support away from services, especially if they are the NHS and psychiatry”* (Participant 3).

*“I realised quite a while ago that psychiatry couldn’t offer me very much”* (Participant 4).

Some activities were mentioned across several interviews in different ways. These formed subthemes relating to the tasks of 1) information-gathering and 2) medication.

### 7.3.1.1 Information

All but participant 3 discussed the role of the healthcare professional as the provider of information. In this quote from psychiatrist participant 1, healthcare professionals are teaching about medication.

*“I think as professionals it’s our responsibility to give them the full range of information so that they are making a very, very informed decision about whether or not to take medication if there is a medication intervention being considered”* (Participant 1).

Nurse participant 2 saw their role as teaching ways to self-manage and introduce new ways of coping.

*“My role would be attempting to teach strategy, skills, that type of thing, to assist the patient to do it alone, and where my remit stops is if you are able to do that, go and do it” (Participant 2).*

They appeared conflicted in this role, however, saying later in the interview saying that they were not a teacher.

*“I don’t want to be a teacher, that is not my role, I am not a teacher, a facilitator, I presume, I would strive to be, a facilitator rather than a teacher” (Participant 2).*

Psychiatrist participant 5 also said they were a facilitator or a coach although when a patient was in crisis their job was *“psychoeducation [...] to make sure that they understand”* and *“explaining their condition”*.

Lived experience participant 4 felt that healthcare information about self-management could be contradictory, generalised, and subject to imperatives and gatekeeping.

*“I could say well for me to manage my condition properly I will need x, I will need this particular medication, and the GP says, oh I don’t think so, that’s not what I would recommend [...] or you might say well I need to be able to do this, and somebody else will say well you know is a gatekeeper to that. [...] [They might say] a lot of self-management say is about exercise, [...] I will get on the exercise, and you say well exercise doesn’t really work for me, and it won’t stop them going oh well have you thought about exercise we can get you to do this, do that” (Participant 4).*

They said that failure to act on healthcare professional advice was used as a way to dismiss patients.

*“It’s a way of, kind of, for the health service and workers to say well, you know, if you are not keeping your mood diary how are we supposed to help you? If you are not doing this, how are we supposed to help you? And dismissing you” (Participant 4).*

Nurse participant 2 agreed about how mandatory nurse advice must seem to patients.

*“You must show commitment and you must try this because it does work, and it is evidence-based work. There is an element of that where, but it does seem very head teacher, punishment, I’m going to whack you with the belt if you don’t do what I’m telling you to do” (Participant 2).*

If not mandatory, healthcare suggestions were strongly recommended in the view of psychiatrist participant 5 who stated that failing to act on healthcare professional advice resulted in *“unmet demand”* for third sector services and repeat presentations.

Despite this pupil/teacher-type relationship, patients were described as *“experts”* by participants 1, 2, 3, and 5.

*“I am the expert in some or most of the conditions, but the patient is the expert in how that condition is affecting them. So, there are two experts in the room that completely respect each other. It is not what I say” (Participant 5).*

Healthcare participants 1 and 2 spoke about the patients’ need to supplement with information from other sources: lived experience participants 3 and 4 agreed. Participant 3 spoke about their working life in the third sector as critical for offering lived experience information about how to self-manage. They did not feel that healthcare professionals were the best people to provide information, lacking expertise in lived experience.

*“I pick up with people who have seen a psychiatrist, or they are coming in from psychology or whatever, and it doesn’t feel good when they go to this meeting and the person sits there in a suit expecting them to you know come up with their inner most fears and everything, and that person gives them nothing you know? And what I hear quite often is, well, they seem to have read the book, but they have no practical experience and lived experience and things. So that does make a difference”* (Participant 3).

They said that their search for information that worked for them had been the result of trial and error, had taken over twenty years, and eventually came from outside healthcare.

Echoing the earlier *“go and do it”* quote from participant 2, lived experience participant 4 saw the designation of expert as an act of responsabilisation.

*“I am hearing about expert patients and it was long term conditions like physical conditions and on one hand I thought this sounds really good, but on the other hand it’s, the patients are becoming experts on their own conditions, that sounds good, because I already thought most people did, you know, eventually you got to sense what was right and wrong for you and that but then it seemed to be about like making you responsible in a way that was yeah... Do you know when you’ve got responsibility but no power? You are responsible for making it work but you’ve no power to actually change the conditions”* (Participant 4).

For healthcare and policymaking participants 1, 2, 5 and 6, expertise was subject to a patient’s ability to know themselves as a person with an illness, and their capacity (Chapter 7.3.3).

### 7.3.1.2 Medication

All interviewees spoke about medication but took different positions on it. Psychiatrists and the policymaking participant (1,5,6) described taking medication as one of the preferred

tasks of self-management. All three spoke about the patients' right to make an informed decision to take medication. In their view the healthcare professional took the lead in terms of deciding which medication to use, when, and to what effect. Further patient involvement involved taking medication as prescribed, reporting efficacy and side-effects, and according to participant 6, choosing the route of administration. Participant 5 indicated that medication may not always be prescribed, even if desired by the patient. Participant 1 considered it part of their role to listen to concerns and provide information in order to overcome patient concerns about medication.

*“It’s a kind of respectful conversation that you have with your patient, listening to what, what their concerns are... And that can actually be really helpful sometimes in encouraging someone to take medication who you think (it) is going to be very, very helpful for them” (Participant 1).*

Other participants were less committed to the central role of medication. Nurse participant 2 felt that, in their view, psychiatrists focused on medication, while nurses attended to the wider healthcare-related tasks. The nurse was less clear regarding the benefits of medication.

*“[medication] will never cure, that’s my feeling, it will never cure. I feel as a nurse I can help you to live better with (a) holistic approach, and therapy and skills, and self-management, but drugs are never going to cure you. They are just going to make it worse in the long run, they will just give you some side effects and you will need to medicate for them, and then you will need to medicate for what the side effects of that medication gives, and you are on a lifelong trajectory then of medication” (Participant 2).*

Lived experience participant 3 agreed, saying that the sedation effects of medication could be useful for the individual and the healthcare professional but that they did not consider it a cure, nor did they take any.

*“I am not saying that there is never a point where it would be useful that somebody might have some form of sedation... don't be giving someone a drug that keeps [people] quiet, defend the risk assessments and risks to other people and stuff, and then they stay on that forever, like that is them cured” (Participant 3).*

Lived experience participant 4 considered medication an optional adjunct but expressed concern that taking medication meant they had to ‘beg’ for review and onward referral, and that the ineffectiveness of medication was interpreted as a failure of the individual.

*“I do feel like a lot of self-management is [...] you are given all the responsibility, but you still have to go begging cap in hand, can you review my medication? Can you refer me to this? You know? I've done all the things and it's still not working and being told well you are not doing them right or you are not doing them consistently or, yeah, I think that the responsibility has shifted and not much of the power has” (Participant 4).*

### *7.3.2 Theme 2. Who wants what?*

Psychiatrist participant 1 said that outcomes were person-centred, with psychiatrist participant 5 saying *“it has to be collaborative otherwise it is doomed to fail”*. All participants spoke about outcomes which included, but were wider than, health-related outcomes. Health-related outcomes included symptom management and lack of repeat crisis presentations (2,3,4,5,6), lack of side-effects (2), reduced self-harm or suicide (1,2,3,4,5), and overarching, vaguer terms such as, ‘health’ or ‘wellness’ (1,2,5). Commonly offered wider outcomes were quality of life/a meaningful life (1,2,3,4,6), control/autonomy/empowerment (2,3,4,5,6), and distress tolerance/resilience i.e., the ability to cope with the past, present and future (2,3,4,5,6). Other wider outcomes included returning to work/education (2,3,6), freedom from loneliness and not being involved with services anymore (2,3,4), confidence, courage, and hope (3), dignity and lawfulness (5), and safety, recovery and finding your true self (6). Two subthemes were noted, in which outcomes were 1) subjective and 2) normative.

### 7.3.2.1 Outcomes as subjective

All participants said that outcomes were subjective i.e., desirable for different reasons by different people. For example, participant 1 said that the desirability of an outcome was dependent on who was asked.

*“For the patient I would think it would be very much improved quality of life, remaining well. If you ask a hospital manager it’s probably about keeping them out of hospital because they are keeping well, you know, family, friends, employers are wanting them to remain a functioning, contributing adult to society. So, I guess it’s really the outcome will depend on who you ask”* (Participant 1).

Participant 2, a nurse, agreed that outcomes were an individual journey. She said that for patients an outcome could mean anything from a return to work to making the bed in the morning. However, they noted that different people may have reasons for wanting goals for patients. They expressed a view that self-management is supported by policymakers as a result of its ability to produce self-congratulatory statistics, albeit not resulting in practical changes at a practice level.

*“Good stats look great, don’t they? Compare them. Scotland compares them to England, England compares them to Europe, you know, self-pat on the back, look at what we are doing at work. That kind of self-gratification almost that haven’t we got it right? Policymakers push(ed) the anti-stigma campaign and the rhetoric that we can deal with this. And isn’t it great that we know all about it and there is help out there for you. On the ground it doesn’t feel like that”* (Participant 2).

This was also the participant that said successful self-management produced, for them, a space on their caseload.

*“Once I’ve taught you these skills, I expect you to go and do them on your own because I can’t hold your hand anymore [...] my outcome is discharge and next one*



*in, yes, the kind of conveyor belt of who needs to be seen next, who is in the most crisis next” (Participant 2).*

Participant 4 indicated that, as a person with lived experience, their awareness of drivers like participant 2’s led to cynicism about self-management outcomes, asking “*whose needs are being served by [self-management] [...]*”, later saying, “*there is also this strong undercurrent of go away, stop bothering us”*.

Policymaking participant 6 spoke about the obligation of others to choose an outcome on behalf of the patient, steering them towards “*a better life*”, and treating a person in order to find their “*true self*”. In their view, the true self was buried beneath the “*ill-self*”: a barrier to being “*how you want to be*”. Outcomes could be split into what the patient wants, and what other people want for them.

*“The job of the clinician is to, as it were, is to take away this thing that is getting in the way of you being your true self so that you can just be yourself. And then it’s down to you how you want to be, but you’ve taken the illness away [...] that does mean that sometimes there is an obligation, or it’s acceptable for other people to say, well actually we are going to try and shift you out of that life into a life which we have some reason to think will be a better life for you” (Participant 6).*

### **7.3.2.2 Outcomes as normative**

Participant 6 noted that a “*better life*” is a normative judgement, based on cultural understandings of what *better* looks like.

*“I don’t think you can get away from that. Normative, but I don’t think that’s necessarily a bad thing. I think you just have to kind of acknowledge that there is a concept and a line of what’s an okay kind of life and what is a not okay kind of life” (Participant 6).*

This aligns with psychiatrist participant 1's comment above about outcomes which result in becoming "a functioning, contributing adult to society", an outcome described as employability or education by participants 1, 3 and 6, and as "high functioning" by participant 2. Participant 3 pointed out the need to fit in with society and cultural norms.

*"Unless someone is obviously walking about, you know, mass murder like with an axe, who is one person really to say that another person's behaviour, you know? A lot of mental health, and we are not talking about people being sectioned and the legality of what psychiatrists are doing, is because people are bothered by the way they behave. Or what they are saying? And it doesn't really take that much for concerns to be raised [...] If one person lived on an island, they are not going to be mad are they? Because there is no one around to judge or to say that is unacceptable, that behaviour"* (Participant 3).

Somewhat in agreement with participant 3, participant 6 also noted the difference between removal of autonomy for transgressions of fitting in to society in mental healthcare, compared to the removal of autonomy in the justice system. He argued that, in law, healthcare was obliged to demonstrate "treatability" and "benefit". In his view, this created an imperative to act, intervene and treat people identified as diagnosable.

*"The other important thing is that we actually have some treatment that can benefit you, and that treatability idea is very, very important in that, because otherwise you know it's giving license to detain people for example because they may be dangerous, even though there is nothing we can do to reduce the level of dangerousness"* (Participant 6).

Lived experience participant 4 felt they had to conform to culturally defined gendered roles but wanted to live life their own way. This autonomous statement contradicted policymaking participant 6's point that other people might determine a sort of life that was better.

*“I was denied the right to be angry, the right to understand what anger was telling me, to act and find appropriate way of acting on it... [In] society, and especially in women, anger is a bad thing [...] but there is this thing about self-management, and what do they call it? Patient experts and all this kind of thing where, yeah, I don’t know, it just feels a bit too neat and tidy and less about what is really feasible and practical in the world, and how I actually want to be and treat myself and live my life”* (Participant 4).

Referring to a bipolar management talk they had attended hosted by nurses, participant 4 noted that the nurses’ idea of a *good life* did not meet their own.

*“It felt to me they were condemning us to a life where you got up at the same time, you ate the same thing at the same time every day and you went to bed at the same time and you never got very excited or upset and you just kind of, and I nearly walked out of the meeting. I was shouting so you want us to live like in a mental prison, and they were like oh no, that’s not we are talking about, giving you a good life and all the rest of it, but everybody else was like I don’t like the sound of this”* (Participant 4).

Participant 5, a psychiatrist, noted that a patient was able to make choices about how they lived their lives. They felt that, in the event the patient made a normatively wrong or inappropriate choice, their role was not to judge, but to give them their view of the consequences.

*“If the patient is making the wrong choices or inappropriate choices then you would lay out the consequences of those choices, so if you are going to make this choice these are the kinds of consequences that might come as a result of that. And they still make an unwise choice they are entitled to make”* (Participant 5).

Unless, that is, the patient was deemed by a healthcare professional not to have capacity and/or presented risk to themselves or others (Chapter 7.3.3).

*“If I sense that the patient has got significant impairment in their decision-making processes as a result of an underlying disease, that is the only time I might intervene by saying listen I think the decision that you are thinking or making is not sensible, and you would not have made this decision if your decision-making processes were not impinged by the underlying disease process” (Participant 5).*

### **7.3.3 Theme 3. Who knows what?**

Nurse participant 2 and psychiatrist participant 5 said they knew how self-management should be done, i.e., they knew when self-management was being done “right”.

*“What if you are self-managing poorly or wrongly, what if you are not doing the technique that I taught you to do, the right way, you are probably doing more harm than you ever did good because you are not doing it right, or you’ve forgot to do it the right way or you’ve adapted it that it’s not right” (Participant 2).*

Healthcare and the policymaking participants (1,2,5,6) said that the healthcare professional knew when the boundary between well and unwell had been crossed. Two (5,6) said that healthcare professionals sometimes experienced doubt in the assessment between well and ill as a result of the patient’s growing expertise in knowing themselves as a person with an illness.

*“You probably would be making a lot of decisions on behalf of patients, but you also need to be mindful that, as the patient is gaining more and more insight into their condition, as they are gaining, feeling more empowered about managing their conditions, then you need to relinquish that aspect so that the patient can self-care” (Participant 5).*

Indeed, several spoke about the patient as the expert (Chapter 7.3.1). As patient expert individuals were able to know what activities were right for them (1,2,4), and to have a view regarding their preferences for treatment and outcomes (1,2,4,6). Participants 2,3 and 4

said that the patient also knew when the boundary between well and ill was crossed. In the view of nurse participant 2, patients should go to their GP who would ratify it. Lived experience participant 3 however, said that they knew what would help, and did not necessarily need to speak to a healthcare professional for validation. Lived experience participant 4 followed a series of self-imposed rules which helped them to determine when to seek help. For them, the person themselves was in a better position to say that they needed help compared to the healthcare professional who sometimes failed to act even when a person felt it was necessary.

In the view of healthcare and policymaking participants (1,2,5,6), the patient's ability to know was constrained by capacity and assessments of risk, subjects in which the healthcare professional had ultimate knowledge, responsibility, and accountability. Healthcare professionals were considered to know the appropriateness of patient decisions and actions (1,2,5,6) and whether they were indicative of capacity (1,2,5,6). Healthcare and policymaking participants spoke about the healthcare professional's responsibility in law for making decisions about treatment, based on knowing how much insight the patient had into their decision-making. Participant 5 felt that lack of capacity and lack of knowledge/expertise were good reasons to take away autonomy. For participant 1, expertise had provisos and capacity marked the limit of knowing.

*"I have actually said to patients you are the expert, you are the best person to know what is right for you and that is absolutely the key thing. And assuming that capacity isn't an issue, and there is not an acute emergency situation where you need to intervene to save the patient's life, for example under common law, then that is what happens" (Participant 1).*

Lived experience participant 3, however, felt that capacity and risk assessments were influenced by cultural norms and subjectivity.

*"It seems to be measured, is there is no risk? So the person doesn't want to kill themselves anymore, or hurt any other people, or be noisy or raucous" (Participant 3).*

Policymaking participant 6 agreed, saying that a mental illness diagnosis, and the perception of potential risk or disruptive behaviour, permits action such as enforced treatment, or removal of autonomy, which would not otherwise be possible.

*“I mean that’s one of the arguments I suppose some of the critics of mental health law would make. That it’s inherently discriminatory. That we put a certain label on people saying because you’ve got a mental disorder, we can do things to detain you that we couldn’t do if you had an alcohol problem or a drug problem, or you were just a very violent, nasty person”* (Participant 6).

Participant 6 talked about the subjectivity of this assessment in law.

*“At what point can somebody else decide where you live, for example? Or what clothes to put on in the morning, or who you associate with? I mean the Adults with Incapacity Act gives you, or potentially gives somebody else, the power to do all of those things. And that is dependent on a test for incapacity, it has to be shown that you are incapable of doing those things for yourself. Which some would argue is a more kind of objective test than some of the tests in the Mental Health Act, but people like the UN Committee argue that it’s also subjective and kind of value laden”* (Participant 6).

He noted that, in law, maximising autonomy and the ability to self-manage is important but, in practice, the law acts to disempower more, and for longer than intended.

