Self-management of chronic pain: a critical interpretive inquiry

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Abstract

Chronic pain is a long-term condition affecting an estimated 28 million people in the UK. Progress has been made in understanding, developing and supporting self-management for those with chronic pain. However, an unknown number of people have been excluded from or been unable to access the kind of multidisciplinary pain management services that are thought to be of benefit for supporting self-management. Little is known about their experiences and what they do that constitutes self-management.

Applying an interdisciplinary logic spanning several research traditions, this thesis examines how self-management of chronic pain is understood and enacted. I ask, "How is 'self-management' achieved by people living with chronic pain who have been excluded from or have dropped out of existing pain management services, and how can they be better supported in policy and practice?"

I start by situating myself as a curious clinician seeking to understand the experiences of my patients as well as the system in which I offer care, before presenting a hermeneutic literature review of self-management of chronic pain to understand the academic context in which this topic is situated, attending to the epistemological positions that have contributed to what is known about self-management of chronic pain. I conducted, then set out findings from an intrinsic case study of self-management of chronic pain combining data from seven qualitative cases of patients living with chronic pain who have been excluded from or dropped out of pain management services, with 16 interviews with health care professionals

and managers, seven interviews with policy actors and analysis of relevant policy documents.

My analysis shows how self-management of chronic pain is not singularly understood or practiced by participants in my study. Drawing on (and extending) the work of Annemarie Mol and Scott Graham, I present multiple ontologies of pain that influence which services are set up and how, and how they're delivered and offered (or not) to patients. I show how those living with pain in my study sometimes bypassed formal services - that typically privilege empirical and biomedical approaches to pain and pain management - in favour of more workable ontologically aligned care. They continually re(form) relational, socio-material entanglements with people, places and objects that offer support for living with pain. This is in stark contrast to the contemporary discourse and practice of 'self-management' in chronic pain, which I argue is a fallacy stemming from neoliberal health policy.

I conclude by arguing that the presence of contrasting pain ontologies has resulted in practitioners experiencing ontological conflict when trying to deliver modernised, technocratic services for chronic pain, and patients and practitioners experiencing uncertainty and distress when negotiating the health care system. I propose a different way of thinking about access to specialist pain services, inviting decision makers and practitioners to extend support for chronic pain to non-health care settings, and to attend more closely to the socio-material entanglements and relational aspects of living with chronic pain.

Abbreviations

NHS	National Health Service
GP	General Practitioner
CCG	Clinical Commissioning Group
MDT	Multidisciplinary team
CBT	Cognitive Behavioural Therapy
BPS	Biopsychosocial model
WHO	World Health Organisation
CDSMP	Chronic Disease Self-Management Programme
EPP	Expert Patient Programme
PPI	Patient Public Involvement
MSK	Musculoskeletal
IASP	International Association for the Study of Pain
EBM	Evidence Based Medicine
BwO	Body without Organs
HRA	Health Research Authority
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health Research
RCT	Randomised Control Trial

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Chapter 1: Introduction

1.1 Overview

Pain is understood by different people in different ways. Underlying beliefs and assumptions influence how clinicians, researchers, policy makers and patients think of and approach pain. In health services, these assumptions appear to be implicitly encoded into modernist tools and practices as well as in how services are organised and delivered. It is unclear how these different ways of knowing and being contribute (or not) to tensions and conflict in pain management practice. My own professional work and research has been strongly influenced by the particular lenses through which I have viewed my patients' concerns and my underlying assumptions about them. These lenses have changed over time. In this introductory chapter, I begin by going through these changing lenses, demonstrating my interest and way into the research presented in this thesis. I then present the fictional case of Jovita to illustrate the increasing complexity of patients I have encountered in my clinical work and contrast her lived experience with the organisation of services available to support her. I conclude by presenting an overview of my thesis to aid in navigating the reading.

1.2 My background

I am a physiotherapist with 19 years' clinical experience. My clinical training, completed in 2003, focused on diagnosing and treating anatomically focussed physical problems within a structural-pathological understanding of pain. Over the next five years I found this biomedical approach limiting as it only partially acknowledges the psychological or social

dimensions shaping people's health. I often felt that I was simplifying complex issues to the potential detriment of some patients.

Diagnoses and rehabilitation plans were informed by a deductive clinical reasoning model, grounded in patho-anatomical knowledge and perspectives which privileges the study of organs and tissues as a means of determining the causes of pain. This work was high volume with busy clinics focussed on physical assessments, accurate diagnosis and treatments based on exercise rehabilitation and manual therapy (see e.g., Lewis, 2016). As practitioners, we assessed clinical outcomes using standardised questionnaires and patient reported outcome measures, many of these were focussed on pain reduction (Chiarotto et al., 2016; Roos & Lohmander, 2003). Our effectiveness as clinicians was inferred from efficiency metrics such as how many patients we referred on to surgery and, of those, how many went on to have surgical procedures (Wood et al., 2016). On the rehabilitation side, effectiveness was inferred by seeing more new patients and following up fewer patients (a low 'new patient to follow up' ratio). The focus on time-efficiency made it difficult to offer the treatment required for successful long-term rehabilitation. The clinical guidelines that formed a cornerstone of my practice working in musculoskeletal services (from 2005 - 2008) espoused adopting a more patient-centred approach to prevalent long-term musculoskeletal conditions. For example, promoting combined psychological and exercise approaches for those with disabling and distressing pain (National Collaborating Centre for Primary Care, 2009). Research trials were demonstrating that stratified care - where patient care was tailored - was superior to a 'one size fits all' approach for musculoskeletal pain thus driving more restrictive triage practices where patients deemed too complex by practitioners were discharged back to primary care (Hill et al., 2008; Hill et al., 2011). This

was especially true for people with more complex lives related to e.g., difficult family relationships, trauma histories, histories of forced migration, substance misuse, poor mental health, insecure incomes, problems with accommodation and homelessness (Hill et al., 2008). Patients with different cultural and health beliefs to those we took for granted in our clinic faced additional barriers in accessing and participating in our structured, rather inflexible services. My own postgraduate research showed that clinicians and managers in musculoskeletal services experienced the implementation of more efficiency driven service models as a trade-off between quality and cost (Walumbe et al., 2016). I found myself working in a way that was removed from the relational work I wanted to do with patients and feeling increasingly dissatisfied.