*“The intention with [the Mental Health Act and the Adults with Incapacity Act] was to be more tailored in the law than happened before so that the interference with people’s self-management and autonomy is the minimum that is absolutely necessary and should be removed as quickly as possible. But I think there are a number of ways in which that doesn’t really happen. That the law actually does more*

*to kind of, as it were, take away your self-management than, for longer and in a more comprehensive way, than is the intention in the legislation” (Participant 6).*

#### **7.3.4 Theme 4. Barriers and opportunities**

Participants talked about social, structural, individual, and wider barriers to self-management across the people and agencies involved with it. They also suggested opportunities for improvement.

##### **7.3.4.1 Social barriers**

For some participants, social factors acted as barriers to self-management. Having said that medication was not a guarantee of wellness (Chapter 7.3.1), participant 2 said that the efficacy of self-management was similarly limited because of social factors.

*“You don’t know what life is going to throw at you [...] a lot of crisis is external, pressures, huge amount of pressures in society, financial pressures, family pressures, educational pressures, work pressures, yes there is a lot of huge, that’s one element to it yes, it can be internal when the drugs don’t work and age, hormones” (Participant 2).*

Participant 5 also talked about the social factors of adverse childhood experiences, intersectional disadvantage, and trauma, as correlated with mental health diagnosis and relapse. They also spoke about the importance of wider society in supporting those with a diagnosis.

*“The people who do fall through the net are the people who are significantly disadvantaged in terms of inequality of wealth, or disproportionately they are living in places where they don’t have access to good housing or schooling or things like that. [...] I think statutory agencies have got a role to play, primary care have got a role to play, social care has a role to play, third sector has a role to play, and also people who are not in the care system” (Participant 5).*

Participant 3 and 4 agreed, with participant 3 talking about the effects of trauma and abuse.

*“There is this bloody illness thing and all these different terms and diagnosis, correct terms might be sexual abuse as a child disorder, physical abuse by an uncle at three disorder, that would be correct you know”* (Participant 3).

As noted in Chapter 7.3.2, participant 6 had a view regarding the role of society in defining normative goals and clinical boundaries.

*“There is a societal norm for how much risk we can tolerate, or a clinical norm for how much risk we can tolerate”* (Participant 6).

#### 7.3.4.2 Barriers – structural

Structural barriers to self-management support in healthcare were described by participants. They included lack of funding (1,2) and clinician workloads (1,2,4,5), limited service options (1,2), and opening hours of services (2). There was also concern about inflexibility in the system in terms of time constraints (2,4,5), strict access and/or discharge policies, including high-threshold access bars (1, 2,4), and lack of follow-up care (2,3). Participant 4 discussed clinician continuity as a problem, and the implication of juggling time and people.

*“Where can we move people onto next? What can we do with them? How can we tick box things? And when you are dealing with people like that, the staff are being dealt with like that too. So, you know, they are just like oh yeah, we’ve got three band twos and five band three’s or whatever, and they just think of it in terms of that. You know we re-jigged services this way, that way, people get shunted around, staff are, patients are, you know, it kind of denies everybody the chance to communicate in ways that are nurturing”* (Participant 4).

Participant 2 felt that care pathways and access to different kinds of support were driven by a diagnosis which was sometimes disputed, rather than by individual choice/needs and



person-centredness. They said that healthcare hierarchy meant that decisions were hard to challenge.

*“The psychiatrist is the God in the decision-making process, if they label you with the right label, you might be lucky and get what you need. But if they label you with a label that is just slightly off then you might not be jettisoned down a trajectory that will be beneficial to you” (Participant 2).*

For nurse participant 2, and lived experience participant 4, psychiatrists’ role was limited to *“you’re fine on medication, cheerio, live your life”*. This was combined with their view of the impact of political pressure to be seen to address population mental health through anti-stigma messaging, albeit without attending to the structural barriers in the healthcare system. This led to pressure on the nursing role. Out of necessity, self-management offered a way for the nurse to meet caseload demands (Chapter 7.3.2).

*“It was great that [anti-stigma messaging has] brought it to the forefront and we are all more aware of it and we all know about it, of course it’s great, but you are pushing the bottle neck, the end result can’t sustain that, my caseload gets bigger and bigger, and my time gets less and less. My ability to deal with non-compliance is less. My fuse is shorter and shorter” (Participant 2).*

Contradicting nurse participant 2, psychiatrist participant 5 said that self-management was not *“a way of relinquishing your statutory responsibilities”*, then went on to suggest that psychiatrists *“need to be aware that you need to keep a closer eye on self-management”*. They did, however, note: *“that of course, is time that none of us have”*.

In the view of participant 2, healthcare support was oriented towards crisis rather than self-management. Healthcare was perceived as medication-focused (2,3) though policymaker participant 6 noted that this was possibly a consequence of mental health legislation which compelled services to intervene in a disempowering way (Chapter 7.3.3). The obligatory

nature of treatment and involvement was perceived by lived experience participants 3 and 4 as imposing and disproportionate.

*“Had I met up with someone like myself rather than the psychiatrist things would have been more positive [...] it’s not optional though unless you are given an option”* (Participant 3).

*“To be honest, mental health services... I mean they did help but it was, it just felt like it was out of proportion to the control they had, or the stress they caused [...] I just felt like all the stress and anxiety and even just like the pointlessness of the questions, it’s like I have to endure all this to get a little bit of help?”* (Participant 4).

For participant 4, ultimately service involvement felt fruitless.

*“I think a lot of it was like a vain hope that it could help me because somebody must be able to help me because I can’t help myself because this is overwhelming and life is too hard and awful to... yeah life is still hard and awful, and I still struggle but I don’t have any illusions of psychiatry’s ability to do anything”* (Participant 4).

Participant 6 said that, for them, imposition was a societal duty, saying *“at what point do we say that these people are due some help by society. Even though they may not be particularly asking for the help”*.

#### 7.3.4.3 Barriers – individual

Participants also spoke about individual barriers affecting self-management. Notwithstanding capacity as the primary barrier to self-management in the view of healthcare and policymaking participants (Chapter 7.3.3), further barriers included stigma and poor previous experiences of care which discouraged people from accessing support (1,2,3,4). Lived experience participants 3 and 4 said that healthcare professional attitudes between clinicians could be variable towards patients, despite each following the same code of practice. Healthcare professionals were said to fear patient dependency (4) and failed to

listen to patients (2, 4). Participant 4 discussed meeting healthcare professionals that were patronising, too quick to offer advice without listening, and who imposed their views. Talking about a positive encounter they noted that kindness was uncommon.

*“...her response and the humanity and kindness [...] part of the reason that makes me so tearful is the impact it had on me, but partly because it's so rare”* (Participant 4).

Nurse participant 2 felt that patients had unrealistic expectations in terms of what their nurse could do, and that they too did not listen, denying their expertise and passing responsibility to the healthcare professional.

*“For some cases, absolutely, they have disempowered themselves and washing their hands of responsibility [that] they can do it”* (Participant 2).

Lived experience participant 3 agreed that individuals forfeited their autonomy but said this was the consequence of the illness construction of their lives.

*“We talk about illness and challenging that word quite often and I guess the reason I do that is the connotations of illness are that there is something that you have, and you can't do anything about. Someone has to help you with it, other people have to do stuff to you, and professions feel they have to do stuff to that individual”* (Participant 3).

Their experiences are in line with participant 6's comments about the imperative in law to intervene (Chapter 7.3.3), and the effect that had for autonomy.

Lived experience participant 4 cited barriers for patients which included lack of energy along with a perception that they did not deserve support, or concern that to articulate their needs would overwhelm a clinician.

*“I would avoid talking to people at all in case they asked me how you were, how I was, because that would just open up so much. I felt I would drown in myself, and I would drag them in with me” (Participant 4).*

#### 7.3.4.4 Barriers - third sector and beyond

Participants also mentioned barriers for the third sector. These included lack of connection between services and third sector (3), and limited understanding in services about the services third sector could provide (5). Participant 5 also referred to the limited accountability and governance in the third sector, which they felt was a barrier to referral. Participant 2 felt that third sector services did not suit a wide range of patients. They said that in their view, third sector service premises were often old-fashioned and unappealing to attend. The basis on which the nurse had built her views was unclear. The third sector lived experience participant 3 felt that peer workers faced stigma from other workers in the third sector. They also said that improving third sector services was challenging as a result of limited and conditional funding which demanded that they operate in certain ways which may not always be to the best advantage of their clients.

In terms of barriers for wider groups involved in self-management, participants 2 and 5 noted that family support was often absent or problematic. In line with barriers for healthcare services, participant 2 noted that social workers were also subject to time and caseload pressures. Although participant 4 spoke positively about support groups, they noted that it was important to find a group that fitted with your values and understanding.

#### 7.3.4.5 Opportunities for improvement

For healthcare participants, opportunities for improvement mentioned included continuity of care (2), and online support options (1). Lived experience participants 3 and 4 felt that it would be beneficial for some healthcare professionals to have lived experience. Participant 4 wanted to see better patient-clinician collaboration, longer term care, joined-up care between physical and mental health physicians, and less variability between clinicians in terms of attitudes. Participant 1 mentioned unmet need and wondered whether further research was needed to understand what happened to patients if they had been discharged

or had failed to meet the criteria for referral to specialist services. Participant 3 wanted to see greater acknowledgement of alternative models of care.

*“I guess what is always missing is the option or the information oh you might try this, this is another way from the medical model” (Participant 3).*

Participant 2 suggested the introduction of emotional coping skills in school as an upstream, proactive measure to counter poor wellbeing in later life.

Despite the barriers for the third sector already discussed, participants spoke about a more prominent role for them. Participants 1, 3 and 5 felt that third sector and peer-led services had more scope and time than statutory services to provide ongoing support. Participants 1 and 3 commented that peers working in the third sector offered aspirational recovery stories, with participant 1 saying that peers were more able to challenge patients. Participant 5 suggested that third sector services offer interventions such as Distress Brief Interventions. They felt that the Scottish Government’s integration agenda for health and social care may help to achieve this. Participant 1 suggested a model of partnership working of the kind seen in addictions services, an aspect of which is tiered or graduated access to and exit from care. Participant 2 wanted to see skills updates built into models of care.

*“There needs to be that safety net, that wee area where we can say right pop in for a wee half day refresher on some skills and we will see if that works” (Participant 2).*

## 7.4 Discussion

During the interviews, the model created from the Stage 2 meta-ethnography proved useful, allowing me to generate detailed responses about how different people understood self-management. I summarise them below in terms of the headings of the model, but also show how further questions arise.

#### *7.4.1 Who does what? Whose involvement is important and why?*

All participants identified that a number of people and agencies were involved in self-management. All participants identified the involvement of the patient themselves, healthcare professionals and family/friends/peers, and all but one mentioned social work or third sector services. There was less consensus about who might be involved more widely. Healthcare and policymaking participants felt that the healthcare role was one of decision-making, support, guidance, and mutual respect. They said their role was intended to help a patient to become an autonomous expert patient. They said that expertise was the result of patients understanding how strategies intended to manage their illness could be tailored to their own lives. Self-management was perceived as a sign that the patient had attained expertise and autonomy. Lived experience participants said that healthcare involvement was less central in their lives but was a means to achieve support. It was perceived by them as autocratic, and insensitive to both their preferences and their unique understanding of their own experiences. Self-management was seen by lived experience Participant 4 as a way for healthcare to shift responsibility for providing ongoing support onto the patient.

This review of the responses leads me to wonder: roles and tasks may not be a challenge when all parties collaborate well but, when they do not, who gets to decide who does what? I argue that power affects those decisions because, in the summary above, healthcare professional views took precedence. With agreement a condition of support, the lived experience participants in my study said they disengaged when support was not required.

#### *7.4.2 Who wants what? Whose outcomes are desirable and achievable, and why?*

All participants said that the range of desirable outcomes was wide. Sometimes an outcome was overtly the same, but desirable for different reasons by different people. This led to assumptions and misinterpretations by others involved in the self-management process. For instance, the notion of 'what' for psychiatrist and policymaking participants was seen as autonomy and self-management success was perceived as unsupported responsabilisation by a participant with lived experience. For the nurse participant, successful self-management also had a different meaning. They talked about psychiatrist contact time being restricted to medication and diagnosis, leaving nurses to deliver the majority of self-management support. In this scenario, the nurse was under pressure to minimise the period of time patients were on their caseload, despite their feeling that they would prefer to spend

longer with patients. This suggests that for the nurse participant, self-management was as a synonym for discharge. Their perception was that the nurse's role was squeezed by competing demands from policymakers, doctors, and patients that they felt powerless to influence. Although healthcare participants indicated that outcomes are determined in collaboration, they came with the assumption that patients aspired to a cultural concept of normality and were sometimes chosen on their behalf as a result. A normative cultural definition of *a better life*, to find a *true-self*, may not accord with a person's understanding: the lived experience participants in this study said that the normative drive interfered with their autonomy to choose a life that had meaning for them. Again, the summary of this theme generates further questions. Wanting the same outcomes for different reasons may not be a challenge if the overt outcomes for all parties dovetail, but when they do not, whose outcomes are prioritised? I argue that power affects priority because, in the examples above, the nurse was unable to affect the driver of discharge as a goal, and the patient was unable to affect the subsequent discharge/responsibilisation.

#### *7.4.3 Who knows what? Who is an expert and when?*

In the relationship between healthcare professional and patient, my fieldwork demonstrated a view that, once sufficiently knowledgeable and experienced, there were two experts in the room. With fluctuating capacity as a feature of the medical construction of their life experience, however, the patient's expertise could be in doubt. In this fieldwork, patients were considered by healthcare professionals to have the autonomy that comes with expertise, until they lost capacity. In the view of the lived experience and policymaking participants this was a subjective judgement made by the healthcare professional and based on normative values and an assessment of risk. Risk management was a responsibility of the healthcare professional and was a result of their professional accountability and governance. In healthcare professional accounts, lack of expertise in knowing themselves as a person with an illness and/or lack of capacity was a reason to remove or restrict autonomy. This study summary of who knows what raises some important questions. Expertise may not be a challenge when all parties agree that everybody has valuable knowledge but, when they do not, who is allowed to decide whose knowledge is most important? I argue that my findings indicate that power affects designation as an expert because I have shown that healthcare professional expertise takes precedence, and this is supported legal frameworks. With the omnipresent power and pressure in place for healthcare professionals to intervene and override autonomy, a patient is never fully

empowered, yet they are discouraged from seeking healthcare support on an ongoing basis.

#### *7.4.4 Barriers and opportunities*

Interviews also included participant views concerning barriers and facilitators which impacted the practice of self-management. Participants said that self-management tasks and outcomes should be established in partnership, yet also talked about pathways which were diagnosis-specific, and the challenges introduced by limited resources, time, and offerings in the face of increasing caseloads and political pressure. Participants also spoke about wider social barriers which influenced mental wellbeing and healthcare practice but were beyond the remit of healthcare to resolve. Input from wider social/family supports, social care and third sector were affected by availability, desirability, and regulatory challenges, leaving the business of self-management predominantly the concern of healthcare professionals and the patient. This summary of the study suggests that the healthcare system, and the professionals within it, have a desire to be more supportive and person-centred. The setting, however, is structured in a way that constrains the ability to achieve this. This creates unmet needs and results in crisis presentation as a way for patients to access support. While these challenges do not characterise every episode of care, the participants in this study described a setting populated by groups of people who have different understandings of the self-management roles and responsibilities of themselves and others. They described a setting in which people are operating with drivers and impediments which affect their ability to set and achieve goals and where power was important as a way to resolve the challenges they faced. Participants suggested opportunities for resolving some of the challenges. In the main, these were ways which have the potential to mitigate or share the workload so that healthcare services could work more collaboratively and proactively with patients. These included improved partnership working with the third sector, access to support which is not medically focused, and education in schools.

#### **7.5 Summary**

In this stage of the study, I learned that the questions derived from synthesising papers focusing on bipolar disorder was a useful way of structuring exploration of understandings about self-management of mental illness more generally. Using it allowed me to tease out



where there is shared understanding about self-management and where views differ. Although there was an element of high-level consensus among participants i.e., many people are involved in self-management, outcomes sought are wide, and expertise is sometimes shared, the answers my participants gave showed that there were differences in detail between them in terms of who does what, who wants what, and who does what. In Stage 2 of my study (meta-ethnography), the selection of papers had examined bipolar disorder as supported within the medical setting. In this stage I spoke to people about diagnoses which were not necessarily bipolar disorder and who were positioned further outside the healthcare system. It is reasonable to consider that the wider range of views might be the result of accessing those with a different experience of mental illness. Although the responses could be broadly split into healthcare/policymakers or lived experience views, I noted that, even within healthcare and within a very small sample, there were differences of opinion. On the basis of the findings presented in this chapter, I conclude the following.

- Self-management is management of the self by more than the self. Each person or agency has a role in the tasks associated with self-management, but their roles are not universally understood or valued. Under pressure, power can determine whose understanding of roles and tasks is prioritised.
- Potential outcomes are wide and there is a desire that they should be patient centred. Subjectivity and normativity are common drivers, however, and this can result in misunderstandings between participants. Under pressure, power can determine priority of goals.
- Though patients are co-constructed as experts in their mental wellbeing, in healthcare their self-knowledge is finite and linked to healthcare professional assessment of capacity and risk. Under pressure, power can determine whose knowledge is important.
- There are social, structural, individual, and wider barriers which put pressure on the practice of self-management, but opportunities exist to mitigate some of them.

## Chapter 8. Discussion

### 8.1 Introduction

In Chapter 1 I summarised the long-standing challenge of self-management as a great idea which did not appear to be working well in practice. I resolved to explore this challenge through the means of a three-stage research study, revisited below, and took a constructionist position looking at the meaning of self-management. In Chapter 6, I synthesised a number of studies looking specifically at bipolar disorder as an example of self-management of a long-term mental illness within the medical model. In the findings I described the headings across which the authors and participants in the selected papers constructed their understanding of self-management in bipolar disorder into who does what, who wants what, and who knows what. Those headings are used in this current chapter to structure a discussion of the findings across all three stages, and to position the findings in the context of the wider literature. I consider whether there is sufficient evidence across the study to support a conclusion that the way that self-management is understood in policy and healthcare practice means that self-management always requires oversight by others, which services are not equipped to support.

This chapter ends with a discussion of the strengths of the study but balances them by acknowledging the limitations of the design and implementation of the study. In the spirit of my discussion about positionality, the importance of reflexivity (Chapter 1.6 and 3.2), and the meta-ethnography reporting guidelines of France et al. (2019a) mentioned in Chapter 4.3, I also include a reflection on my experience of conducting this study. In it, I consider the strengths and limitations I have brought to the research table with me.

### 8.2 Bringing the study together

Chapter 1 introduced a conundrum concerning the mental wellbeing of the population; if good mental wellbeing is widely considered to be a priority aspiration, and self-management of mental illness one of the means through which to achieve it, why is self-management perceived not to be living up to expectations despite decades of effort? In Chapter 2 I began to tease this puzzle apart and argued that mental illness as a concept is understood in many ways. I suggested that this background was important because it shows that differences of understanding can lead to differences in action i.e., the way mental illness is understood

impacts how self-management is done. This led me to question whether the way self-management for mental illness is understood underlies the challenges experienced in the practice. The aim of the study, therefore, was to explore how self-management is understood in mental health policy and practice. The following questions were asked.

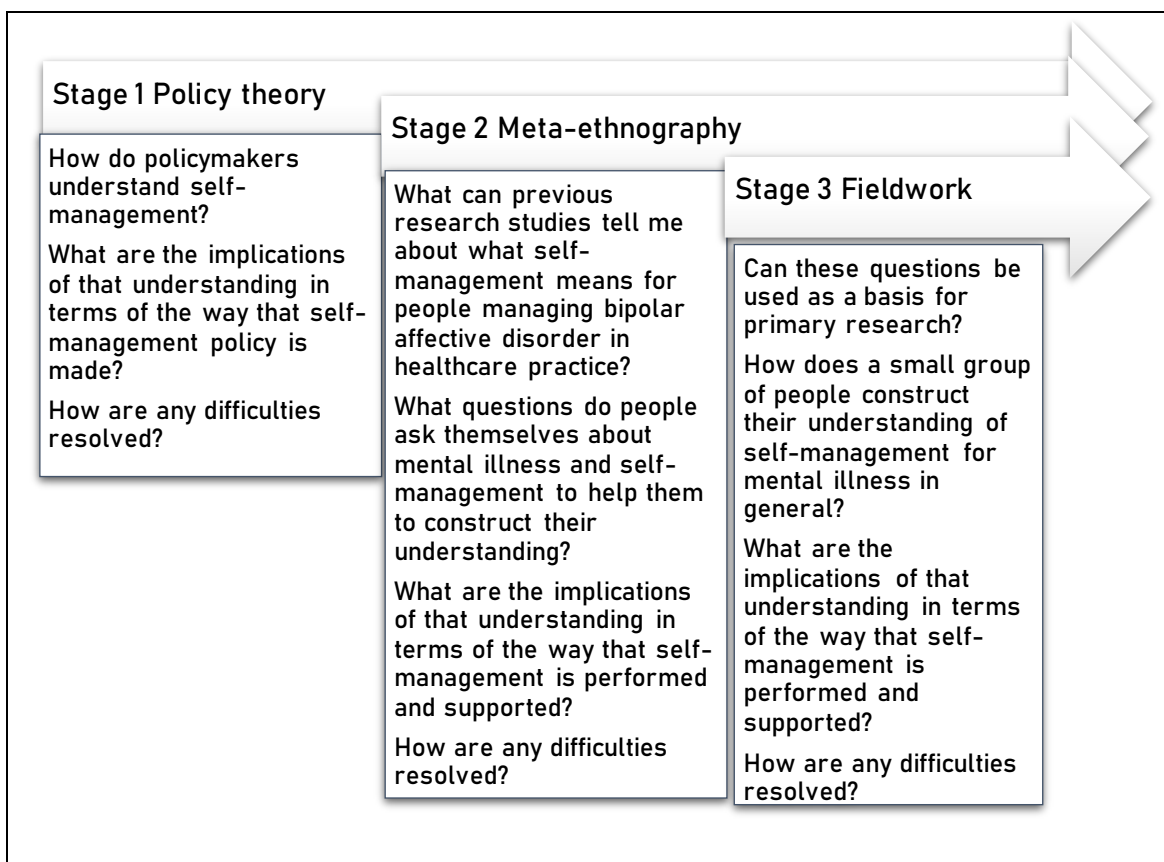
How do policymakers, healthcare practitioners and people with lived experience of a diagnosis of a mental illness understand self-management?

How is that understanding reflected in the way that self-management is performed and supported?

How are any difficulties resolved?

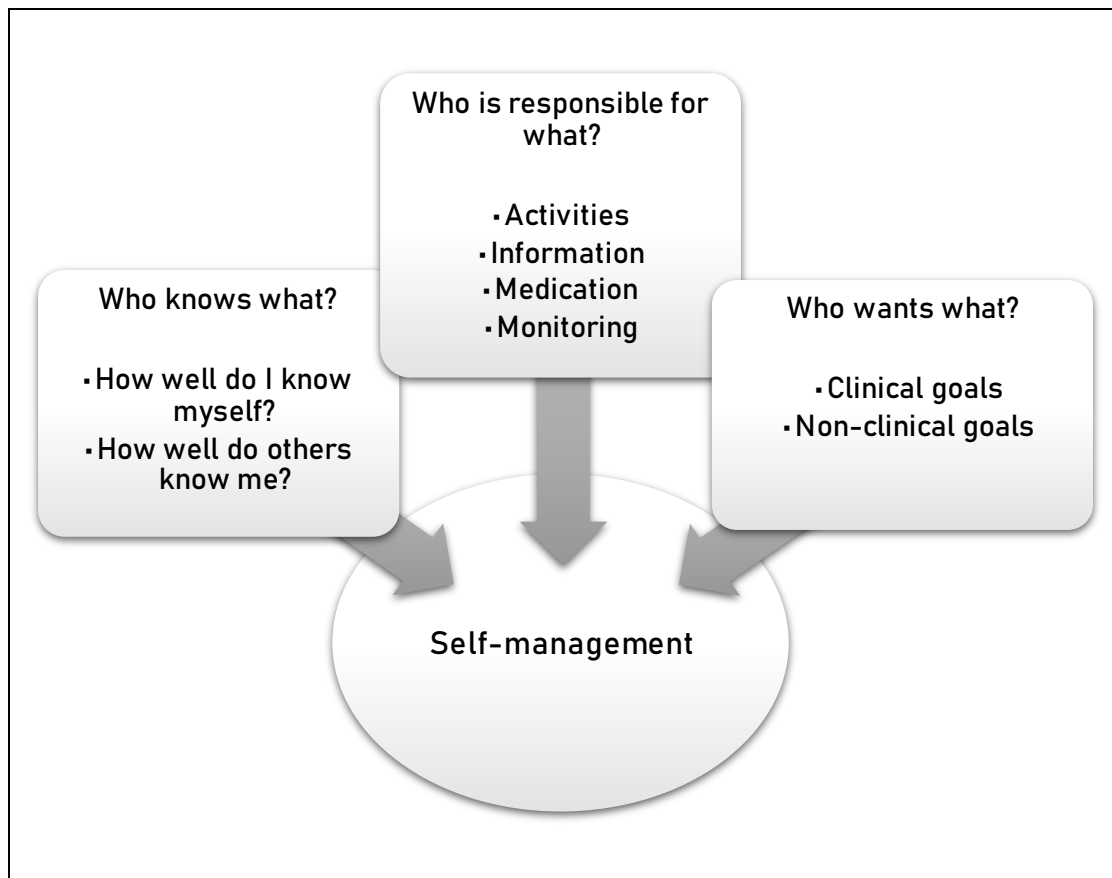
In Chapter 3 I explained how a study which was informed by social constructionism could help, because it takes as a starting point a view that meaning matters and that how people understand self-management impacts how they do it. This resulted in a three-stage qualitative study, the methods for which were discussed in Chapter 4. Graphic 8.1 below re-presents the stages of the study in graphic form.

Graphic 8.1 Stages which are designed to complement each other



Each stage asked specific questions. In Stage 1 I wanted to know how policymakers understood self-management, how they used this understanding to make policy, and how they dealt with disagreement. In Stage 2 I examined previous research which considered self-management of bipolar disorder as it was understood in practice. This helped me to determine the questions across which people construct their understanding of self-management in bipolar disorder (Graphic 8.2).

Graphic 8.2 How understanding of self-management is constructed by participants in the papers of the meta-ethnography



These questions were used as the basis for interview questions in Stage 3, where a small group of individuals were asked about their understanding of self-management of mental illness in general. The findings from Stage 2 suggested that self-management is understood across the three key headings of who does what, who wants what and who knows what, and that there are differences of understanding within each. The following sections discuss what can be concluded about those differences, how they are resolved, and what that means for the practice of self-management in healthcare services.

### 8.3 Who does what?

Table 8.1 collates study findings concerning *who does what*. While it reveals high level agreement, it also indicates unresolved questions regarding the detail of who does what between different groups of people and, in some cases, within groups.

Table 8.1 Agreement and unresolved questions about who does what

	High level agreement	Unresolved questions
Who is involved?	<ul style="list-style-type: none"> <li>• A range of people are involved</li> </ul>	<ul style="list-style-type: none"> <li>• Whose involvement is important, why, and when?</li> </ul>
Who does what?	<p><b>Policymakers</b></p> <ul style="list-style-type: none"> <li>• Set the agenda in response to problems affecting society</li> <li>• Respond to input from experts and selected interested parties about the nature of the problem and the possible policy options.</li> <li>• Create policy which applies to the people involved and responds to the problem</li> <li>• Apportion funding from the public purse to institutions, agencies and people</li> </ul> <p><b>Healthcare</b></p> <ul style="list-style-type: none"> <li>• Provide information and advice.</li> <li>• Assess and respond to capacity and risk</li> <li>• Diagnose</li> <li>• Prescribe medication and monitor it</li> </ul> <p><b>People with lived experience</b></p> <ul style="list-style-type: none"> <li>• Undertake self-care activities</li> <li>• Gather information from a variety of sources and adapt advice to own life</li> <li>• Take medication sometimes</li> <li>• Seek healthcare support in crisis at a minimum</li> </ul>	<ul style="list-style-type: none"> <li>• How is the problem described and/or understood?</li> <li>• Who is able to influence and/or challenge policymakers and how?</li> <li>• How important are social factors, what are they, and who is responsible for resolving them?</li> <li>• How important is healthcare?</li> <li>• Who does which healthcare role?</li> <li>• What activities are important? Who is monitoring what and when? How important is medication and when is it useful?</li> <li>• Whose knowledge is important?</li> </ul>

### *8.3.1 Agreement and disagreement about who does what*

Across the three stages of the study, policymakers, healthcare professionals, and those with lived experience agreed that a range of people are involved in the process of self-management, with Chapter 7.3.1 showing just how wide the range of supporters could be. Of those involved, policymakers were generally considered to be responsible for setting the

agenda and establishing policy. Also discussed in Chapter 5 was the policymakers' role in assigning funding for services and requiring evidence that outcomes were being achieved. There was general agreement by participants in Chapters 6 and 7 that the healthcare professional role was to work with individuals, providing advice and information, monitoring patients, and making decisions about capacity and risk. Chapter 7 participants noted the differences between healthcare professional roles, saying that doctors were considered to take a more prominent role in diagnosing and prescribing, where nurses focused on information and advice. The patient role was to source and respond to information, adapt it, manage their lives, monitor themselves for changes, and seek healthcare involvement during crisis. Throughout the study I have, however, argued that in practice there is devil in the detail. Understanding the nature of disagreements is important because they lead to foundational questions which must be resolved in practice. For instance, if the key role of policymakers is to set the agenda, how do they decide how the problem is described and/or understood, and who is able to influence and/or challenge their views? With self-management of mental illness defined as a healthcare problem, how important are social factors, and who is responsible for resolving them? Who does which healthcare role, and what activities are important i.e., who is monitoring what and when, and how important is medication, when is it useful, and whose information is important?

### *8.3.2 Differences about who does what, how they are resolved, and implications for self-management*

In Chapter 5 I noted that in policy self-management is defined predominantly as a health problem. It was argued that opportunities to challenge this key decision and consider self-management as a wider health, financial, and social concern are limited. Policy is based on limited input from those outside the traditional policymaking setting. This way of defining the problem mainly as a health problem has significant consequences because it has resulted in allocating the problem and funding to healthcare services. Considering the involvement of wider social factors implies a need for wider partnership working well beyond healthcare which, in policy, remains a work-in-progress. There is evidence across all stages of the study which suggests healthcare would benefit from formalised cross-sector working. Yet in Chapter 6.4 I showed that healthcare professionals are working with individuals to meet wider outcomes such as employability which they do not have the resources to achieve without wider social involvement beyond that facilitated by the integration agenda. A growing acknowledgement of financial factors also suggests there should be significant

increase in welfare and health budgets, yet there continues to be concern that the demand from statutory and third sector healthcare continues to outstrip the money available (Bach-Mortenson and Montgomery 2018, Charlesworth and Johnson 2018, Cummins and Gomez-Ciriano 2021).

The definition of self-management as a healthcare concern has led to a squeeze on services which are dealing with the challenging budgetary demands such as increased caseloads, a staffing crisis and reduced availability in services (RCN 2016, Audit Scotland 2017, Scottish Government 2020), more so during the pandemic (Mental Welfare Commission for Scotland 2020). This means that, despite growing demand at a policy and practice level for person-centred care, economies of scale have become a way to meet competing demands. This has presented challenges for staff providing care, and consequences for patients. In 1980 Lipsky (2010) first described a working world in which perceived ambiguity in policy was resolved within individual working practices. Lipsky's work has since been revisited because in an increasingly regulated workplace there is less manoeuvrability for individuals to adapt working practices (Durose 2011). Some of that tension is seen through this study, where individuals might want to work differently but have limited scope to do so. This is exemplified in Chapter 7.3.4 where nurse participant 2 indicated that services employ pathway algorithms which create a standardised, diagnosis-led care experience, rather than one which is patient-led. In the opinion of this nurse, contemporary practice meant that doctors focused on diagnosis and medication review, leaving the bulk of self-management support to nursing staff. They said that they would like to work more proactively and longer-term but were structurally obliged to focus on crisis management through time-limited episodes of care, rather than provision of ongoing support for self-management. Similarly, psychiatrist participant 5 wanted healthcare professionals to be able to provide more support for self-management but said they lacked time to achieve this. Healthcare participants in Chapter 7 suggested that the third sector would be well-positioned to provide additional support for individuals, yet third sector peer worker participant 3 said that lack of funding constrained the ability to provide third sector services which met needs. Importantly, lived experience participants in Chapter 7 felt that services as they were currently organised did not meet their self-management needs.



As a healthcare problem, there is a focus on the importance and quality of the doctor/nurse/patient relationship within which most self-management support takes place (Kee et al. 2018, Staniszewska et al. 2019, Horgan et al. 2021). There was some evidence of disagreement in the study about how important that relationship was. For policymakers, healthcare professionals, and the patient participants in Chapter 6, patients and healthcare providers share a primary, collaborative role. Conversely, participants with lived experience in Chapter 7 preferred that healthcare had a more distant role in their self-management, commenting that the healthcare role was useful only for crisis management rather than ongoing self-management. In Chapter 7, policymakers and healthcare professionals said that healthcare professionals were perceived to work in a collaborative, respectful way, reflecting practice guidelines (NICE 2021). The lived experience participants in Chapter 7.3.4 disagreed, stating that that healthcare professionals sometimes had undesirable attitudes towards patients, that they were not collaborative, did not listen, and were imposing, which for them resulted in a reluctance to use services. These concerns are reflected across survivor testimony and wider literature than just within self-management (as discussed in Chapter 2.2, Parliamentary and Health Service Ombudsman 2018). In the same chapter, nurse participant 2 said that patients sometimes had a poor attitude towards healthcare professionals, having high expectations but taking little responsibility. In this, they reflect much earlier works by Stockwell (1972) which contended that individuals needed to display the oxymoronic qualities of self-efficacy *and* compliancy to be considered popular patients. Yet, in Chapter 6.4.3, the notion of ‘distributed agency’ was discussed, where agreement to ongoing co-monitoring is a condition of care. This is reflected in Chapter 7 where participant 3 talked about the medical model of mental health as intrinsically disempowering, reflecting Seligman’s seminal body of work about ‘learned helplessness’ which suggests that, after repeated failure to influence events, people stop trying (Millar and Seligman 1975).

Despite high level agreement in Chapters 6 and 7 that there are several activities, there was disagreement about which activities are central or essential. Medication (Chapters 6.4.1 and 7.3.1) was seen as centrally important by policymakers and doctors, while for others medication should be optional, and only under some circumstances. Although it was generally agreed that information gathering was an important task, participant 3 in Chapter 7.3.1 said that they felt that healthcare information lacked authority due to the healthcare professional’s lack of lived experience. Nonetheless there was a view from healthcare and

lived experience participants in Chapter 7 that healthcare information was delivered in a way that implied it was mandatory, and that not following it correctly would result in patients being blamed for outcomes not being met. In the study I also noted conflicts about the activities of monitoring, expertise, risk, and capacity to make decisions. As a task related to *knowing* this is discussed in Chapter 8.5.

In summary, in this section I have argued that study findings point to a high level of agreement about who does what in self-management, but disagreement in the detail. Much of this disagreement flows from a foundational policy decision that the problem described as mental health self-management should be orchestrated from within the healthcare system. Power is important when it comes to resolving disagreements about who does what. I argued in Chapter 5 that, in policy, the ability to resolve differences is reserved to those who have access to policymakers, can understand the “rules of the game”, and can frame their arguments according to the complex political landscape. This leaves people with less power to make compromises in order to exert an influence on the policymaking process. This has ramifications in the practice setting. In practice, the ability to decide who is involved, when their involvement is necessary, and how they operate, is reserved to those who have more power. This leaves people with less power to make their best effort to work within the structures which are set. This includes the power to decide which activities are important, and leaves those with less power to negotiate their preference regarding activities that are meaningful for them. The people involved in self-management, and the things that they do are not universally understood or valued but, as I concluded in Chapter 7, there is a sense in this study that, under pressure to make a decision about who does what, power determines whose understanding is prioritised.