In 2008 I began working in a specialist pain management role, still focusing on musculoskeletal pain. I worked in an inner-city urban population with a high proportion of both forced and economic migrants, low socioeconomic status families and lots of cultural variation. We applied the models and concepts aligned with established pain management to all our patients uniformly but noticed differential outcomes for different population groups when using standardised psychometric tests. To better understand these differences, I conducted a systematic review on the effect of ethnicity on the outcomes of cognitive behavioural and multidisciplinary rehabilitation in pain. Both these approaches were the most frequently used within the National Health Service (NHS) for long term pain at the time. I followed established research protocols from evidence-based medicine to interrogate the published academic literature, completing an empty review (Lang et al., 2007) as I was unable to identify any research that met my inclusion criteria. The existing

and available evidence, and the chosen research method was not sufficient for my specific research questions.

In 2016 I joined a multidisciplinary team supporting self-management of complex pain with hospital in-patients. In this, my current role, I work with patients with diverse clinical presentations and complex physical and psychological symptoms who experience significant negative impact on their quality of life. My move into the pain management field gave me professional freedom to think beyond existing normative approaches to conceptualising pain. Working with different professionals and completing a post graduate degree in which I learned about the wider determinants of health such as relative income, social circumstances and built environments (Marmot & Wilkinson, 2001), I began to draw on other interdisciplinary approaches (e.g., psychologically informed practice (Denneny et al., 2020)) that included attention to contextual issues contributing to complex pain.

In my current field of clinical work, pain management, the dominant view of chronic pain is framed within the biopsychosocial model (Engel, 1977), though there are critics of the model as originally described (e.g., Wade & Halligan, 2017). The broad consensus in clinical practice is that the biopsychosocial model accounts for more facets of human experience and behaviour than the biomedical model. From this perspective tissue damage is neither necessary nor sufficient for a person to experience pain. Pain relief, resolution or cure are often not the intended outcome of pain management interventions (Lotze & Moseley, 2015). In my own multi-disciplinary (MDT) pain team we tend to conceptualise chronic pain broadly as a long-term condition (Smith et al., 2019). Rather than giving a definitive tissue

specific diagnosis and treatment plan, we focus on exploring and understanding patients' own beliefs and supporting them in learning self-management skills and improving their function (Carnes et al., 2012; Harding & Williams, 1995; Lennox Thompson et al., 2019). Through this lens, we emphasize supporting people to live well despite pain with self-management being an essential component part. Our discharge letter templates to referring General Practitioners (GP) state that patients are "successfully self-managing". We typically make a recommendation to the patient's GP to encourage self-management should the patient's pain problem recur. The meaning of this 'self-management' is often implied rather than explicit; we generally do not add any details for the GP on what 'self-management' might look like in practice. It is common for different services and practitioners to understand and describe pain management (Lotze & Moseley, 2015) and self-management in different ways (Carnes et al., 2012).

1.3 Working with complexity

My current thinking about pain has evolved and been shaped by my professional experiences, academic work, and wider exposure to interdisciplinary perspectives in the sociology of health and illness, philosophy of science and empirical pain research. I have adopted a wider range of perspectives when trying to make sense of the health care experiences of some of my more complex patients and developed an interest in alternative models of pain management that differ to existing approaches.

Since 2016, my work as a clinical physiotherapist has been within a multidisciplinary, specialised pain service located unusually within an inpatient setting of a large city tertiary

level hospital (Mordecai et al., 2018b). The service was developed in response to the recognition that a number of complex patients were unable to make use of existing tertiary level outpatient services for hitherto unknown reasons and were spending more time as hospital inpatients or in emergency services. There is an explicit recognition that the work is iterative in nature and is often explained using technocratic complexity models (e.g., Stacey, 1996). We work across services, speciality, organisational and geographical boundaries, guided by a wraparound approach to care[1] (Winters & Metz, 2009) and engaging with teams outside the traditional pain management sphere e.g., social services, drug and alcohol liaison, learning disabilities, homeless health, mental health liaison and multiple other services across primary and secondary care.

In sum, I started from a broadly biomedical perspective focussing on diagnosis and treatment of specific disorders. As I've shifted roles, I've come to realise that people living with pain often present with complex and multi-layered concerns that are not always visible or attended to in mainstream NHS services. I now present a fictional case of Jovita, based on a composite of typical patients I have encountered in this role to offer insight into how I developed my research interests.

1.4 Jovita

Jovita, a Black British, single mother of one, living with multiple health conditions including irritable bowel syndrome, recurrent abdominal pain, non-specific widespread pain (or

[1] "Wraparound is an empirically supported, family-driven, strengths-based planning approach that provides individualized care using an array of formal services and natural supports" p135 (Winters & Metz, 2009)

fibromyalgia) and borderline personality disorder is in her early thirties. We first met in 2016 when the complex pain service was launched. Jovita had been admitted to the gynaecology ward three weeks earlier with severe abdominal pain and was still an inpatient as no cause had been identified. She had been reviewed by the surgical team earlier in her admission, but no new investigations or surgical interventions were required. She was already on an 18-month waiting list to see a specialist surgeon to consider removal of surgical mesh (previously inserted to address incontinence after childbirth). During her current admission, Jovita's mother was looking after her daughter. Her daughter had briefly been taken into foster care by social services due to concerns about her safety. Jovita had a history of problematic use of her prescription drugs and her GP was concerned that she was being exploited by friends who were diverting her prescription medication for illicit use. The pain team had been asked to advise on pain relief as Jovita was reporting severe pain despite an increasing opioid medication regime. The ward nurses were concerned about what they described as 'drug seeking' behaviour. Jovita did not have access to her own medication on the ward and she was asking the nurses for pain relief before her scheduled dose. She was often visibly distressed, crying for long periods of time and was under review by the hospital liaison psychiatry team.