#### 8.4 Who wants what?

Table 8.2 collates findings from across the study about *who wants what*. It reveals high level agreement, but also shows that there are unresolved questions regarding the detail of who wants what, and why, between different groups, and in some cases within them.

Table 8.2 Agreement and unresolved questions about who wants what

	High level agreement	Unresolved questions
Who wants what	<p>The goals of self-management are wider than medical goals</p> <p>People need to have a sense of wellbeing</p> <p>People need to be autonomous</p>	<p>Whose outcomes are desirable, acceptable, and achievable?</p> <p>What role does subjectivity and normativity play?</p> <p>What does wellbeing mean?</p> <p>Is autonomy achievable?</p>

#### *8.4.1 Agreement and disagreement about who wants what*

Across the study, there was agreement that the outcomes sought in policy and practice include, but are wider than, medical outcomes such as reduced symptomology, and avoidance of suicide, self-harm, or crisis presentations. There was agreement that wider outcomes included a desire to improve wellbeing and increase autonomy. Throughout the study, however, evidence has been offered to support an argument that, in practice, there is disagreement in the detail of those agreements. If the outcomes are broadly considered to be wider than medical outcomes, which are most desirable, achievable, and acceptable, and is there a degree of subjectivity about them? For instance, what is wellbeing? How important are autonomy and normativity as goals, and how achievable are they within the present system?

#### *8.4.2 Differences about who wants what, how they are resolved, and implications for self-management*

In response to the increasing prominence of patient rights, policymakers have developed policy which expects healthcare professionals to establish person-centred goals (Scottish Government 2017b, NHS Scotland 2019, 2010). The findings of this study support the conclusion in Chapter 7 that person-centred goals are desirable and that it is not inconceivable to achieve outcomes even if different people want the same outcome for different reasons, so long as those outcomes align. I have suggested, however, that understandings about outcomes do not always align. The desire to improve wellbeing is challenging without a universal understanding of what it means to be well, and more general agreement about the desirability and measurability of goals. Chapter 6.4.2 noted that medical goals are measurable, but subjective goals such as wellness and self-respect less

so. Yet subjectivity of goals was noted across the study. In Chapter 7 self-management success for policymakers and doctor participants was proof that care was effective but, for the nurse participant, success was a space on their caseload.

In this study it has been argued that, under the healthcare lens, individuals took action to monitor and moderate behaviour towards a notion of wellness that is synonymous with normativity. In her 2020 paper, Popa noted that 'normal' was subjective, in that it is a construct which changes over time and geography. This suggests that, for those involved with self-management, wellness becomes a moving goal which is hard to define. Nonetheless, for patients in Chapter 6.4.2 and 7.3.3, it was important to fit in to cultural expectations and reduce the consequences of being seen to be different. The selected papers in Chapter 6 identified activities of self-management as positive thought, healthy living, self-monitoring, and stress avoidance. In this, one might wonder whether those with lived experience of a diagnosis reach for an idealised way of living which is questionably achievable within the general population. In the substance use literature, Collins and McCamley (2018) call this 'better than well', saying it is "*less a return to "normal", but more [...] a process towards higher levels of appreciation and fulfilment of quality of life*". In Chapter 6, lived experience participants expressed a desire to avoid negative outcomes and access socially normative outcomes such as social integration, employment, and lack of stigma. This need to comply with social norms and avoid the negative social consequences which result from failing to do so, is also seen in the wider literature which concur with the findings in this study, namely that negative social consequences for those living with a mental illness diagnosis include stigma, and access to the benefits of society such as career, housing, money, and education (McDaid et al. 2019). Healthcare professional and policymaking participants in Chapter 7 also talked about wanting social acceptability for people living with a diagnosis. The influence of normativity for the healthcare professionals in this study should not be surprising because authors have already considered the role it plays in mental health. In his 2019 paper, Glas (2019) argued that psychiatry can only be properly understood through normativity.

*"The practice of psychiatry is inherently value laden and [responds] to norms, principles, values, and ideals. I argue that these norms, principles, values, and ideals manifest a certain order, with qualifying, foundational, and conditioning norms and*

*principles on the one hand and regulative ideals and core values on the other hand. These norms and principles are constitutive for psychiatric practice and define its inherently normative conditions. They are necessary elements, without which the practice of psychiatry cannot properly be understood (Glas 2019, p. 33).*

It is important to consider, however, that some of the negative social and personal consequences of being perceived as unwell arise as a result of being diagnosed and originate within the healthcare system itself. Outcomes can include withdrawal of care (discharge), or compulsory treatment and hospitalisation, due to normative assessments of risk and capacity by healthcare professionals. These are additional consequences which might never have been part of an individual's experience had they not been diagnosed in the first place. The negative consequences associated with being part of the healthcare system aligns with the notion of epistemic injustice as introduced by Fricker in 2007 who described events including removal of autonomy and enforced treatment. Fricker said that these actions are enacted upon others because they cannot know themselves and sanctions the need for others to intercede in their best interests. Both the policymaking participant 6 and lived experience participant 3 in Chapter 7.3.2 said that normativity and subjectivity were both involved in the decisions that healthcare professionals made about capacity and risk. The policymaking participant in Chapter 7 noted the normative drive throughout law and policy, commenting that normativity sometimes led to goals being chosen for patients. Lived experience participant 4 in Chapter 7 noted, however, that this normative drive interfered with their autonomy through the imposition of goals and values from others which did not accord with their own.

The desire to improve autonomy was identified as a key outcome for all participants in this study. It is an outcome which features widely in policy and practice guidelines (Mental Health Care and Treatment (Scotland) Act 2003, NICE 2018). It is challenging, however, to achieve autonomy under the current model of care because autonomy is linked to the fragility of the patient's ability to know themselves (Chapter 8.5). In summary, there is high level agreement about what people want, but the detail of who wants what and why is not universally understood. As concluded in Chapter 7, there is a sense across the data collated in this study that, under pressure, power determines whose understanding about who wants what is prioritised. In this area of self-management practice, the ability to resolve differences

is reserved to those who have the power to decide which outcomes are important when outcomes do not align, and to decide what normal should look like. This leaves those with less power to negotiate priorities and to decide what normality is for them.

## 8.5 Who knows what?

Table 8.3 collates agreement about who knows what from the findings across the study. It reveals high level agreement, but also notes unresolved questions regarding the detail about who knows what between different groups, and in some cases within them.

Table 8.3 Agreement and unresolved questions about who knows what

	High level agreement	Unresolved questions
Who knows what	<p><b>Policymakers</b></p> <ul style="list-style-type: none"> <li>• That there is a medical problem affecting society</li> <li>• That healthcare services can attend to medical problems</li> </ul> <p><b>Healthcare professionals</b></p> <ul style="list-style-type: none"> <li>• Have expertise in medical knowledge and can deal with medical problems</li> </ul> <p><b>People with lived experience</b></p> <ul style="list-style-type: none"> <li>• Know themselves sometimes</li> <li>• Know what works for them</li> <li>• Know what their goals are</li> </ul>	<ul style="list-style-type: none"> <li>• Is there a limit to what a patient knows about themselves?</li> <li>• If there is a limit, when is that limit reached and who decides that it has been?</li> <li>• Who knows best when a person does not have capacity to make their own decisions?</li> <li>• Who knows when a person presents unacceptable risk?</li> <li>• Who knows the person best/most consistently?</li> </ul>

### *8.5.1 Agreement and disagreement about who knows what*

All stages of the study evidenced agreement that there is a health problem which affects individuals in society and that it needed to be addressed. It was agreed that healthcare professionals were experts in healthcare matters, and that people with lived experience knew what was feasible and important in their lives and what they wanted for themselves. For instance, does this health problem limit how a person is known to themselves and others? If so, does the extent to which a person is known to themselves and others under that lens have consequences for self-management?

### *8.5.2 Differences about who knows what, how they are resolved, and implications for self-management*

Understanding mental illness and self-management as a health problem (Chapter 8.3) sets in place a chain of events that have consequences for how knowledge is constructed. Professionals and patients operating within the healthcare system of knowledge understand patients' experiences of life in a certain way. Of particular importance is how much a person knows about themselves, and how much is known about them by others, and when.

The tasks of knowing oneself is accomplished through self-monitoring and acknowledged as a task of self-management beyond this study. Consideration of this task has resulted in a variety of tools and approaches designed to facilitate it, though evidence of efficacy remains limited (Neary and Schueller 2018, Petros and Soloman 2020). In this study, self-monitoring was noted, but it was not without challenges. A participant in Chapter 6.4.3 said that monitoring was difficult because they did not understand how they were supposed to feel. They appear to be troubled by "*epistemic self-doubt*" (Roush 2017) i.e., they do not trust themselves to know themselves, and "*epistemic akrasia*" (Owens 2002) i.e., they hold a belief they do not believe they should. Roush (2017) noted that this can create a state of internal crisis which the individual tries to resolve. In the papers of Chapter 6, and by the participants in Chapter 7 this is a crisis which participants said they resolved through co-monitoring.

Co-monitoring was mentioned across the study as a means of verifying that a person was well or unwell. Lived experience participants in Chapter 6 described sharing the task of monitoring with others including family, friends, and healthcare professionals, because they were not able to know when they were becoming unwell. Healthcare participants in Chapters 6 and 7 also noted their role in monitoring patients. The notion of insight as knowing oneself, versus lack of insight as the inability to know oneself, is discussed as problematic by Hamilton and Roper (2006, p. 416) who discuss its role in "*creating punitive scrutineers out of well-intentioned practitioners*". Galasinski and Opalinski (2012, p. 1460) ask whether assessment of insight by psychiatrists is, in fact, an assessment of "*a sense of illness, criticism, and readiness to receive treatment*". This way of understanding the nature of mental illness as involving a person who experiences interruptions of insight suggests that a diagnosed individual will always need oversight by others. In this scenario

empowerment for individuals living with the consequences of a diagnosis is limited by their power to know themselves. This is the epistemic paradox described by Wiener in 2011 which she describes as a state of being through which an individual is expected to know and control themselves yet are conversely expected to know when they no longer know themselves. The findings from this study suggest that this results in a situation whereby individuals willingly seek co-monitors i.e., they hand over their power and ability to know themselves to others. I have termed this “*epistemic forfeit*”. This situation means that although participants in the study spoke about the patient as an expert, it is an expertise with boundaries. Accordingly, I argue that, in this study, the healthcare approach to understanding self-management has contra-indications for autonomy, despite the finding that autonomy is an agreed outcome. My findings suggest that an individual living under the medical gaze neither can, nor will, assume the responsibility that others wish them to have because it is a condition of the support they receive to acknowledge that their ability to know themselves is impermanent i.e., they can never achieve full autonomy. Under the healthcare lens described in this study, individuals cannot be fully responsabilised into self-management because they can never be truly empowered.

I conclude that, according to the healthcare way of knowing madness described in this study, individuals become an expert in knowing themselves through an illness lens as a *patient*. This construction of a life has implications for what a person knows about themselves, how long they can know it, what other people can know, and when others can know them better than they know themselves. This aligns with the work of Terkelson (2009) who suggested that medical information is provided with the aim of teaching a person to identify as a patient with an illness, thereby privileging the expertise of the healthcare professional. In this area of self-management practice, the findings of this study suggest that the ability to resolve differences concerning who knows what is reserved to those who have the power to decide who knows most about the person living with the diagnosis. This means that, in order to receive support within the healthcare system, the individual living with the diagnosis must acknowledge that they can never have full power or autonomy. This creates an unresolvable paradox for self-management, particularly as practiced within a system which is unable to meet the resource and time demands for oversight and ongoing care which, according to the findings of this study, are an intrinsic part of its ethos. Chapter 9 considers the ways in which healthcare services might be organised such that self-management as it is understood within them might be better supported.



In Chapter 6, however, it was noted that some patients and authors understood bipolar disorder in less medical ways, with some describing positive aspects of their lives with a diagnosis and others expressing uncertainty about knowing where they ended and illness began. Chapter 7 presented data from lived experience participants with mental health diagnoses beyond that of a diagnosis of bipolar disorder who also did not understand their experiences as entirely health-related. The two participants with lived experience in that chapter described resisting the relinquishment of authority to know them and rejecting the mandatory nature of involvement and advice. Participant 3 in Chapter 7.3.4 expressed a desire for a support which did not confine itself to the medical model. One wonders whether the need to align with the medical model in order to access support may influence, for some, the inclination to engage with healthcare.

## 8.6 Self-management and empowerment

Table 8.4 Revisiting the research questions according to the findings of the study

*How do policymakers, healthcare practitioners and people with lived experience of a diagnosis of a mental illness understand self-management for mental illness?*

With increasing acceptance of social factors, self-management is understood, in the main, using a medical model which defines who does what, who wants what, and who knows what

*What are the implications of that understanding in terms of the way that self-management is performed and supported?*

The implication of using the medical lens is that the person receiving support will accept that self-management is a task that will always require the oversight of others, because self-knowledge is inconsistent.

*How are any difficulties resolved?*

For the person in receipt of care, they must forfeit their ability to know themselves and accept oversight. For healthcare professionals, ongoing oversight must be provided.

When revisiting the research questions based on the findings of the study (Table 8.4), I conclude that when constructing self-management using a medical lens ‘who does what, who wants what, and who knows what’ has a particular meaning. Although self-management is promoted as a route to empowerment, it is a condition of receiving support that power must always be shared. In the preceding section I argued that using a medical lens to understand their lives creates a situation in which people with lived experience of a

diagnosis must have ongoing support and oversight. This study has shown, however, that healthcare professionals do not commonly have the resources to offer prolonged oversight in terms of time, resources, or the ability and desire to influence wider social factors at a policy level. I detail below a summary about how, according to this study, power appears to operate through self-management.

- Policymakers have significant power and are widely connected across the network of influence. As described in Chapter 5, with wide-ranging responsibilities and a limited purse to address many pressing political and social problems, their attention and action is limited. Though they are open to public opinion and lobbying from representatives, the nature of the policymaking process limits how challenge may be made and by whom. In the main, and with only slow change in the face of limited pressure, they act according to their beliefs and hold their long-standing policy direction.
- With expertise in the medical model, which results in a belief that they can resolve the problem primarily through medical means with some support from additional sources, this study suggests that healthcare professionals assume ownership of the health problem.
- In Chapters 6 and 7 I showed that those with lived can experience a sense of pressure from many directions, as they are encouraged to accord with cultural norms, become socially valuable individuals, and use a healthcare way of understanding their lives. The third sector can offer advocacy to mitigate pressure but is itself limited in power. Many of those represented in this study who were living with a diagnosis responded by acquiescing to the power of healthcare professionals to know them according to a healthcare view of their lives.
- Among the healthcare professionals represented in this study I suggest that there may be a nested hierarchy of power relationships. I base this on the finding that the nurse in Chapter 7 was under greater pressure from medical staff and policymakers to respond to increasing caseloads but had at their disposal limited resources and options to address the challenges of mental health self-management and the wider

financial and social problems associated with it. She had less power to affect these pressures. While she was under pressure from patients to work more collaboratively, more widely, and longer-term, and despite an awareness that self-management is management by more than the self, the nurse sought instead to respond to the greater power of the healthcare institution by discharging their responsibility to care to their patient as soon as practicable.

While discharge is intended to empower patients to manage their mental illness with minimal support from services, this study has shown that patients do not have much power to affect any of the wider pressures or decisions at societal, political, or healthcare levels. Participants in this study talked about sharing the self-management responsibility with an informal network of supporters who assume co-monitoring tasks: were relapse to happen, their only recourse to further care would be to present in crisis. As Chapter 6 showed, crisis was perceived as a failure of their efforts to self-manage. It was a perception shared by everybody, including the person with the diagnosis and their wider support network.

### 8.7 Strengths of this study

Exploring understanding about what self-management means to different people is rarely the focus of attention in policy, practice, or research. Using a constructionist lens to explore understanding across policy and practice has added value to the field and offered new knowledge. Particularly helpful for this constructionist study was the use of meta-ethnography since the method required a detailed focus on participant, author, and my own levels of construct. The decision to request ethical approval for in-person and online interviews meant that there were fewer impacts on my study resulting from the COVID-19 pandemic. The use of policy theory, meta-ethnography, and fieldwork in three stages was powerful as a way to explore self-management across the people who use it. Together they allowed me to create a study that was thorough and helped me “*to develop a comprehensive understanding of phenomena*” (Carter et al. 2014, p. 545). Additionally, my position as a healthcare professional with lived experience of a mental health diagnosis, and a social scientist, has brought a variety of perspectives to the research, including a peer-researcher dimension which, though desirable, remains less common (Survivor Researcher Network 2021). Finally, this study uses the findings to suggest routes for change. In Chapter 9 I offer policy and practice-based recommendations based on the findings which offer practical solutions to a long-standing problem which has, thus far, evaded resolution.

## 8.8 Limitations of this study

Broadly, this study was limited because of its specificity. The policy review was conducted using three Scottish policies. Given the nuance of the political and policymaking contexts across countries, a cautious approach is needed when transferring knowledge from one context to another. The meta-ethnography was conducted with a search focused on bipolar disorder, discussed further below, and, though the questions arising were used to good effect across mental health more generally in the final stage of the study, that stage sought the views of only six participants. Other limitations of this PhD study could be grouped into two broad categories. The first relates to design i.e., what was done, and in what way did it introduce limitations and biases? The second relates to the personal i.e., who am I and in what way did I introduce limitations and biases?

### *8.8.1 Design limitations*

In this study, many decisions were made about methods and methodology, and these are noted in Chapters 3 and 4. As discussed in those chapters, choices and interpretations are subjective and reflect the values of the research and the researcher. A different researcher using the same method might make different decisions and interpretations. This is an embodiment of the notion of the lack of knowable truths in the qualitative world (Chapter 3). I now note limitations relating to the design which are more procedural and worthy of consideration when thinking about the findings of this study and the development of future research.

#### 8.8.1.1 Adapting a new policy framework

The Policy Conflict Framework was first reported in 2017 and, at the time Stage 1 of this study was undertaken, had only been applied once (Heikkila and Weible 2017). Chapter 3 justified its use, noting that it was the framework best-suited to exploring conflict and defending the decision to use Bacchi's discourse analysis approach (2009). Though different from their first application of their PCF, this decision is consistent with Weible and Heikkila's ambitions for the Framework. They were not prescriptive about the detail of how the Framework should be used. At a talk given to Stirling University attendees in 2018, Weible suggested that, as a new Framework, some development through use was anticipated and desirable. In some ways the situation is like that of the meta-ethnography

whereby France et al. developed guidelines for researchers because they noted that a lack of clarity in Noblit and Hare's original work had led to poor quality reporting (France et al. 2014, 2019a, Noblit and Hare 1988). A full review of the experience of using the Framework, particularly when using a qualitative lens, is beyond the scope of this thesis but is recommended to add value for future researchers to use it with confidence. This suggests that a paper is written which details the experience and makes recommendations for effective future qualitative use of the Framework.

### 8.8.1.2 Ethics

Stage 2 also raised interesting concerns about the ethics of research in the contemporary era. The authors of one paper (Mandla et al. 2017) took as their data Mad-authored blogs which were published online. No consent was sought to use this data. The ethics regarding the use of online public domain information such as Twitter, Facebook and blogs are not clear (Golder et al. 2017). It is argued that use of these kinds of data permit access to knowledge undiscovered through conventional research, which this study notes is curated and interpreted by others. It is, however, morally questionable to use an individual's information without asking. There is a concern that by using data from this paper, this study perpetuates this harm and further erodes trust in researchers and their research. Also of relevance was the need to preserve anonymity which meant that participants in Stage 3 were not fully described in this thesis, and it was not possible to say exactly why they were so well suited to speak to the topic.

### 8.8.1.3 Meta-ethnography using bipolar as a case study

The qualitative evidence synthesis in Chapter 6 was structured using the meta-ethnography method. The search strategy was very specific and included a decision to focus on self-management alone as a descriptor, and one diagnostic label, bipolar affective disorder, along with its older descriptor 'manic depression'. Searches intentionally focused on the academic literature, rather than grey literature, in line with the decision to access a health professional view because the aim of the study was to understand self-management as supported through healthcare services. This was a view that was most likely to be in peer reviewed papers. The intention was for the synthesis to act as a case study within the broader phenomenon. This introduced limitations. The decision to focus on one diagnostic label means that caution must be taken when considering the applicability of the findings to

other diagnostic labels. Also worthy of note was that the studies represented in the selected papers were based in high income countries, had more female participants than male, and none focused on the experiences of families or informal carers. As noted in Chapter 9.2.4, further research including a qualitative synthesis of other diagnostic labels, grey literature, studies based in a wider range of countries, equivalence in gender representation, and/or the experiences of informal carers would be valuable, particularly as a means to explore self-management among people who do not use a medical lens to understand their experiences.

#### 8.8.1.4 Peer review and guidance in the meta-ethnography

Collaborative research i.e., working in teams is useful in qualitative research (Nystrom et al. 2018). In meta-ethnography teamwork makes it possible to discuss whether a paper meets or fails to meet the criteria, whether or not to exclude first person accounts, interpretations of the first and second person constructs, and feedback about the developing model. A PhD is, however, intended as the work of a solo researcher rather than a co-produced task. That notwithstanding, feedback and guidance regarding these meta-ethnography tasks was achieved through regular supervision with one of the key authors of the eMERGe guidelines (France et al. 2019a). Professor Ring had significant meta-ethnography experience. Her position as a qualified nurse in adult and child nursing distanced her from the specialist mental health field and offered a level of impartiality which was useful. Also important from a process point of view was building in informal teamwork with a PGR peer, Wendy Masterton, who acted as a second reviewer to check decisions. This provided an opportunity for shared learning. Supervision with Professor Ring offered valuable method guidance and an experienced third view when consensus could not be reached between myself and my second reviewer peer.

#### 8.8.1.5 Fieldwork during COVID-19

The interviews reported in Chapter 7 were limited by the small number of participants, but this was considered carefully at design stage and the rationale was discussed in Chapter 3. The main challenge encountered during the fieldwork stage was entirely unforeseen. Interviews took place between 21 February - 17 April 2020 and the timing proved unfortunate for this health-related study. The COVID-19 pandemic emerged in Winter 2019-2020 and led to an escalating series of social-distancing measures, culminating in national

lockdown starting in late March 2020. This had a significant impact on recruitment and data collection even for this small-scale fieldwork. It was apparent even in the lead-up to lockdown that potential NHS, third sector, and policymaker participants were required quickly to divert their efforts to deal with the practical consequences of the pandemic. Pragmatism was necessary to ensure that the fieldwork remained sufficiently coherent in the face of these challenges. Although a community mental health nurse was recruited and interviewed before lockdown and their redeployment to front-line ward nursing, it became impossible to recruit a policymaker who had the time to meet. As a result, an interview was finally arranged with an individual who had had policymaking experience, but who was no longer working in the field. This was still within the parameters of the ethical approval, but distance from the experience may have altered their views. Participant 5 had limited time to talk due to workload pressures and their thoughts were frequently interrupted by people seeking their input during the interview. Although one participant had suggested speaking to a social worker or occupational therapist, additional interviews proved impossible to arrange in the pandemic-challenged world. Of the six interviews finally recorded, two were conducted by video-call rather than face-face. While permitted within the ethical approval, this option was not optimal. Rapport was harder to build, and intermittent connections meant that the conversation was sometimes stuttered and stilted. Unexpected benefits were that ethical approval did allow online interviews and that meant that the study continued when many were halted by the impact of COVID-19 the required agile response to unexpected challenges proved a valuable learning experience for any future role in research.

### *8.8.2 Personal limitations*

The impact of the personal in research is acknowledged as an attribute of qualitative work and I discussed this in Chapter 3.2 where I note that who I am is intrinsically interweaved into my qualitative research. I said that who we are impacts how studies are designed, the questions that are asked and the interpretations that are made. Yet, in Chapter 6, rarely was positionality explicitly stated across the selected qualitative papers of the meta-ethnography. Those with lived experience tended to be the objects of study while the researchers were more likely to come from a healthcare background: the impact of that dynamic was not explored. While this is a limitation of the selected papers, in this thesis that limitation is replicated. There are no alternative lived experience voices in this research except those that are the objects of the study. In part, this is because the PhD model is often less conducive to meaningful and wider collaboration in terms of defining questions,

establishing a design, and conducting analysis. PhDs are constrained by time and finance and must result in the output of the individual student, rather than a wider team. My own voice as a person with lived experience as stated in Chapter 1.6 is certainly insufficient to mitigate this limitation. While I have living experience of Madness, I am a nurse and a researcher-in-training. I am white, educated, and have good social support. In terms of Chapter 5.6.3, I recognise my precarious position as an insider-outsider with all that represents. I occupy a space of disadvantaged advantage. I cannot, nor should I, speak for all those with lived experience (Appendix 3 and 4). This underpins why, as indicated in Chapter 9.2.4), meaningful inclusion of lived experience in any future research is extremely important, and researchers should commit to undertake careful consideration about who they are, and why it matters for their study.

For me, despite my privilege, the study proved challenging as a result of my lived experience and the emotions it aroused. The academy is historically and structurally unused to supporting the emotional labour of research and has tended to disregard, silence, or devalue the accounts of those who try to bring it to their work. Vicarious trauma is a possible outcome of dealing with difficult emotion in others and, while originally thought mostly to be a challenge for people who work with those affected by trauma, it is now acknowledged to extend to researchers that research these vulnerable groups (McCann and Pearlman 1990, Fine 1994, Dickson-Swift et al. 2009, Camacho 2016). In my case, there was an element of re-living trauma (Appendix 3). Immersion in the papers for the meta-ethnography was sometimes upsetting, especially where the language was 'othering' (Maccallum 2002). At times introductory sections full of misery statistics felt like prophecy. Interviews with participants 3 and 4 surfaced emotions I had long buried. I had not anticipated how difficult I would find it to retain sight of my research questions, and engage with the process, yet mediate my own emotional response to the work. In hindsight, I wondered whether I should have chosen a different mental health condition, but immersion in the wider mental health literature tells me that this negative positioning of people living with a diagnosis is general, not specific to bipolar disorder. Ongoing reflection, superb pastoral supervision, and attentive self-care have been necessary. The process has taken longer than I might have wished as a result. This is recorded in my diaries. It is advised that all qualitative researchers keep a research diary for reasons of rigour, reliability, and validity (Darawsheh 2014), and my own proved invaluable (Appendix 3). This study was as much a personal odyssey as an



academic one. Within my diaries I eventually learned to sit with my own experiences and reframe them without succumbing to overwhelm, leaving space to stay on topic.

Coupled with these challenges were those experienced by many PhD students. A PhD thesis is the novice researcher's apprentice-piece and the process through which it is achieved is intensely reflexive and critical. With the benefit of hindsight, there is often a great deal one might wish had been different, not least of all confidence and experience with new methods, knowledge and writing skills. My PhD often made me feel inept. I often felt like an imposter, though I reflect on an event I attended in 2018 which reframed this: I felt like an imposter because in the contemporary University, as an older woman living with a mental health diagnosis, I *am* an imposter (Breeze 2017, Brown and Leigh 2018, The answer is 2018). Strong supervision and the support of peers were valuable weapons against this, to build confidence without entirely silencing the important inner critic which inspires learning and development. I agree with Belavy et al. (2020) who argue that the strength of the supervisory team alone was likely the most salient factor in my ability to complete. I am profoundly grateful to acknowledge that the accumulated yet broad experience within the supervisory team ensured that interpretative bias was always challenged. Together I believe that I, and we, have produced a final document which is authentic, yet respectful of all the people in this complex, Mad world.

## 8.9 Summary of the discussion

This chapter has discussed the findings of a three-stage study which sought to explore how self-management was understood in policy and mental healthcare practice. Based on these findings, and cognisant of the limitations articulated here which call for further research, I have concluded that in mental healthcare, self-management is understood in a particular way. Access to healthcare support is conditional upon agreement regarding an understanding that:

- self-management involves more than the self;
- outcomes are wide, and include autonomy;
- individuals are required to know themselves well, and to know when they no longer know themselves (epistemic paradox);

- individuals resolve this paradox by forfeiting their ability to know themselves consistently through co-monitoring (epistemic forfeit). Under this lens, autonomy has boundaries;
- services, however, are under pressure to discharge patients, despite an understanding that a patient cannot achieve consistent self-knowledge and that oversight is required.

If a paradox lies at the heart of the way self-management in healthcare is understood which results in the need for ongoing oversight, it is important to think about how policy and practice might change to make it more likely that self-management can operate optimally. This is the topic of discussion in the next chapter.

## Chapter 9. Implications for policy and practice

### 9.1 Introduction

As discussed in Chapter 8, the three stages of this study have presented a unique opportunity to argue that the challenges for self-management are founded in how it is understood, and the consequence of that understanding in practice. I have discussed a paradox at the heart of practice which results in the need for ongoing oversight. This is a requirement which is impacted due to time and resource pressures. There are opportunities for change which, if taken, might disrupt long-standing problems which prevent self-management working well in healthcare practice and beyond. In this chapter these opportunities are explored in more detail. I make suggestions for changes to the way that policy is made and practice conducted with the intention of improving both and consider how future research might help to increase knowledge such that it is possible to improve matters further.

### 9.2 Opportunities for change

Outlined here are the challenges identified in the Chapter 8 discussion (Table 9.1). Addressing these challenges offers key opportunities for change. They revolve around developing ways for healthcare professionals to accommodate more people in a way that is more person-centred. They include ways to reduce the pressure, work more efficiently, provide training, and seek wider understanding. Also discussed here is the more challenging need to address the policy mechanisms through which wider change within and beyond healthcare is influenced. Finally, this section considers how contemporary events might offer hope and opportunity.

Table 9.1 Challenges and opportunities

The challenge	The opportunity
A condition of receiving healthcare support for self-management is to agree that self-knowledge is fallible, meaning that oversight is always required, but healthcare services are under pressure to discharge a person as soon as practicable	Reducing the pressure (Chapter 9.2.1) Developing early intervention and training (Chapter 9.2.2)
There are many activities and tools which people might use in self-management, but it is not clear how, when, or why they work	Working more efficiently (Chapter 9.2.3)
There is a lack of awareness of the nuanced ways that mental illness and self-management might be understood. Healthcare professionals cannot work in a person-centred way and policymakers cannot make policy if they are not open to considering how a wide range of people understand their lives	Promoting wider understanding (Chapter 9.2.4)
Policy and practice change very slowly. Advocates of change must compromise to be invited to the policy table	Widening influence (Chapter 9.2.5) Learning lessons from a global pandemic (Chapter 9.2.6)

### *9.2.1 Reducing the pressure*

Chapter 6 asserted that key to receiving care in the healthcare system is for patients to understand their experiences in a medical way. This way of understanding people's experiences as a chronic illness means that patients within healthcare services can never have full autonomy. It was argued in Chapter 8 that the medical model creates dependence. If it is acknowledged that the individual can never be fully empowered, and must always have access to support, it is important to provide it. It has been noted that there is a political and professional will to provide healthcare services which are proactive, longer term and patient centred. I am encouraged to witness shifts towards a wider policy environment which is considering social factors, and by the integration agenda, both of which were discussed in Chapter 5. I argued however, that change at a practice level is slow and largely driven by healthcare agendas. Within healthcare, I noted in Chapter 7 that many of the negative care experiences are the result of the pressure services are under which results in professionals deprioritising patient needs. Participant 2 spoke about the challenge of managing increasing caseloads which led to a service focus on crisis care rather than self-management support and operationalised care algorithms which restricted the opportunity to work toward patient-defined goals. Services may want to respond to the need they have created, but they are not able.

Participants in Chapter 7 suggested practical opportunities which might enable services to reduce the pressure they are under, liberating professionals to provide care which is more person-centred. Participants suggested that enhancing third sector partnerships might be a way to reduce pressure on statutory services. Worthy of consideration is a model of care described by Rush and Urbanski (2019), relating to services which offer low threshold, tiered, and multi-disciplinary multi-agency access to support for physical, mental, and social challenges relating to drug and alcohol use. Similarly tiered, low threshold access which does not rely on a medical model of service provision, and includes third sector and peer-working, would address some of the barriers to accessing support mentioned by participants 3 and 4, allowing them to dip in and out as needed to services which operate in a less medical, peer-supported way. Proactive self-referral can be accommodated under this model of care, increasing a person's sense of agency. If there are clear lines of referral between statutory services and a visible, organised network of third sector agencies, escalation and de-escalation is simplified, and wider networks of social and financial support are accessible. A model of this type will be more easily achieved once social integration legislation filters into front-line practice (Public Bodies (Joint Working) (Scotland) Act 2014). It would allow self-managers to have the '*wee half day refresher*' that nurse participant 2 in Chapter 7.3 felt would be useful.

There are, however, barriers to this arrangement. Healthcare professional participant 5 noted their concerns about a lack of governance and proof of efficacy in the third sector which meant they were disinclined to refer. According to Bach-Mortenson and Montgomery (2018) this is a fear that is well-founded. One might wonder whether replicating statutory service governance and targets in the third sector risks creating a mirror service beset by the same limitations for users, albeit with less funding. Healthcare professional participant 2 talked about limited offerings in the third sector and a perceived lack of appeal which left them reluctant to point people in that direction. They also said it was difficult to know which service to refer to. Third sector services are not uniform and are underpinned by different ways of conceptualising the support they provide. Indeed, participant 4 noted that, in order to feel supported, they had to find a third sector service which accorded with their way of understanding their experiences. The variety of approaches is one of the third sector's advantages but also a weakness when it comes to working in partnerships with statutory bodies. It allows the third sector to offer choice of approach but is sometimes poorly funded,

drifting in and out of existence and hard to find/map/refer to as a result. Further, as outlined in Chapter 5, the third sector may find themselves compromised in their ability to advocate for and support people with lived experience in ways that are meaningful for them because of their need to secure funding and influence policy. Indeed, Bode and Brandsen (2019) discussed these points, and argued that closer collaboration with statutory services would lead to homogenisation, instrumentalisation of services and increased bureaucracy among third sector providers.

### *9.2.2 Developing early intervention and training*

Participant 2 in Chapter 7.3.4.5 suggested that an opportunity to reduce the pressure on services resulting from crisis presentations, and increasing demand for ongoing support in adult services, may be found through early intervention measures i.e., training in schools. Such training would equip children and young people with awareness and knowledge to manage the challenges that they might encounter in later life. This would reduce the need for reactive care in which services respond to problems once they have happened in later life. Although the need for early intervention is identified (Scottish Government 2018a, Mentally Healthy Schools 2021), no national government-sponsored initiative of this kind exists at time of writing and there remains a gap in provision for children and young people. The third sector has responded to this gap, for example the national agency, Scottish Association for Mental Health, has created the *We all have mental health* initiative, aimed at teachers (Scottish Association for Mental Health 2021b). Place2Be (2021) also runs courses for young people across 45 of Scotland's 2000+ schools.

Although some online mental health training is available for adults (Healthy Working Lives 2019), mental health training options are generally reactive, helping people to respond to emerging problems. The mental health first aid initiative was launched in Scotland as early as 2003 (Scottish Mental Health First Aid 2021). This lay-training is one of several in-person and online resources which include the suicide prevention training module, ASIST (Public Health Scotland 2021b). These are intended to give people skills to respond to mental health crises. As noted in Chapter 5, anti-stigma and support initiatives of this type are designed to encourage individuals to access care and are hampered by the lack of capacity in the healthcare system. In the main, initiatives are underpinned by a healthcare framing

which situates the ‘problem’ within the person and are designed to help people respond to a need, label the need medically, then signpost to services.