Jovita described struggling with increased abdominal pain which she attributed to the surgical mesh implant. In addition, her fibromyalgia symptoms were worse than usual, and the medication did not seem to help this pain at all. Her routine at home to manage pain flare ups involved increasing the dose of one of her opioids "just a bit" to allow her to attend mandatory appointments at the job centre, go for a short walk and pick up her

daughter from school before her mum came home and took over. In the hospital, the doctors had refused to increase her dose and instead increased the frequency of the prescription. However, the nursing team were busy and often did not dispense the medication on time which led to her pain increasing to intolerable levels. She was scared about what the mesh was doing to her insides and “just wanted it removed” during this admission.

During this admission, we convened a large multidisciplinary meeting with all the speciality teams involved in her care including emergency care, the ambulance service, gastroenterology, gynaecology, liaison psychiatry and primary care. Jovita and her mum joined the meeting and were supported by the consultant clinical psychologist. The focus of this meeting was to better understand the whole of Jovita’s experiences and health issues. It was apparent that many of the issues intersected and that managing any single issue in a silo had an unknown impact on other parts of the system. The gastroenterology team felt her gut symptoms were caused by opioid use and wanted to stop her opioid prescription all together. Jovita’s GP had been advised by the local pain clinic to increase the opioid prescription in the past to help with fibromyalgia. The GP had previously referred her to the specialist pain management service due to the complexity of the case but following a couple of appointments, she had been discharged. Gynaecology were concerned about the internal damage that the mesh was causing and had advised Jovita to attend A&E for review if her pain flare up was severe. A&E were concerned about her repeated attendances which they felt were unwarranted for fibromyalgia and often did not examine her abdomen. Jovita had found it increasingly difficult to get through the routine system of triage at A&E and had

started calling an ambulance instead. This bypassed the triage team and usually resulted in her being reviewed and admitted onto the gynaecology ward, hence justifying her concerns. In primary care, her increasing and variable opioid use had led the CCG pharmacist to flag her records in line with new guidance on opioid use. The pharmacist had instructed the GP to reduce the dose, but the GP did not feel able to do so without specialist advice as previous attempts had resulted in considerable deterioration of Jovita's mental health. The gynaecology team agreed that removal of the surgical mesh may improve her abdominal pain and reduce the requirement for high dose opioids. However, the service had a very long waiting list and high demand, so this was not likely to happen quickly. The MDT concluded that Jovita would be best supported by the expertise offered by the outpatient specialised pain clinic.

Jovita had previously been seen in this service and had already had two appointments with the pain MDT around nine months previously. The records showed that the team in the pain clinic judged that she was not appropriate for the service due to having ongoing medical issues, specifically that she was waiting for surgery. The reasoning given in her discharge letter, was that she would not be able to take on board the messages of 'moving on' and 'living well despite pain' if she was anticipating having a procedure that it was hoped would reduce or eliminate her pain. This expectation of symptom relief by Jovita was seen by clinicians in the pain service as a barrier to engagement and directly contradicted the message that chronic pain is life long and should be seen as a long-term condition. The doctors on the team were happy to take on prescribing responsibility and offer interventions if required, suggesting that they did consider pain as potentially ameliorable.

The psychologists and physiotherapists maintained their position that 'self-management' approaches would be inappropriate and could even potentially be detrimental if Jovita then felt she had tried and failed pain management and would subsequently not feel the approach and strategies offered could be helpful in the future. Jovita, it was assumed, would be unable to 'engage' fully with the hope of a surgical cure for her pain on the horizon - and without engagement there was no possibility of success.

Jovita's case exemplifies the messy realities of living with chronic pain and the messy realities of the professional world that seeks to attend to it. It surfaces the way real-life deviates from neat disease definitions and their diagnoses, from service specifications that are more diagnosis-centred than patient-centred and how non-biomedical explanations are often not considered in pain management. It highlights that people may be living with medical conditions that require treatment under a medical model some of the time, alongside more diagnostically ambiguous long-term chronic pain. I was interested in better understanding the meaning of self-management of chronic pain by different actors as well as how people living with pain (often in messy and complex environments) achieved self-management with or without support.

1.5 Self-management of chronic pain: an overview of my thesis

I have described my professional background and the origins of my thesis, including a fictional case to help surface the tensions and dilemmas in self-management of chronic pain. In the following chapters, I present my interpretive research into self-management of chronic pain. In Chapter 2 I begin with an epistemological enquiry of different ways of

knowing pain. This does not cover every aspect of chronic pain; however, it provides the relevant background into the varied and sometimes contested ways of knowing pain. In Chapter 3, I present a hermeneutic literature review of self-management of chronic pain from an interpretive stance. In Chapter 4, I set out the rationale for my chosen research methods and the methodological principles that guided the empirical work, including a summary of my research questions, aims and objectives. I then present my findings across four chapters, starting with an overview of an anonymised case within which the work was situated in Chapter 5; multiple ontologies of pain in Chapter 6; socio-material entanglements and assemblages involved in how people live with chronic pain in Chapter 7; and how policy contributes to and potentially sustains various discourses on self-management of chronic pain in Chapter 8. I conclude my thesis in Chapter 9 with a summary of my findings and my contribution to knowledge and practice on self-management of chronic pain.

Chapter 2: Knowing pain: An epistemological inquiry

2.1 Introduction

Pain is a common and often burdensome condition of being human. Though common, it is understood, described, interpreted, and experienced in many different ways. People generally describe painful events as unpleasant and aversive (Wall, 2000). There are exceptions, with a small number of people demonstrating a congenital inability to feel pain (Daneshjou et al., 2012) and some individuals who find pain pleasurable in certain circumstances (Dunkley et al., 2020). Pain can be experienced bodily, emotionally, or both and the wider context in which it is experienced matters. One common way of understanding pain is that it is a symptom of underlying disease, a warning of damage within the body. This biomedical framing best explains short term or acute pain which tends to resolve as the healing and repair of injured tissue takes place. There remain many instances in which the aetiology (i.e., the cause of pain) is opaque through a biomedical lens and the interpretation of causality is more complex.

My interest in this chapter is on *chronic* pain, which is pain that persists beyond expected healing times or when no identifiable pathology to explain the pain can be found (Merskey & Bogduk, 1994). I begin by outlining why chronic pain matters and the different lenses through which this common condition is understood. I then discuss how different epistemological understandings shape common health care practices for treating and managing chronic pain.

Chronic pain is subject to multiple interpretations which can lead to uncertainty, tension, and paradoxes in terms of how pain is managed (Costa et al., 2022). Adopting an approach deliberately oriented to unveiling and describing the breadth of this confusing landscape, I seek to illuminate the range and source of varied epistemological accounts of chronic pain. This is not meant to be an exhaustive reading of the pain literature, but rather a summary of the main perspectives relevant to understanding the self-management of chronic pain (my main focus) and to allow the reader to orient themselves to the rest of the thesis. All my sources were published in English predisposing a bias towards knowledge practices in Western high-income countries thus reflecting Western cultural perspectives. As a result, the epistemological distinctions I outline may not reflect practices outside this context.

2.2 Impact of pain

Chronic pain, sometimes referred to as persistent pain, is a contested condition affecting approximately 28 million adults in the UK (Fayaz et al., 2016). It is a global concern with epidemiological data suggesting a prevalence of 19% amongst adults across Europe (Breivik et al., 2006) and similar figures for Australia (Blyth et al., 2001). Data for the prevalence of chronic pain in low and middle-income countries is lacking though proxy measures of diseases associated with painful sequalae indicate that the burden is potentially high (International Association for the Study of Pain, 2004). Chronic pain conditions including low back and neck pain make a significant contribution to the overall global burden of disease, with low back pain being the 7th leading cause of disability adjusted life years (the number of years lost to ill-health, disability or early death) (Kyu et al., 2018). The impact of chronic pain is unequally distributed across the population. Older age, female gender, low

socioeconomic status, poor education, poor health, employment disadvantage, experiencing homelessness and surviving torture are all associated with higher rates of chronic pain (Blyth et al., 2001; Craig et al., 2020; van Hecke et al., 2013). Younger adults with chronic pain report high levels of interference with daily activities which in the working age population has a negative impact on the wider economy (Blyth et al., 2001). The cumulative cost of illness due to chronic pain has been estimated to be between 2%-10% of GDP in higher income countries (Azevedo et al., 2016; Mayer et al., 2019; Phillips, 2009) conferring significant economic burden on society.

From a biomedical perspective, chronic pain is usually defined as pain that persists or recurs for longer than three months beyond the time expected for any tissue damage to heal (Merskey & Bogduk, 1994). It is associated with significant emotional distress and poor functioning, often exacerbated by the absence of an explanatory diagnosis or by the presence of conflicting ones (Breivik et al., 2006; Bridges, 2012; Deyo & Phillips, 1996). Health care provision is often structured around the presumed *cause* of pain, which then shapes diagnosis and treatment, but this can be problematic when the cause of pain is unknown, contested or multifactorial (Deyo & Phillips, 1996). Disease specific explanations lead to a focus on treating known underlying pathologies e.g., pharmacological agents for rheumatoid arthritis (Lee, 2013), whilst more psychologically oriented explanations favour talking therapies, such as cognitive behavioural therapy (CBT) (Jensen, 2011). Other perspectives exist. For instance, a mechanism-based approach, grounded in cognitive neuroscience assumes that underlying physiological processes such as neuro-inflammation contribute to the pain experience informing treatments targeted at tackling these processes

(Woolf, 2011). There is also growing interest in the role of social factors in the aetiology of pain (Karos et al., 2019), including history of abuse, trauma, or persistent hardship (Eccleston, 2015; Kirkengen, 2001). It is unclear to what extent current services pay attention to such perspectives.

2.3 Biomedical theories of pain

Biomedical interpretations of pain remain the most common in health care. On the whole, these interpretations are helpful in understanding acute pain. According to the most widely used classification system from the International Association for the Study of Pain (Smith et al., 2019), *acute* pain is that which has been experienced for less than three months and is associated with known pathology or insult to body tissues (such as infection, broken bones, sprains and other injuries). In these instances, pain is generally considered to be a reliable marker of damage to body tissues, a symptom of underlying dysfunction. Inflammatory responses at a molecular level associated with cellular healing and repair, interact with the body's immune, endocrine, and nervous systems and lead to the conscious experience of pain (Watkins & Maier, 2000; Woolf, 2011). This account of pain is oriented towards motivating the person who is suffering pain to change their behaviour and seek help, to address the insult to the body. It invites pharmacological management of pain using medicines such as non-steroidal anti-inflammatory drugs, opioids and other analgesic medicines. The active ingredients in these medicines work on different parts of the pain 'pathway' thus influencing the pain experience (McQuay, 2008).