There is a lack of awareness of other models of understanding among the public, media, policymakers, and healthcare professionals. Individuals who do not understand their lives in this way but are seeking support must first navigate lack of understanding as the preliminary barrier. There is a need for wider, accessible educational resources which offer a broader and more critical view of the phenomenon described as mental illness. More recently it has been possible to access Mad Studies training in Scotland (Queen Margaret University 2021) though training of this type is neither widespread nor mandatory for health professionals. Such training may be challenging for those invested in the dominant medical model, but might initiate dialogue, facilitating meaningful collaboration in policy and practice in terms of who knows what, who does what and who wants what, and who is best placed to support it. Creating awareness of other ways of conceptualising the lived experience would work best if there were non-healthcare support options available to offer people who present to services, but this study notes the lack of alternative options within the current system to support those who do not subscribe wholly to the healthcare model of understanding.

### *9.2.3 Working more efficiently*

The papers in Chapter 6 described several activities considered broadly to be self-management. It was also noted that a number of tools have been developed which aim to support a range of those activities. Teams developing tools have undertaken their own process of tool evaluation and claim promising results, but the circumstances in which a particular activity or tool works for a specific person are unclear (Karasouli and Adams 2014, Fletcher et al. 2018, O’Brian et al. 2020). Knowing this information would allow those using and supporting self-management to target their decisions regarding activities and/or tools most likely to be helpful in specific situations. Indeed, Paper 2 in Chapter 6 had already noted that the needs of a person diagnosed with bipolar affective disorder were different depending on how long the person had lived with the diagnosis. A useful method through which this might be established is realist evaluation. Realist methods are growing in popularity as a way to establish greater detail about the context in which an intervention works (Pawson et al. 2005). Winsper et al. published a paper in 2020 using rigorous

systematic review and theory driven (realist) logic model techniques focusing on the efficacy of recovery-oriented interventions. This is a promising move in the direction of using realist techniques to answer questions in this field. It is important to note, however, the argument outlined in this thesis which says that *working* is a subjective notion.

#### *9.2.4 Promoting wider understanding*

Much of the evidence base concerns itself with those already in contact with services with a view to encouraging better engagement. While in Chapter 2 I noted that there are other ways of understanding, in Chapter 6 I showed that it is a condition of access to mental healthcare support that the person accessing support agrees with a medical model of understanding. The extent to which this is a dealbreaker for people experiencing crisis and results in unmet demand and need is unclear. Despite the conclusion in Chapter 7 that self-management involves more than the self, for some people this is their only option because they do not seek support. It is important to understand why people who have been in services disengage, and why others refuse to engage at all. For this group of people who disengage or will not engage with healthcare services, more research is needed. Possible questions might be, *how do people understand their lives, how do they look after themselves, how do they understand crisis and ongoing support and what do they do? Is there any place in their lives for the medical model, and if so, how would they like others to work with them?"*

A new qualitative evidence synthesis is warranted which draws its sample from sources more likely to yield non-medical accounts, conducted by those more distanced from healthcare, and by or with meaningful involvement of those with lived experience. In Chapter 7 I suggested that, by making the opportunity to speak to people that are disengaged with services, this study offered insights which are not routinely available. However, only a small sample of people were interviewed. While purposive sampling was a conscious decision (Chapter 3), there would be value in a further study with wider sampling. Research built around the three headings in Chapter 6 but without the boundaries of positionality and sampling, might provide further information about how divergent and nuanced alternative views may be and what needs to be put in place to support a wider range of people. As this study has shown, however, taking action on the findings without committing to concurrent system change may be challenging.



### *9.2.5 Widening influence*

Already outlined in this chapter are opportunities to improve services, based on the finding that services under pressure cannot accommodate the need for oversight which is central to the principles of self-management. Those options, however, do not address the evolving understanding of self-management as a phenomenon which is not purely medical in nature. Healthcare services have been tasked with turning increasingly socially aware policy into action despite their inability to respond to wider social factors. Such policy action suggests that a wider range of voices need to be heard at the policymaking table, but they are not. It was argued that this was an artefact of the fact that policymakers have limited capacity to respond to policy concerns because of the wide-ranging issues to which government must attend. I argued that when policymakers do attend to a specific policy area, they access only limited input from others. The upstream task is to find ways to focus policymaker attention such that action is taken and ensure that policymakers access a wider range of views upon which to develop turn policy intent into action.

In Chapter 5 it was noted that policy and practice changes if there is sufficient pressure and incentive to do so. Yet it was argued that there is limited scope for those with lived experience to be heard. Their representation is predominantly through third sector advocacy which is itself compromised by the need to conform to 'the rules of the game'. Policymaking theory suggests that direct policymaking influence could be accomplished by forming groups/coalitions which have the collective power to lobby the political process (Weible and Sabatier 2011, Cairney 2012). In this field, such grouping is challenging. As described in Chapter 2.2, while Mad activism has existed for many years, its members are only loosely connected, poorly funded if at all, and often required to navigate multiple intersectional disadvantages. These factors dilute the ability to mobilise action collectively. In addition, people with lived experience do not hold a unified position on their experiences, nor do they have a unified view regarding how policymakers and services should respond to it. This should not be a surprise. This study has concluded that it is simplistic to group people according to their position because understanding is more nuanced within groups. Chapter 7 showed positional variation between participant 2 and participants 1 and 5 i.e., nurse and psychiatrists. Participant 4 noted positional differences between third sector agencies. In Chapter 6 there were positional differences between patients within services. A possible option might be strategic essentialism, referring to a state of temporary solidarity for the purpose of mobilising social action. It allows those with somewhat different positions

to determine their common ground, allowing them to work together towards shared goals. As Kurzweil et al. (2020) report in their paper which explains then refutes essentialism, the originator of the term, Spivak, has since rejected strategic essentialism because it “*carries a latency to be used for pernicious ends*” (p. 65). The risk of co-option notwithstanding, the challenges of achieving strategic essentialism without significant finance and leadership of a type that disempowered individuals resist cannot be understated, and Voronka (2016b) notes that those with lived experience cannot and should not be grouped homogeneously.

Another route to promote the lived experience voice in the political process is through research. In recent years, the concept of evidence-based policy and practice has gained prominence suggesting that policy and practice are always informed by evidence; a claim which Hammersley challenges in his 2013 book. The findings of this study indicate that I must agree with Hammersley. For instance, it was noted in Chapter 6 that there was little in the way of peer involvement in the papers of the metaethnography. Although researchers are encouraged to include lived experience representation, and Patient and Public Involvement (PPI) has become important (Brett et al. 2014, INVOLVE 2021, Skivington et al. 2021, UK Standards for Public Involvement 2021), in practice barriers remain in terms of training, cost, access and time (Jackson et al. 2020). There remains a strong preference for decisions to be made on the basis of quantitative evidence rather than qualitative accounts, reflecting the ongoing healthcare dominance of the research hierarchy of evidence (Ingham-Brookfield 2016). This is linked to the financial and structural barriers of academic publishing which leave lived experience accounts and peer-led research with a reduced audience. They are a legacy of an historical disinclination to value expertise of the individuals involved. These barriers are hard to overcome, linked as they are to wider understandings demonstrated in this study about whose knowledge is important.

Even in the event that qualitative peer-led research overcomes these barriers and is conducted, Cairney and Kwiatkowski (2017) argue that many fail to appreciate the complexity of navigating the complex policy environment. They say that, as a result, evidence falls flat or is ignored. In his blog from 2018, Cairney offers a solution, suggesting that academics pursue “*framing and storytelling rather than expecting evidence to speak for itself*”, and listed suggestions for academics to better influence policymakers (Table 9.2).

In many ways, this is salutary advice for whomever seeks to influence policy, not just academics.

Table 9.2 Influencing policymakers (from Cairney 2018)

<ul style="list-style-type: none"><li>• There are many policymakers and influencers spread across government, so find out where the action is, or the key venues in which people are making authoritative decisions</li><li>• Each venue has its own 'institutions' – the formal and written, or informal and unwritten rules of policymaking – so learn the rules of each venue in which you engage</li><li>• Each venue is guided by a fundamental set of ideas – as paradigms, core beliefs, monopolies of understanding – so learn that language</li><li>• Each venue has its own networks – the relationships between policy makers and influencers – so build trust and form alliances within networks</li><li>• Policymaking attention is often driven by changes in socioeconomic factors, or routine/ non-routine events, so be prepared to exploit the 'windows of opportunity' to present your solution during heightened attention to a policy problem</li></ul>
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### *9.2.6 Learning lessons from a global pandemic*

In Chapter 5.5 I argued that seeking and acting upon a wide range of views represents threat because it may mean moving towards changes which are too difficult, expensive and/or disruptive, but hope comes in the form of recent events. The prediction of a 'tsunami of mental illness' in the wake of COVID-19 has presented a new imperative to tackle how the mental wellbeing of the nation is handled (Torjesen 2020). Of the options still available during lockdown, medication has been one of the few consistent tools to tackle issues of mood, yet the need continues to rise. Emerging evidence suggests that those experiencing intersectional disadvantage have been disproportionately affected during the pandemic (Bibby et al. 2020, Coronini-Cronberg et al. 2020). It might be argued that this underscores more deeply the importance of social factors, self-care activities, and face-to-face support, most of which have been impacted significantly by lockdown and social distancing. There is concern future services will face greater demand for ongoing support and crisis. What will happen for those individuals rejected from support and crisis care as services manage demand by raising thresholds? Given the findings of this study which show that when services are under pressure, person-centred needs and goals are de-prioritised, it is likely

that there are challenges ahead. Cairney et al. (2021) argued that the barriers to evidence-based policymaking continued to be evident during the pandemic. There is, however, hope. We have learned that policymakers and services have responded with agility and creativity to adopt new working practices across healthcare services during the crisis, and initiatives previously thought impossible have been implemented (Collins 2020, NHS Confederation 2020). In Chapter 5.3 it was argued that policy change is mobilised when a groundswell of events demand attention. The pandemic has been a significant healthcare event, physically and mentally. In the wake of the profound darkness of so many COVID-19 deaths the pandemic may yet act as a window of opportunity to find new ways forward and mobilise support for change.

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## Appendices

1	Stage 3 interviews. Copies of key documents as agreed by the ethics panel a) Participant information sheet b) Indicative topic guide c) Consent form
2	Additional characteristics of the included papers used in Chapter 6. Stage 2 meta-ethnography
3	Expanded positionality statement
4	With love

## Appendix 1. Ethics documents

### Participant Information Sheet

#### Research Project Title

Self-management for mental wellbeing

#### Background

After people have experienced a period of mental distress or crisis, they are commonly asked to self-manage their mental wellbeing, but what does that actually mean? Who does it? Who should help them? How is self-management done? What outcome is self-management meant to achieve? Importantly, does everybody answer these questions the same way?

I have been doing some research which suggests that the concept of self-management for mental wellbeing is understood in lots of different ways by the wide range of people who work with it; from those who make policy about it, to those who 'do it', and those who support them as they try to put it in place in their lives. My research suggests that this might be the reason that self-management is still not working well, in spite of being desired by many and part of policy and care guidelines for a long time.

Were you aware that there is variety in the ways that self-management is understood? Do you think there is a 'right' and 'wrong' way to understand it? Is it necessary to move towards a shared understanding about self-management in order to make it more effective, and if so, how could it be done? If not, how do we manage differences in the ways people understand and use self-management?

During this part of my study I will be interviewing a number of people, all of whom have a different role in self-management. I would like to share some of my findings in each one-to-one interview and ask what each person thinks about some of the lingering questions my research has raised.



**Why have I been invited to take part?**

You have been approached because you are a person that is involved in some way with self-management for mental wellbeing, either as a person who has been involved in making any kind of policy about mental health, a person who has used some form of self-management in their own life, or somebody that has worked in some way with people that are trying to self-manage. I'm very interested to hear what you have to say about my findings, and to learn how you see the way forward.

**Do I have to take part?**

No. You do not have to take part. If you do decide to take part, you can withdraw your participation at any time without needing to explain and without penalty, by advising the researcher of this decision. You can also withdraw your data up to 7 days after the interview. To withdraw your data, email me at the email address below. After that time, your data will have been included as part of the analysis.

**What will happen if I take part?**

You will need to complete one interview. The interview should take approximately 40-90 minutes depending on how much you have to say. Interviews can take place in a variety of places in order to be as convenient as possible for you. This could mean that you visit an office at the University of Stirling, we meet at a mutually agreed private and confidential location such as a workplace office, or we conduct the interview by telephone or skype. Before you start the interview, you will be given this information sheet to keep, and asked sign a consent form. Your decision to participate or not will have no effect on your employment or care.

**Are there any potential risks in taking part?**

There are no foreseeable risks in taking part as the interviewer will not be asking about things that have happened to you personally. It is slightly possible that as a result of sharing your views you discuss things which are distressing for you, but this is not expected. If such a situation occurs you will be reminded that you don't have to answer a question and you are able to stop the interview at any time. You can withdraw completely from the study if you prefer and ask for your data to be removed. Sources of support are listed at the bottom of this document, so that you may approach them if you feel you would like to.

**Are there any benefits in taking part?**

There will be no direct benefit to you from taking part in this research although some people say they enjoy being part of research. The responses you give will improve this study, and through that, may help others in the future. Those that are not drawing a salary for the time they give to the research will be offered a £20 'thank you' voucher.

**What happens to the data I provide?**

The research data will be kept anonymous and confidential, except in the unlikely event that you disclose information relating to intended harm to yourself or others, child protection offences, the physical abuse of vulnerable adults, money laundering and crimes covered by the prevention of terrorism legislation.

Only the researcher and her supervisors will have access to your data. A transcriber (who is external to the University of Stirling) will also access the audio recording, which may include some personal data; they have signed a confidentiality agreement. The audio files from the interview will only be used to transcribe the interviews and will not be available to anyone else. These files will be deleted at the end of the project. All data will be stored in a secure location and will be kept confidential. All information that could be used to identify you, such as your name, will be removed from all study outputs. We might use direct quotes in study outputs, but these will have names and other identifiable data removed. However, you may still be identified by people you know through the stories you tell. The details linking you to your participant number will be kept for 5 years in a secure data centre on the Stirling campus and will then be securely destroyed.

**Will you record my interview?**

Your interview will be audio-recorded by the interviewer in order to provide an accurate record of what you say. Consent to being audio-recorded will be part of the participation consent process before the interview begins. The audio file of the interview will be submitted for transcription using secure communication, at which point it will be deleted.

**Will the research be published?**

The findings from the interviews will be incorporated into the overall PhD study. Once the study is complete, you can ask to be sent a summary of the findings. The study findings

will be shared further in several ways. The research may be published, including in journal papers and media articles, and it may be presented at conferences. The University of Stirling is committed to making the outputs of research publicly accessible and supports this commitment through our online open access repository STORRE. Unless funder/publisher requirements prevent it, this research will be publicly disseminated through the University's open access repository. It is also hoped that the information will be used in additional activities such as the production of teaching materials. Due to the nature of this research, it is very likely that other researchers may find the data useful for answering other research questions. We will ask for your explicit consent for your data to be shared in this way. Your confidentiality will always be maintained.

**Who is organising and funding the research?**

This research is part of a PhD study conducted by Hazel Booth who is funded by the Economic and Social Research Council (ESRC).

**Who has reviewed this research project?**

This project has been approved by The University of Stirling General University Ethics Panel.

**What are my rights?**

You have the right to request to see a copy of the information we hold about you and to request corrections or deletions of the information that is no longer required.

You have the right to withdraw from this project at any time without giving reasons and without consequences to you. You also have the right to object to us processing relevant personal data however, please note that once the data are being analysed and/or results published it may not be possible to remove your data from the study.

**Who do I contact if I have concerns about this study or I wish to complain?**

If you have a concern about any aspect of this study, you should speak the researcher, Hazel Booth on 07973 460290 or [h.i.booth@stir.ac.uk](mailto:h.i.booth@stir.ac.uk). Alternatively, please contact the researcher's lead supervisor, Dr Tessa Parkes on 01786 467747 or [t.s.parkes@stir.ac.uk](mailto:t.s.parkes@stir.ac.uk).

If you remain unhappy and wish to speak to someone independent of the study, you can do this by contacting Professor Alison Bowes (Dean of Faculty of Social Sciences, University of Stirling [a.m.bowes@stir.ac.uk](mailto:a.m.bowes@stir.ac.uk) ).

You have the right to lodge a complaint against the University regarding data protection issues with the Information Commissioner's Office (<https://ico.org.uk/concerns/>). The University's Data Protection Officer is Joanna Morrow, Deputy Secretary. If you have any questions relating to data protection these can be addressed to [data.protection@stir.ac.uk](mailto:data.protection@stir.ac.uk) in the first instance. You will be given a copy of this information sheet to keep so that you have access to these details.

### **Who can I contact for more support?**

Below is a list of services that you can contact if you'd like more support.

Samaritans ☎116 123

Breathing Space ☎0800 83 85 87

Saneline ☎0300 304 7000

Rape Crisis Scotland ☎08088 01 03 02

Scottish Domestic Abuse ☎0800 027 1234

Advice Direct Scotland ☎0808 800 9060

Shelter Scotland Housing Advice ☎ 0808 800 4444

Victim Support Scotland ☎0345 603 9213

Thank you for your participation.

## Topic guide

After people have experienced a period of mental crisis they are often asked to self-manage their mental wellbeing. So we can get started, I'm interested to understand what *you* think self-management means.

### Who has responsibility for what?

I'd like to start by asking you who you think 'does' self-management?

Who might be involved in self-management?

For each of these groups

People with lived experience:

psychiatrists

mental health nurses

care in the community (GPs, outpatient clinics, social workers)

family/friends/community

third sector

peers with lived experience

government

What sorts of things should they be doing? What are they responsible for?