At the anatomical, bodily level, rather than the molecular level, the biomedical logic focuses on supporting the healing and repair of disrupted tissues via surgical approaches, wound healing techniques and rehabilitation back to function and independence. In these scenarios, *acute* pain is expected to subside as the tissues undergo the physiological processes of healing. At a molecular level, the biomedical logic frames disease and illness as being caused by the presence of pathogens that can lead to pain, such as with infections. These are treated using antimicrobial agents such as antibiotics, antiviral and antifungal agents. A reduction in colonies of pathogen species is expected to lead to improvements in pain and other symptoms. Pharmacological agents with molecular and cellular targets have proved invaluable in treating autoimmune disorders, where a person's own immune response malfunctions and begins to attack bodily tissues. In all these examples, historically, pain is explained by the so-called specificity theory which co-locates pain and injury in the body via neural systems that form a pain pathway (Melzack & Wall, 1965).

There are numerous circumstances that highlight the limits of this theory and point to its explanatory potential as partial. For example, the absence of pain in the presence of observable tissue damage, pain in the absence of body tissue (e.g., phantom limb pain), pain in the absence of demonstrable tissue damage and pain that is disproportionate to tissue damage (e.g., poor correlation between experience of pain and imaging findings). Overreliance on biomedical theory can lead clinicians to disbelieve people describing these pain presentations (Doebl et al., 2020). As a result, there is the risk of pain (and the person experiencing it) being dismissed, assumed 'untreatable' (Gjesdal et al., 2018).

2.4 The Biopsychosocial model of pain

In 1977 George Engel, a psychiatrist, proposed the 'biopsychosocial' (BPS) model (Engel, 1977). He outlined how the biomedical model did not adequately explain mental health conditions. In response to calls for psychiatry to cleave itself completely from medicine, he argued that incorporating psychological and social understanding to existing biomedical framings had the potential to enhance care, not only in psychiatry, but also across medicine. This expanded view of health, illness and disease offered a framework for integrating different approaches to more complex clinical presentations and address dominant Cartesian mind-body dualism[2].

The BPS model has been adopted as the main conceptual framing for thinking about pain, particularly chronic pain that escapes orthodox biomedical explanations. It provides the rationale for the practice of pain management that purportedly incorporates psychological and social perspectives within its remit (Gatchel et al., 2007). Multidisciplinary pain management teams, long considered the ideal professional configuration to deliver modern pain care, subscribe to the BPS model and their collective interventions are broadly expected to fit this frame.

Nevertheless, even within the BPS model, dominant explanations of pain and pathways to pain are rooted in neurophysiological understandings as described earlier. Emotional

[2] Renés Descartes was an 17th century philosopher who theorised that 1) the body was a machine; 2) the mind controlled the body; 3) the mind and body were separate; and 4) the subjective mind acted on the objective body. These ideas (commonly referred to as 'mind-body' dualism) have prevailed and continue to inform many forms of modern biomedical thinking (Searle, 2004).

distress that is associated with increased pain, for example, is often explained as the impact of higher centres within the central nervous system (the brain) acting on spinal and peripheral neurones via descending modulation processes leading to increased nociceptor (so-called danger sensing neurones) activity and subsequent painful experiences (Ossipov et al., 2014). More recent critical observations of the BPS have argued that Engel's original proposal did not provide sufficient theoretical considerations, sustained dualistic modes of thinking, and failed to offer practical solutions as to how to address the 'tri-factors' (Stilwell & Harman, 2019). Though Engel argued against a pure biomedical model and for a rejection of Cartesian dualism, he did not situate his own thinking within any particular ontology. This omission has resulted in different and often fragmented interpretations of the biopsychosocial model. Practitioners of different disciplines delivering pain care have embraced specific constructs (or combination of constructs) that resonate most closely with their discipline with the result that care delivery can become fragmented with some practitioners focussing on 'bio' or 'psycho' rather than on their integration (Mescouto et al., 2020). The widespread omission of the 'social' in considering interventions for chronic pain has been suggested as a reason for the failure of the BPS model as applied to chronic pain. Critics argue that pain is relational and that the relational, socially-networked aspects of pain as experienced by humans in their capacity as connected individuals has been underexplored (Karos, 2017). Despite these criticisms, the BPS model remains the dominant discourse embedded within organisational approaches to chronic pain management.

2.5 Subjective perspectives of pain

The perspectives I have presented thus far position the person experiencing chronic pain largely from the point of view of clinicians and scientists making sense of the subjective phenomenon via assessment and measurement. The resultant explanations tend not to prioritise experiential perspectives and speak to particular forms of 'management'. Subjective approaches recognise personal accounts of pain as a legitimate and valid way of understanding pain, especially in the absence of known biomarkers or standardised objective measures to indicate its presence or absence. McCaffery, an early pioneer of pain management in nursing stated that "pain is whatever the experiencing person says it is, existing whenever and wherever the person says it does" (1968).

The subjective nature of pain has been a point of professional debate. On the one hand, a biomedical understanding of pain with structural-pathological assumptions suggests that pain can be co-located with objective tissue damage and therefore measured against the same. On the other hand, there are no known objective biomarkers for pain as it is a wholly subjective experience and reports of pain can be at odds with biomedical assumptions that privilege 'known' markers. There have been numerous efforts to create observable and measurable (i.e., 'manageable') objectivity out of the subjective experience of pain. These range from the use of numerical and visual pain scales that purportedly quantify pain intensity (Levy et al., 2018a), questionnaires to evaluate psychological variables and their impact on pain (Gatchel et al., 2007) and biological correlates of the pain experience (Denk et al., 2014). Pain intensity scales and psychometric questionnaires have been embedded in both research and practice as a way of evaluating the outcomes of existing and new

treatment approaches (Dworkin et al., 2005). Basic pain scientists continue to identify and characterise biomarkers related to pain syndromes with the hope of developing new therapeutic agents (e.g., Iannuccelli et al., 2022). Critics have argued that the uncritical use of these measures is imperfect and that they (these measures) support and embed thinking about pain as being a singular, universal experience that can only be understood in reductionist terms (McCaffery, 1968). This contrasts with that the view of chronic pain as emerging in a context and always subject to interpretation.

First person accounts of pain, told from the perspective of those living with pain are rarely found in the clinical academic literature. First person accounts often highlight discrepancies between so-called objective findings and lived experience, with stories of pain referring both to the absence of tissue damage (see e.g. Greenhalgh, 2001) and to no pain in the presence of significant tissue trauma (Bonica, 1979). In first person accounts, pain does not follow the patterns and rules of standard biomedical practice which rely on making sense of phenomena (illness and disease) through biology and physiology. Instead, accounts offer an alternative perspective from those experiencing pain. In the book, *Giving up the Ghost*, Hilary Mantel (2009) provides an autobiographical account of her making sense of debilitating and unexplained physical pain and other symptoms through a spiritual lens that includes meanings drawn from her religious catholic upbringing. Tim Parks (2011) draws on language, travel, art and meditation to make sense of pelvic pain that had also been deemed to have no biomedical explanation. Both these accounts are evocative and portray aspects of the richly lived experience of pain rarely captured in academic literature. Both Mantel and Parks are accomplished authors who turned their literary talents to articulate,

through prose, what has been described as “the inexpressibility of physical pain” (Scarry, 1985, 3).

A small but growing academic literature has focused on subjective experiences of pain often drawing on interdisciplinary social science and the humanities. Elaine Scarry’s book, *The Body in Pain* is an extensive exposition of pain covering literary, philosophical, political, medical, and religious languages used to describe it. Other similar books from different academic disciplines include David Morris’s (1991) early work exploring culture and pain, challenging purely biomedical understandings of pain; Joanna Bourke’s historical investigation of pain and its meaning from the eighteenth century onwards (2014); and Drew Leder’s (1990) phenomenological philosophy critique of Cartesian dualism as a position that neglects important aspects of embodiment.

Scholars have also written of their own experiences of pain (as its own condition or as a component of other illnesses) offering a rich picture of the lived reality of pain and challenging accepted biomedical approaches and thinking. For example, philosopher Havi Carel (2013) wrote about her experience of being diagnosed with a chronic lung condition, advocating for a phenomenological approach to illness as distinct from the biological body where most of her care was directed. Other scholars have advocated for the incorporation of illness narratives into health care, arguing that narratives provide unique insights into lived experience that cannot otherwise be appreciated (e.g., Frank, 2013; Kleinman, 1988).

Grounded in health services research, literature reporting on researchers' analyses of the experiences of living with pain, are increasingly common in the academic literature (Aymerich et al., 2022; Ryan et al., 2020; Toye et al., 2021; Toye et al., 2017). Most of these have focussed on highlighting broadly negative experiences of people living with chronic pain, particularly as they navigate and try to access health care (pain management). A meta-ethnographic review synthesising a selection of qualitative research on experiences of living with chronic pain, concluded that hearing a patient's story and validating the illness experience is necessary in order to counter the usually adversarial nature of health care encounters (Toye et al., 2017). There are fewer instances of people living *well* with chronic pain, but the available literature has focussed on individual capacity and capability (such as flexibly persisting with occupational tasks) as being supportive of living well in the presence of pain (Lennox Thompson et al., 2019). A recent qualitative synthesis has demonstrated that social and relational factors are important alongside individual ones (Toye et al., 2021).

Attending to patient stories, their biographical narratives, may offer more insight into both causality and lived experience (Anjum et al., 2020; Kirkengen, 2018) .These more subjective ways of knowing pain take multiple perspectives into account including lived experience, as well as socio-cultural, political, and historical perspectives.

2.6 Contemporary approaches to delivering clinical pain care

The different approaches to framing the nature of chronic pain outlined above underscore varying disciplinary lenses through which chronic pain is viewed and how clinical pain care is delivered. Different disciplinary perspectives broadly align with one or more of the three

approaches but not exclusively. To better understand how these approaches are enacted in terms of the clinical interventions offered, I focus on three areas: pain treatment, pain management and pain rehabilitation. The terms are used interchangeably in research and in practice, often with little effort to clarify their meaning. None of the descriptors or characteristics are distinct and therefore the professional and disciplinary perspectives I describe will move across boundaries and there will be exceptions to examples provided. I explored how the three ways of knowing pain, align with broad clinical and disciplinary perspectives, epistemic positions, and underlying models of pain. I illustrate this broader mapping of positions that has informed my review and analysis in appendix 1 for reference. My focus here is on the practice-based arrangements in which these perspectives play out and the knowledges that they typically draw on.

2.6.1 Pain treatment: biomedical approaches

The speciality of pain medicine developed in the 1950s, in part as a counter to disease- and injury-focussed interpretations of pain. The focus moved to *treating* pain with analgesics and not just treating the underlying cause. This movement was accelerated by innovation in analgesic drug development. Though the initial target for this analgesic 'turn' was post-surgical *acute* pain, proponents recognised that there were underserved groups of patients living with unrelieved pain from common longstanding conditions such as chronic low back pain. John Bonica (an anaesthetist in the USA who lived with pain following a long history of wrestling injuries) recognised the benefits of approaching pain from a multidisciplinary perspective and pioneered (with others) the first iterations of the modern pain clinic (Bonica, 1979). These clinics gathered different medical and rehabilitation specialities

together to offer multimodal treatments in attempts to resolve what they called the ‘‘puzzle of pain’’ (Bonica, 1979, 204). Technical developments in pain medicine have brought about a proliferation of treatments such as injections and infusions of local anaesthetics and steroids, minimally invasive surgical interventions targeted at the structures of the peripheral and central nervous system and the availability of different classes of analgesic drugs (McQuay, 2008).