Who are they responsible/answerable to?

Why?

Who bears the most responsibility?

Why?

Of those *people* you have identified, tell me whose involvement you think is vital.

Is anybody optional?

Of the *activities* you have mentioned, which activities are vital?

Are any optional?

If the People with lived experience: doesn't want to involve some of the people or do some of the activities that health care professionals feel are more 'vital' than 'optional', what should be done about it, if anything? (e.g., if they have a history of recurrent crises

but are currently well, but do not want to take medication. Alternatively, we are in the same sort of situation, but they do not want to have an ongoing HCP relationship)

### **Outcomes and who knows what**

Now, I'd like you to think about how useful SM is.

How can you tell that SM is '*working*'?

What outcomes does it achieve?

Which is most important to you?

Why?

What other goals do you think might be important?

Who to? (think about the list of people you said was involved)

Why do you think is it important to them?

How can you tell that SM is '*not working*'?

Who decides it's not working?

When the wellbeing of a person who has been self-managing starts to deteriorate but they are not yet in crisis, who should decide that action must be taken?

What might that action be?

Why?

What is the difference between 'not managing well' and 'crisis'?

Who decides the boundary has been crossed?

Who or what has failed?

What should be done about it?

*(Only ask if this question seems appropriate based on previous discussion)*

We've talked a fair bit about self-management, and it seems you're talking about an activity that is intentionally collaborative and patient-led. It involves shared responsibility and shared decision-making. But I'm also hearing that the HCP always makes the final call?

It seems like quite a paradox. What do you think the implications of this might be?

### **Background**

The 'problem'. SM is a good idea but it's not working. The question is why?

Meta-ethnography suggests that self-management is constructed in nuanced ways.

Different groups of people hold different ideas about

Epistemology - Who knows what (in terms of knowledge of self and actions required)

Responsibility - Who is responsible for what

Outcomes - Who wants what

Policy analysis suggests that inequality of power means that some constructions are privileged.

## Participant Consent Form

**GUEP/NICR Approval Number** GUEP 816

**Participant number**

### Research Project Title. Self-management for mental wellbeing

Please read the statements carefully and put your initials in each box to confirm that you agree to each statement. You do not need to consent to all statements.

I confirm that I have read and understood the information sheet version 1 dated December 2019 explaining the above research project. I have had the opportunity to ask questions about the project.

I understand that my participation is voluntary and that I am free to withdraw at any time during the study and withdraw my data within 7 days without giving a reason, and without any penalty. I understand that beyond 7 days it may not be possible to remove my data from the study.

I consent to being audio recorded.

I understand that my responses will be anonymised (no names/details will be associated with your responses) and I give permission for members of the research team to have access to my anonymised responses.

I understand that while all information will be kept confidential, the researcher will break confidentiality if they feel that I am at risk of being harmed or if another person is at risk of being harmed.

I give permission to be quoted in any publications coming from this study and understand that all identifiable information will be removed from these quotes, and my real name will not be used. I understand that I could still be identified by people I know through the stories I tell.

I agree to take part in this study

**Name of Participant:**

**Signature:**

**Date:**

**Name of Researcher:**

**Signature:**

**Date**



## Appendix 2 Additional characteristics of selected papers from Chapter 6

Paper	Impact factor	Citation	# participants	Age	Gender		Ethnicity	Education	Occupation	Clinical	Other non-clinical	To note
					M	F						
1	2.103	5	40	10–19 1 20–29 1 30–39 4 40–49 15 50–59 10 60–69 9	12	18	not reported	No post-school qualifications 5 Post-school qualifications 35	not reported	no additional characteristics reported	no additional characteristics reported	Reported gender totals don't add up to reported participant total
2	2.604	25	27	18–24 3 25–34 2 35–44 4 45–54 6 55–64 6 65–74 2 75+ 1 No data 3	9	18	Afro-Caribbean 1 Mixed other 1 White British 21 White Other 1 No data 3	not reported	not reported	no additional characteristics reported	no additional characteristics reported	
3	1.37	4	21	mean age 47.29	6	15	African American 13 Caucasian 5 Hispanic 1 Other 3	not reported	Disabled or unemployed 18	Reports mean number of hospitalisations, BD1 or BD2, co-morbid health conditions, mean age of onset of BD.	Reports marital status.	Reported ethnicity totals don't add up to reported participant total.  Unclear why/how disability and unemployment statuses were grouped

4	2.097	7	21	mean age 47.20	6	15	African American 13 Caucasian 5 Hispanic 1 Other 3	Mean level of education was 12.10 years (SD 2.31)	Disabled or unemployed 18	Reports mean number of hospitalisation s, type of BD diagnosis, co- morbid health conditions, mean age of onset of BD.	Reports marital status.	Same participants as paper 3
5	4.084	12	10	Ages were 29, 30, 31, 31, 32, 36, 37, 42, 43, 50	5	5	not reported	not reported	Self- employed 2 Employed 4 Unemployed 3 Student 1	Reports type of BD diagnosis, number of hospitalisation s, mean time off medication, time since last episode and mood type, number of episodes	no additional characteristics reported	m:f not formally reported other than by gendered names
6	0.977	4	22	35-50 50+ unknown	4	15	not reported	not reported	not reported	no additional characteristics reported	Reports country of blog origin as USA 10 South Africa 1 Unknown 11	3 participants reported as unknown gender

7	2.335	92	33	not reported	12	20	not reported	not reported	Have a job 16 (51.6%) Work for self 14 (45.2%) Volunteer work 13 (41.9%)	Reports type of BD diagnosis, mean number of hospitalisations, mean number of depressive/manic episodes, scores across a range of rating scales including quality of life, social adjustment and depression.	no additional characteristics reported	Reported gender totals do not add up to reported participant total
8	4.084	77	32	not reported	12	20	not reported	not reported	not reported	Reports type of BD diagnosis, mean number of hospitalisations, mean number of depressive/manic episodes, scores across a range of rating scales including quality of life, social adjustment and depression.	no additional characteristics reported	Same participants as paper 7 but reports different total and does not report the occupation information reported in paper 7

9	2.604	59	12	Ages were 29, 30, 31, 37, 37, 42, 43, 45, 47, 49, 52, 56	7	5	"All bar one of white British descent"	not reported	Full-time 6 Part-time 2 Voluntary 2 Unemployed 2	Reports type of BD diagnosis, mean number of days since last episode, and scores on a self-rated mood scale (MDQ), whether or not taking medication and whether bipolar is 'serious' or 'moderate' according to clinical notes.	no additional characteristics reported	Does not report the ethnicity of 1 'non-white British' person
10	2.009	13	16	Ages were 23, 24, 24, 29, 34, 35, 35, 40, 43, 50, 55, 59, 64, 64, 65, 66	8	8	not reported	Lower vocational 1 Vocational 5 Bachelor 7 Master 3	not reported	Reports type of BD diagnosis, scores on a self-rated mood scale (VAS) and date of first diagnosis according to a) the patient b) the clinical file.	Reports marital status.	
11	0.27	8	9	not reported	4	5	Chinese	not reported	Part time tertiary education 2 Paid part-time employment 4	Reports number of hospitalisations, age of onset of symptoms, and years with diagnosis.	no additional characteristics reported	

									Housewife 1 Unemployed 2			
12	1.456	42	5	not reported	3	2	not reported	not reported	not reported	no additional characteristics reported	no additional characteristics reported	Participant characteristics not reported in a table, but within narrative

### Appendix 3. An expanded positionality statement

In Chapter 1.6 I said that positionality is important but when I stated my own positionality, I did so in an academic way. I conformed to the expectations of how a thesis should be written. Yet, the academic style is necessarily short. It irons out the wrinkles of the experiences I brought to my work and renders it almost sterile. The truth is very different. In this expanded positionality I wanted to sully the sterility of my academic statement with the grit of my real life. I wanted to show how the themes I discussed have such resonance for me, how I managed to be integral yet apart, and to reveal why there were times I thought I would never be able to complete my thesis.

Bringing my raw experiences to my research may well be inevitable, but it is challenging. It is my belief that I shouldn't disrespect the work and experiences of others by bringing myself to the fore. While doing my PhD, I reminded myself daily that that I should stay with my findings, writing nothing that I could not support with evidence. For the integrity of the analysis, for the respect of the original participants and authors, and for my own peace of mind, it was important that I didn't insert myself into the process. Yet throughout I was there, fashioned by my experiences. I added a positionality statement to the thesis body (Chapter 1.6) because that is what you do, but it was an unsatisfactory solution.

*The positionality statement is a task expected of any qualitative work and as you will note from my own, it is generally sterile, and devoid of the misery and confusion that lies behind it. It acknowledges a view that a person is the sum of their experiences, and that those experiences shape how you think and act, and how you perceive, affect and are affected by the world around you. To me, the convention of stating positionality is a problematic practice. More often than not, it defines a person in terms of a narrow range of widely-understood social roles a person has held – in my case, Mad, nurse and researcher, rather than the myriad influences from cradle to grave which we know shape a life. It assumes you know how those experiences have shaped you and have sufficient self-knowledge to acknowledge the most relevant. To write your positionality down on a bit of paper is an act of crystallising that you-ness. It fails to acknowledge that who you are evolves over time, even as you produce the work. Our self-hood ebbs and flows, shifts and changes. It is*

*sandcastles made in drying sand. While we may know these things instinctively, we somehow fail to really know them. They ought to be written with a caveat, 'this is who I am today, ask me again tomorrow'. Furthermore, although the statement is there to show that you acknowledge that your experience of life has shaped your work, it is provided primarily to allow others to make assumptions about how your experiences have potentially 'clouded your judgement' and how they have helped you to construct your critical understanding of your work, and your life in general. How could a mere paragraph do justice to that, and after all, isn't their interpretation of your position similarly affected by their own experience of life? As it is the positionality statement is thereby rendered so anodyne, it is meaningless. And so, we circle the epistemological drain.*

*Insertion of autobiographical memoirs as footnotes [...] allows me to present the memoir and the thesis as standalone products and keeps my voice literally 'hidden' from my academic voice, illustrating the division I feel inside me. I can pretend to myself and others that they do not influence each other, when in fact they are intrinsically linked within the same person and the same document. The two ways of presenting my work exist side by side, one conventional and valued. The other? Not so much. It is illustrative of how the lived experience view needs to be presented in a way that is valued and understood by the many and how failure to conform may result in their view being entirely dismissed. I like the idea of doing something risky and presenting my work in a non-standard way which may cause controversy. It is a metaphor for the different way Mad-identified people see their position in the world, how their difference presents challenge, and the risks they have to take to be heard above the noise of the orthodoxy.*

I bring therefore, the history of my personal experience to the themes of the thesis, and in that direction because I did so after I had analysed and plotted out the main thrust of my thesis. The links to this appendix from the thesis are minimal because the lived experience has limited authority in an academic world. Where I have linked from this appendix to the thesis, the links are indicative because so much of my writing from years past touches on so many of the themes I describe in the thesis. I extracted chunks from my journals, blogs, emails and (common decency be damned) Vogon-worthy poems, which were written over many years. I curated and chose carefully, because every word counts in a thesis and to 'waste' a chunk on this would be wrong even if they were hidden right at the very, very end

like a rancid easter egg. The extracts are reproduced here largely as they were written over a long period up to the present day; imperfect, with swearing intact (sorry Mum), and with edits added as sparingly as possible for comprehensibility. As I said in a recent email defending my decision not to edit the language and opinions.

*The content is lifted directly from the journals I have kept for many years. To be authentic to the 'me' that lived through those years it felt wrong to sanitise them. It seems I'm such a foul-mouthed person I couldn't restrict myself to bits of journal that were polite because it wouldn't have left me with much! I don't even agree with myself on some of it now, but that's the point of its inclusion in some ways; to show that our position shifts, twists, and turns.*

The quotes I use here illustrate why I struggled when analysing the selection of papers and conducting interviews. I was apart, yet always entwined in the process, fearful that I was seeing and hearing that which I wanted to see or hear, rather than what was there. I proceeded with supervision, writing, talking, and thinking, on the premise that to acknowledge and work through this risk would, in some way mitigate it.

I have sometimes wondered if this whole PhD thing was a shameless vanity project, or a fruitless attempt at self-expression. Then I realise that if that's what it *has* been (and I genuinely believe I had more altruistic aims) then I could have found a more tolerable way to do it. At times, the Mad PhD process has been unbearable.

*There have been times during this PhD process that I have left the today-ness of my today. Reading a paper, writing a paragraph, listening to a participant during fieldwork; all are sometimes, though not always risky. On days like those not-todays, I am whisked into my past and it feels as real as it did then. I can smell the world as it smelled and feel it in my body as it felt. It's no particular memory, yet all memories. It's so hard to explain because it is utterly visceral. I feel teary but can't cry. My heart races. My head hurts. I put my head down and try to disengage from it. I want to sleep, but I can't. And then when I do sleep, I dream about it, then wake, frightened and upset. If I'm unlucky the feeling lasts for hours, days, weeks. I push it to one side*



*and press on with my work, but it's magnetic and pulls me back, and I find myself just... feeling. On those days I down tools early, because my brain is too full. I get confused too easily. I feel trapped indoors. I need to leave the house. I want to drink, but I don't. I do all the things that help, until they actually help. Eventually, it passes.*

For me, things had always been a little challenging, but life went really wrong in my early 30s after a combination of circumstances came to a head and I trashed my life and my relationships trying to make sense of it all. I found myself labelled and medicated and designated as ill. I didn't feel ill as such, but it was clear I struggled to cope sometimes. I used to love to write appallingly bad poetry about wanting to be accepted for who I am/was. For context, my medication made me tremble constantly. I was always thirsty, always tired, and gained 4 stones of blubber. The interminable nausea was awful, to the point I often puked up my pills.

*When I take my meds  
I vomit  
Right there  
On the bedroom carpet  
A mocking damp mess of food and chemicals.  
I think it's my body's way of telling me it likes the way I am  
That chaos is the only way  
For me  
To be.  
It's not the first time  
My body has whispered good sense  
While the suits  
the coats  
and the normals  
Try in vain  
to push me into Tiny  
Round  
Holes  
And I hold my arms aloft  
Praising life as a square peg*

In this rhyming travesty, I was warning others that their world could be ripped away too, just as mine had been (see Chapter 7.3.2.2).

*I am the fuck up fairy  
Beware my little wand,  
it conjures mental nana skins  
a subtle tangling frond  
of secret buggeration  
and vexing malcontent  
you'll hardly feel the gentle touch  
you'll barely see the rent  
though the fabric of your ordered life  
the comfy status quo  
the furlined rut, unseeing eyes  
all that and more must go.  
I challenge every single thought  
I rumple every quilt  
of comfort that you've lain beneath,  
I unearth buried guilt.  
I scratch the tarnished surface  
on the varnish of your life  
d'you think you're strong, you're different?  
The parallels are rife  
with every single soul I see  
you're all the bloody same.  
And so I sprinkle fairy dust  
it lands without a shame.  
Attracted by complacency.  
it lands on every man,  
I am the fuck up fairy.  
Avoid me.  
Think you can?*

If medication was meant to make me feel normal, and normal is subjective, how was I to know when I had achieved Valhalla? In this excerpt I described my meeting with a psychiatrist that was trying to get me to 'adhere' to my medication. In that appointment I concluded that medication was meant to make me feel like he did (see Chapter 7.3.1).

*'I think', I said, 'you want me to be your version of normal. What you need to understand, is that that version of normal, is not my version of normal. 'This', I flapped my hands loosely in the air [...] 'this is my normal. This is my life. All this upping and downing and upset is my normal. The only difference is the intensity, or my ability to withstand the intensity at times.*

*We stared at each other.*

*'You know', I said, getting into my swing and feeling braver than I should, 'I sometimes wonder about your normal. I feel a little sad that your normal is so...' I fumbled for the word. I had plenty, but most were too cheeky. I picked the least offensive. I picked it and ran with it, [...] your version of normal seems so neutral. It is the limp handshake of life.*

*You see', I expanded, 'My normal means that I feel everything. Life, love, and sadness has sharp edges. It is a little dangerous. Sometimes it is very dangerous. Sometimes I can't bear it. But I do know that when I take your pills to reach your version of normal, I can't bear how smooth everything feels. Not forever. Sometimes, when it all gets too much and a bit too dangerous, it's nice to get a break and take the pills, but that neutrality is my 'not normal'. It's a break from the sharp edges of me. I know that I have to return to my normal eventually. Your 'normal' is my 'abnormal'.*

*He just sat and looked at me. I sighed with exasperation. This was not the first time I'd tried to explain this to somebody. I'd failed then. I was failing now.*

*'You want me to be you. I just want to be me', I said in a smaller voice, and knew how this ended.*

Is 'normal' just a synonym for 'fitting in'? How can anybody decide what normal is, and what qualifies them to know this? It's a theme I return to many times in my journals.

*And seriously, you 'normal people', do you feel like everybody else feels? How do you know? Is it because you can pass for normal? Do you do all the things normal people do? If I probed your thoughts the way people have been allowed to probe mine, would you turn out to be quite as normal as you seem? Is anybody? The extreme version of me cannot pass for normal, but when I'm me – although not quite you -- I can. Unless you have an open ticket into my head, that's when you can see it's a little skew-whiff. A bit, I would hazard, like you. So I am, by the measure of things, normal unless you take a magnifying glass to mind. Luckily you are spared that scrutiny. Sadly I am not. Because being normal actually just means 'fitting in'. Not rocking the boat. Not standing out. It's a kind of social policing. I am held to ransom by the thought police even when I fit in, because the people who get to decide what normal people think, have license to walk around inside my head and police it. Think yourself lucky they've never been allowed to trample around in the crazy in you.*

My own experience suggests that it is not just healthcare professionals that are the arbiters of 'normal' and acceptable behaviour. Here, the police and my husband were policing me. I had not long been discharged from hospital. I had just come home after going out for a (admittedly long) drive to clear my head, only to discover that my husband had notified the police, fearful for my 'state of mind'.