This model of the pain clinic has evolved, and since the 1990’s includes non-medical professionals (e.g., physiotherapy , psychology, and occupational therapy) in recognition that pain is more complex and approaches beyond a purely biomedical perspective may be helpful (Harding & Williams, 1995; Lewis et al., 2019). However, the biomedically aligned pain clinic continues to dominate in many places (see e.g., Price et al., 2019).

From a biomedical perspective, fields of practice that place high value on a structural-pathological causal explanation of pain tend to shape their interventions and target their treatments to the presumed dysfunctional anatomical or physiological processes within the human body. Here, the underlying assumption is that pain is a sensation produced by the body in response to identifiable damage or injury. Disciplines working with these assumptions are broadly aligned with an empiricist epistemic position where objective observation is given credence over subjective experience. The approach has success within many biomedical fields particularly when the focus is on acute pain e.g., orthopaedics. The assumption is that repair of the offending injury or subsequent resolution and healing of the underlying *causal* process allows the body to heal and revert to normal. From this

perspective, pain is understood to be an accurate indicator of the state of the tissues that will resolve as the body repairs and recovers.

The modern pain clinic rose out of the recognition that some pain presentations could be influenced by the application of pharmacological agents in novel ways (e.g., by nerve root injections and epidurals). Increasingly, accepted forms of evidence do not support these approaches (see e.g., National Institute for Health and Care Excellence, 2021) and as such practitioners who continue to advocate them typically either work to subvert the system or practice outside of it. I revisit this point in more detail in Chapter 8.

2.6.1.1 Unintended consequences of biomedical pain treatment

In 1986 the World Health Organisation (WHO) developed the analgesic pain ladder in response to concerns that pain was being undertreated, leading to unnecessary human suffering. The ladder guides prescribers to offer stronger medication classes with increasing reports of pain intensity, starting with paracetamol and non-steroidal anti-inflammatory drugs for mild to moderate pain and rising to opioids for more severe pain. This model worked well for acute pain that broadly followed a clear trajectory as expected for tissue healing and repair, but was problematic when applied to chronic pain with its unclear aetiology and varied trajectory (Ballantyne et al., 2016). It is now generally accepted that opioids are not effective for treating chronic pain and this class of drugs is associated with potential harms including risk of tolerance, dependence and addiction as well as higher mortality from accidental overdoses (Vowles et al., 2015). The risks associated with the use of high dose opioids were known at the time the ladder was introduced but were accepted

in selected instances like end-of-life cancer care. With prolonged use in chronic pain conditions, the negative effects are increasingly visible most evidently in the ongoing opioid crisis in some regions of the USA but also increasingly recognised in the UK (Curtis et al., 2019) [3].

Along with opioids, other classes of drugs used for pain relief (benzodiazepines, anti-epileptics and antidepressants) have been identified as susceptible to illicit supply and diversion and carry risks of tolerance and dependence (Advisory Council on the Misuse of Drugs, 2016). I have highlighted the unforeseen consequences of the pharmacological management of chronic pain which have led to ongoing attempts to limit their use. However, in the absence of other acceptable treatment options, prescribers often continue prescribing these medicines (Mordecai et al., 2018a).

2.6.2 Pain treatment: neuroscientific perspectives

A further perspective developed in response to dominant disease-orientated specificity explanations of chronic pain, was that of Patrick Wall and Ronald Melzack. A neuroscientist and psychologist by background, they found that, on a physiological level, different classes of neurons responded to varying stimuli and that the eventual response (dependent on the dose of stimulus received) could also be modulated up and down depending on peripheral stimuli and centrally driven processes, such as cognition and emotional components. They set out the gate control theory of pain (Melzack & Wall, 1965), arguing that the neural

[3] Precipitated by aggressive marketing by the pharmaceutical industry which created a market for opioids, altered prescribing practices and generated dependency across communities. In reaction, a blunt regulatory response to restrict prescriptions generated a market for illicit drugs (Humphreys et al., 2022; Levy et al., 2020; Mordecai et al., 2018a).

pathways within the nervous system were important in both detecting 'noxious' (potentially dangerous) stimuli and in modulating the responses to potentially pain producing experiences. Their work sought to explain issues such as suffering using neurobiological explanations, arguing that pain was more than just the response to a specific injury or insult. They also proposed a biological explanation for how non-painful stimuli e.g., touch, could potentially dampen the pain experience.

This seminal work heralded a shift away from understanding pain as a symptom to the inclusion of psycho-social perspectives (albeit through biological pathways) and opening the field to multidisciplinary perspectives and the emergence of pain neuroscience. This work has since been taken up by specialist neuroscientific groups, each viewing pain through their own lens. Cognitive neuroscientists have focussed on identifying and characterising the areas of the brain involved in pain processing (e.g., Denk et al., 2014), molecular biologists on the individual molecules and receptors that support transmission and signalling (e.g., Latremoliere & Woolf, 2009) and physiologists on further explorations of the neural architecture involved in pain perception (e.g., Apkarian, 2011). Broadly, this body of work has been criticised for being too reductionist with its ever narrowing focus on neural substrates of pain in the body at the expense of richer explorations of pain as an embodied human experience (Thacker, 2015). To date advances in pain neuroscience have so far failed to yield newer or more effective therapeutics or medicines (Tabor et al., 2017).