*I felt caged by the bodies in my living room. Everybody was looking at me expectantly. 'Cosy', I said, eyebrow raised, a trifle unnecessarily. I failed to sever the tension. 'Thank you' said [my husband], turning to the policeman and policewoman, 'I'm glad she's back, I'm sorry about...well, I'm sorry.'*

*The policewoman turned to me. 'You are a silly, silly girl'. I was in my mid-30s. I reviewed the face of a 20-something policewoman, unrealistically fortified by the power of her uniform. [...] 'You should have thought about other people before you took off. We have a proper job to do. Did you even consider the feelings of your son and your husband? Your selfishness has inconvenienced everybody.'*

*I didn't realise for a couple of seconds that the shouting was coming from me, 'Get her out of my house! Get her out. Fuck off, just fucking fuck off'. I launched herself at the open-mouthed policewoman, and was restrained, with difficulty, by [my husband].*

By the end of the day, I was back in hospital. I was admitted as a 'voluntary' patient, but in this tango of power, there was nothing voluntary about it. These days, I know there's a word for it, coercion. I didn't know that word in the context of mental healthcare then (see Chapter 2.2.2).

*[My CPN] had waited for the drama to dissipate. Her sad eyes locked onto mine. There was no surprise in her statement, 'you have to go back to hospital'.*

*There had been no suicide attempt, but they didn't know that. My head swam with options but resolved at only one. Though I had only been free a short while, I would have to go back to hospital. As far as I could see resistance would result in a section, after all, hadn't I just launched herself at a policeman? Hadn't I painted a clear illustration of my fractured mind? With the events since my last hospitalisation still fresh, I certainly felt fractured. I did not know what else to do, my options were exhausted.*

Co-monitoring is not always formal, and it is not always done by people who want the job. This is from an essay written by my then 15-year-old son, talking about how he had felt when he was 5. I found it in his school exercise book, years later when he was in his 20s. The shame of it. The heartbreak of it. It will not be surprising to know that through subjecting him to these early childhood experiences I worry that I have perpetuated the harm into the next generation of my family. He has given me permission to share this.

*I often find myself checking up on my mum even now, 10 years later. I constantly ask her if she is ok and cannot leave her without reminding her that I love her. I suppose I was so close to not having her and don't want to even think of it happening again.*

For me, diagnosis was an assault on self-identity. Diagnosis meant I had to refashion my own idea of me.

*When I was in hospital, I wanted to know how to reframe my understanding of who I was. I had been told that everything about me was a lie. Everything I thought I understood about me, was the product of my madness. I wanted to know where I ended and the illness began. What was left of me? But nobody wanted to talk about that. They just wanted to talk to me about taking my pills, stopping wanting to die, and getting back to normal. Only in the last year have I decided that there was never an ending of me. There was never a beginning of illness. There was only ever just me. A little different from many it is true, but only ever me.*

To live with a diagnosis is to live with an awareness that I will never again have full autonomy (see Chapter 8.5.2).

*Disclosure of crisis, certainly for me, has always had consequences for my autonomy. The received narrative is that disclosing crisis should mean that many hands emerge from the darkness and hold you lovingly and with acceptance. To an extent the hands do emerge, but they have probing, prying fingers. In my truth, I have found that disclosure means that my personal life becomes anything but. It is open season on my soul. It is sanctioned pillage of my inner self, in a way that most people never have to face. How many strangers do you tell your darkest thoughts to? I am exposed to imperatives disguised as well-intentioned advice, 'see the doctor, take these pills, don't think that, think this, exercise, see friends, rest, slow down'. Every thought in my head is now fair game to be pulled out for inspection by people I don't really know, and every emotion challenged. It is overwhelming and stressful to be treated this way, and for somebody who has already been hospitalised, it is frightening to have people take away any of my autonomy because I know it's a slippery slope. It makes me retreat even faster. I'll say the right thing to get you off my back, and then do what I know I need to do. If you find out I've not done as you said, you push harder to get me to do it your way, and then we end up*

*in a silent war, neither winning; and you get to call it caring. After all, you think you know better than me. Then, when it's all over, the hands evaporate and I can breathe again in the remnants of whatever the 'caring intervention' has left me with. It adds to my list of life experiences that tell me that disclosure has bad consequences.*

Being ill as an excuse for not fitting in has its benefits. Having an excuse for bad behaviour is incredibly convenient and intoxicating. Closing the door on that creates unpleasant personal consequences (See Chapter 2.2.2).

*In the days when I constructed my experiences as an illness which wasn't my fault and over which I had no control, I did some appalling things and blamed the diagnosis. The diagnosis was my get-out-of-jail-free card. Spent all your money, taken drugs, had sex with strangers? Manic. Stayed in bed, self-harmed, tried to kill yourself? Depressed. That diagnosis meant I didn't trust me and I didn't inspire trust in others. Now, I construct my experiences as what it is to be me; that I am a person who, under (fairly minimal amounts of) pressure, struggles with impulse control, is inclined to fight ('exhibit behaviours labelled as manic') or freeze (exhibit behaviours labelled as 'depressed'), and has a lot of anger and worry because my past has taught me to be angry and worry. As a result, I must own the behaviours I undertake, and attempt to manage them in order to be allowed to access the benefits that society offers as a result of being a socially acceptable human. Society however, needs to accept that it has a part to play by not adding undue pressure. You help me to operate in your world, and I'll find it easier to operate as you desire. We become two grown-ups doing the best they can to be respectful to each other. In a respectful relationship, you don't take the piss, and neither do I.*

Society needs to get better in recognising the part it plays in producing behaviour which doesn't 'fit in'. It shouldn't be possible to reject a person's self-hood and disadvantage them as a result and expect them to take it lying down. Sometimes the distress being tolerated is unnecessarily inflicted and the only 'appropriate emotion' is anger. Swallowing down anger or swallowing medication to quieten anger is not always the answer, but we all know that people are unsettled by angry people. (See Chapter 7.3.2).

*The controlled person is the person that can manage almost anything life throws at them with equanimity. The responsible, controlled person needs nought but a steely will, a dogged work ethic, and a healthy wodge of stoicism. They do not complain. They do not get angry. They make the best of it. They make their lemonade from donated lemons. They keep calm and carry on.*

*In some ways this is a useful way of dealing with life's slings and arrows because it is active and productive. It concentrates on what you can do to make things better, but it doesn't quite tell you what to do with the damn feelings that arise when life boots you up the backside for the umpteenth time, especially when you had very little hand in the process. That's because the controlled person is also responsible for controlling their distress. But is that always possible, or fair? Accepting your fate is all very well, but it doesn't teach you how to channel your feelings towards the unfairness that brought this situation to your door. When "shit happens", it is sometimes – though not always - because some rotten git somewhere in the bigger picture lobbed a lump of excrement, and sometimes that cockwomble needs to be called to account. Sometimes it is right and appropriate that you're angry or sad that you've been spattered with brown stuff. By telling you to be responsible for how you respond to life's challenges, there's an element of 'suck it up buttercup' that comes from a position of privilege of never having to deal with the load that you bear or else having greater power to influence life. Having difficulty with the feelings of powerlessness, frustration, confusion, and anxiety that arise when bad things happen that are not your fault and cannot be influenced, can be stultifying. It can create a sense of inertia which is hard to shake free. It's not always easy (or right) to 'accept and move on'. If the only clear action open to you is coping with the fallout, is it surprising when we don't feel too good about it?... I think this is a long essay which I could have covered by writing 'it's ok to be upset'.*

Anger is hardly surprising. There is privilege in passing for normal, but it costs.

*Shall I tell them? Ah yes, that old chestnut. Should I tell a potential employer that I live with a mental health diagnosis or should I keep it under my hat? I asked the opinion of somebody whose opinion I respect, and keeping schtum was the advice*



*[...] to stand a chance of getting the job, I grudgingly agreed that I had to slice off a part of me [...]*

*Since the emails about keeping schtum, I've been off my game. I thought I was sad and worried. Normally I'd 'write it out' in my blog, and then I realised I couldn't write one because my blog is in the public sphere. I realised that I need to climb back in my closet, and god knows it was hard enough climbing out. Coming out of the closet during this PhD was the making of me. Through it, I was liberated. Lightened. I had reconstructed my life, and I found peace with who I was and what I'd done. Was it all for nothing? I decided to redact some of my blog and delete some Mad-proud tweets, only to acknowledge that that particular beast has long since cantered right down the highway. It was pointless. I began to feel ashamed for being me. I hadn't felt that for a long time.*

*Then in a sudden brain-fart I realised I wasn't sad and worried. I was a little frustrated and a big lot angry. Haven't I spent 3 years talking about Madness and power? I've writ large about how the world is happy to listen to the Mad person so long as they talk about their Madness the right way, at the right time, to the right people. How they mustn't rock the boat or be too angry or too threatening. How they must be grateful and positive. How they mustn't expect too much, ask for too much money, expect a career. How they must accept their role as...less. How they must always, always, play the game.*

*Going back in the closet is playing the game. It is me exploiting my privilege as a white, able-bodied, well-supported person to pass as somebody without my lived experience. I can almost pretend to be 'normal' which is all very fine and dandy for me, but a real kick in the bum for those without my privilege. What kind of traitor budes the door open for a while, then clangs it shut when they're done? (see Chapter 5.6.3)*

I had learned to play the game after quite a lot of false starts in my quest for acceptance. To the onlooker, I 'recovered' because I found a way to belong, but I'm nobody's poster child. The narrative of recovery has a malign normative edge, to which Mad folk are held prisoner. Years after I wrote the excerpt below, I was privileged as a PhD student to spend a month working with Dr J. Voronka in Canada. She is part of the Mad Studies field and a

true inspiration. Her 2019 paper presents a similar argument about the commodification of survival narratives, but she says it much, much better of course.

*When I was first diagnosed I read Kay Redfield Jamieson's book. A year later I reviewed it on Amazon.*

*"One-year post diagnosis, I re-read it to discover it is somewhat oversimplistic in its summary of the illness and consequent social, mental and pharmacological effects. It also possibly even over-confident in terms of the return to 'normality' one can hope to achieve, though I admit it is early days for me".*

*I stand by my comments. Mad memoirs which reach the wider public consciousness are stories of triumph over adversity. They are written by folk who are articulate and resourceful otherwise they would not have been picked up by the publisher. Their stories bring Mad tales to the wider world and this is good, but there is a malign side-effect. "If that poor bugger can develop a FTSE 100 company while Mad, why can't they all"? This narrative entirely silences those sitting in the thick end of a very big wedge. These are the folk without the privilege to overcome the circumstances which are part and parcel of their Madness; poverty, exclusion, disrupted education, disempowerment, fractured relationships and isolation. The thick end is full of very different tales.*

So 'recovered' was I, that I trained to become a mental health nurse. I wanted to be a better nurse for others than some of the Ratchets that had 'cared' for me. It wasn't easy from the off. When I first started nurse training, my very first placement was on an inpatient ward. It was a baptism of fire. Life as an insider-outsider is not easy (see Chapter 5.6.3).

*The price of playing that game came into sharp relief one day when a woman who was an inpatient looked at me closely, then grabbed at me. 'What's this?' she asked, drawing my left forearm between us. That arm is particularly messy, tracked with scars from self-harm and incomplete suicides. I have never hidden them. Why the hell should I? No matter, had I wanted to, I couldn't, not in a nurse's uniform. I honestly didn't know how to respond. I had been startled by the unexpected physical*

*contact and didn't anticipate so personal a question. That's the rules of the game isn't it, a unidirectional sharing of experiences and feelings, with only superficiality in return. As I fumbled for a nurse-y response, she continued. 'Oh my god, you're one of us!' she exclaimed.*

*One of us. One of us. One of them? One of us? Who am I? Am I both? Is that ok? Is that who you need me to be? Am I neither? One of us.*

*[...] With the nurses I felt like a cuckoo, sneakily shitting in their carefully feathered nest. With the patients, I felt like a traitor, carefully curating an image of the distance between their abnormal and my apparently attainable and desirable normality. By seeking this dual identity, I found that I belonged to both, yet neither.*

*Recovery is meant to be about a bringing together of the rational and irrational, the Mad and the normal. It is a slow repair of a rent in the fabric of the psyche, whereby the madperson is re-connected with the world, forcibly so. It assumes that the aspiration of the Mad is to be like 'us', not them, and in hospital the nurses are the only role models. Yet they remain separated emotionally and structurally by words, actions, doors, keys, and uniforms. My experience as nurse and patient is characterised by distance. It is a dance to the tune of daytime tv, infused with the scent of eggs. As one closes in, the other moves back. A malign parry, unspoken reinforcement of a boundary that can never really be crossed.*

The challenges of my experience of life continue though. I am very new to understanding myself in a non-medical way, though I know I was always a sceptic that lacked the language to articulate my deep disquiet. The PhD has proved to be a learning process, and an imperfect reframing of me which is still a work-in-progress. These days I sometimes find myself adrift without the comfort of the medical model and I wonder what it would be like to return to the understanding I had.

*When you take away the belief in the illness metaphor, it doesn't leave much to soothe the pain, and sometimes you simply crave a little peace until you find the energy to prevail. I have a shabby bag of tricks that sometimes helps. I'll have a rummage, but I don't know if one of them will help today. Perhaps this is why the illness construct is so beguiling, even for those of us who feel let down by the system.*

*It has a leviathan of tricks that puts my shabby bag to shame, but I know I have to sacrifice my me-ness to access it. Yet it offers a prop, a sanctuary, a fucked-up reassurance, however contestable it may be in my new world of understanding. To sell my soul to a devil? When the chips are down and being me is hard, it would be lovely to think that somebody else can help me not to be like me. But I can only be me. It's what I'm best at, and deep down I am aware that I quite like being me. Sometimes. Unfortunately, today is not one of those days. But with time and acceptance, one of my tomorrows will be better. This, I know to be true. That's a belief I can cleave to.*

At the top of this Appendix I said that I understand the utility of the academic style even though I find it a little sterile and unsatisfactory in practice. Here, I have been able to add flesh to the bones of my academically stated positionality statement. I have reintroduced the wrinkles of my life in a raw, personal way. *Now you see me. Now you know why this PhD was challenging, why I did it, how I changed, and how I had to battle to stand as far apart from me as I could manage. Now you know why I sometimes failed. Now you know why this expanded positionality was so important.*

## Appendix 4. With love

In another break with tradition, I offer this wider statement of acknowledgement. Written a mere 8 months into the PhD, it was too personal to share at the time. Aside from one important reader it languished in my personal journal. It ends with a clear and pivotal message about the sustaining power of love and compassion and underscores the importance of those who made this thesis possible.

*I live with survivor guilt. I may have found a recipe of skills and tools that worked for me, but I knew that for others my bespoke menu produced nothing but the flatulence of empty hope. Though derided and toxic the pills played a role – for a while. I remember yelling at a world that I just wanted the unendurable confusion and struggle to stop. The pills made that happen. While I took them, I was so utterly numb and tired I felt nothing, and it was what I wanted. For years I teetered at the edge of a cliff, but pills helped me to crawl far enough back from the edge to the point of hysteresis where I could tolerate the bouts of energy and profound inertia when they came. The hospitalisations helped too, albeit in some messed-up way. It was not because of the kind ministrations of the professionals therein, because there was precious little compassion to be found, but inside, I could hide until I was able to engage again. Both helped, but for goodness sake, did either have to be so cruelly and persistently imposed? To this day, the fear of being subjected to those particular hammers to deal with my sweet little broken nut is the stuff of ongoing nightmares.*

*Now, my days are shaped by mood-monitoring, stress-management, exercise, sleep and countless other funky tools and skills. But what really made the difference was the compassion of family and friends, the hope of champions and the faithful forbearance of all who have dealt with my inconsistent labours ever since. The unswerving emotional support of my husband notwithstanding, his financial support shields me from the twin-headed spectre of poverty and exclusion that would surely be my lot were he not there. For a while I almost lost my friends, family, husband, son and life, but I have them back - though they are almost as scarred as me. I am fortunate and privileged to have them all with me.*

*I count my blessings daily. I daren't dwell on the mess in my head other than the cautious self-monitoring that informs my days actions. Nor dare I agonise over the*

*dignities I have forfeited in order to achieve this fragile peace. The safety of my privilege permits the selective memory I've described and allows me to move forward. I knew that the core of my survival lay only partly in tasks and tools. In the main it was centred on people and privilege. 'She survives', they say pointing to me, 'why can't you,' they exclaim, pointing at those who languish still. This prevalent attitude makes me furious for those who must toil alone in an uncaring, reductive world that looks for simple solutions and hides in the herd. I wish the world recognised that far from a utopian Disney fantasy, love really is the way. Undertaking this PhD has often reminded me that the world can be very dark. I try to live in the light. Thankfully, there are people in my life that make this possible.*

To the compassionate family and friends, to the hopeful champions and the forbearing faithful, I owe you more than this measly thesis. I owe you this life. You are the love that has sustained me.

*With love from me to compassionate family and friends*

To Andrew, Jamie, Mum and Dad, who have seen it all, yet *never* given up on me. To the cackling wigwam massive, Adele, Amanda, Dawn and Janie, who kept me laughing and loving until the lockdown stopped us. To my PhD pals who grounded me, and sometimes stopped me from stropping off into the sunset. To Avril, for all the conversations about philosophy and supreme Canadian prog-rock Gods, Rush. "Conform or be cast out" indeed (Lee, Lifeson, Peart 1982). To Anne, who has guided me into the Mad world. To Lynne, Judy and Laura, who wrote alongside me in those horrendous final months which nearly ended me. To Wendy, my brilliant peer reviewer and now, friend.

*With love from me to hopeful champions*

To the dream team, Tessa, Paul, and Nicola. Inspirational, brilliant, supremely tolerant, and unbelievably supportive supervisors par excellence. You carried my hope when I could not. I promise to pay it forward and be a champion for others.

*With love from me to the forbearing faithful*

To the select band of others who have smoothed my path and are still there despite everything. Thank you. Thank you all.