Clinically, neuroscientific perspectives have been adopted by different professional disciplines as part of education interventions purported to provide more scientific (hence

more valid) explanations for otherwise 'invisible' pains. Growing in popularity since 2003, so-called 'explain pain' interventions are now a common addition to pain treatment interventions with varied reports of effectiveness (Lee et al., 2016; Malfliet et al., 2018; Moseley & Butler, 2015). The explanations have also been distilled into patient and public facing literature (Mosley & Butler, 2017) and built in to new technological interventions for pain (Machado et al., 2016; MacPherson et al., 2022), arguably further embedding biomedical theories into pain treatment. More recent evaluations of the pain education approach have cast doubt on its widespread adoption, including in practice guidelines for preventing chronic pain (Traeger et al., 2019).

2.6.3 Pain management: multidisciplinary approaches

Services and clinicians that focus on 'pain management' generally aim to support patients in living well despite pain, especially when prior approaches have been unhelpful (Nicholas, 2004). First described in the 1970s by clinical psychologist Wilbert Fordyce, these services tend to include multi-professional and multidisciplinary teams offering their unique perspectives to the task of supporting pain management from a behavioural perspective (Butler, 2017). Thus, pain management is used both as a descriptor of the interventions offered and as the desired outcome. Pain management programmes are group programmes delivered by health care professionals with the aim of supporting patients to develop behavioural coping skills and strategies that allow them to live well, with low levels of disability, despite ongoing pain regardless of presumed cause (Lewis et al., 2019).

Since their inception in the 1970s, multidisciplinary pain management programmes have been delivered mainly by physiotherapists and clinical or health psychologists with varied involvement from medicine, nursing, occupational therapy, and pharmacy (Gatchel et al., 2007; Hill, 2016; Lewis et al., 2019). Reference to pain management programmes as combined physical and psychological programmes reflects this trend (National Institute for Health and Care Excellence, 2021). Health care professionals with no formal psychology training often describe their work with chronic pain as being psychologically informed, meaning that the skills and knowledge inherent in working in these programmes are informed by psychological ways of thinking (Harding & Williams, 1995). Specialist physiotherapists working in pain management services and programmes have demonstrated close alignment with the competencies, skills and knowledge required to work within a cognitive behavioural therapy model (see e.g., Denneny et al., 2020).

The affinity to behavioural psychology and behavioural medicine in pain management is reflected in the academic research in this field (see e.g., Linton et al., 2018). Research grounded in experimental and health psychology that aligns with a positivist paradigm contributes to a large volume of evidence in the field of pain management (McCracken & Vowles, 2014; Williams et al., 2020). Psycho-social constructs are identified and evaluated through numerical measures which supposedly capture and distil subjective experience in an objective form with, for instance, questionnaires, patient reported outcomes and surveys of pain intensity used as a proxy for the subjective and personalised nature of pain. Once quantified, the numerical data can be analysed statistically with findings generalised to more heterogeneous populations to demonstrate effectiveness (or lack of effectiveness) of

the iterations of treatment. Practitioners are encouraged to remain, in research terms, as close to the research conditions (usually randomised controlled trials) where efficacy was demonstrated, so-called fidelity to the intervention (McCracken & Vowles, 2014). It has been argued that the utility of these multidisciplinary approaches across wider populations is limited "since efficacy has mainly been shown among upper-middle class patients in English-speaking countries and in controlled studies, with expert professionals guiding the intervention and with a limited number of domains of painful experience evaluated" (Cano-García et al., 2017, 1).

To counter apparent reinforcement of mind-body dualism in pain management, some clinical and health psychologists researching in pain have proposed that both researchers and practitioners should incorporate more embodied theories, which acknowledge that human experiences occur in and through the corporeal body (Eccleston, 2015). Other disciplinary perspectives that consider embodied experience have explored pain beyond the dualist Cartesian thinking, and in the context of pain rehabilitation. I turn to these below.

2.6.4 Pain rehabilitation approaches

Rehabilitation is a philosophy of care constituting multiple interventions, grounded in the biopsychosocial model, delivered by multidisciplinary teams adopting a relatively flat hierarchy, tasked with supporting patients with long term conditions to achieve valued goals (Wade, 2020). It has common features with multidisciplinary pain management. For example early iterations of pain management included significant movement and exercise components alongside cognitive behavioural approaches, thus attending to both the mind

and the body (Harding & Williams, 1995). Recent descriptions of the constitutive components of pain management programmes indicate a decreased emphasis on regaining physical function and more focus on individual behaviour change via cognitive approaches (Flink et al., 2020). Furthermore, contemporary approaches to multidisciplinary pain management rarely attend to relational and contextual concerns associated with a human experience of living with pain (Stilwell & Harman, 2019).

Rather than adopting the dominant behavioural psychological paradigm adopted in pain management, rehabilitation interventions for other health conditions include broad psychological support, exercise for functional improvement in tasks as well as physiological capacity, education, disease management and self-management (Wade, 2020; Wade & Halligan, 2017). In principle, these rehabilitation orientated pathways account for variance in diagnoses, environments, service settings, individual patient variability and complex inter-subjective relationships. In doing so, the intention is to enable embodied practices that attempt to overcome mind-body dualism. Practitioners drawn from various disciplines and interested in working with biographical complexity and inter-subjectivity have adopted this rehabilitative focus to support patients living with chronic pain and other so-called medically unexplained symptoms (see e.g., Gilmour et al., 2020; Stilwell & Harman, 2019).

A small but growing literature supports a shift to other holistic rehabilitation approaches for chronic pain. Drawn from the social sciences, philosophy, public health, and cognitive neuroscience, it offers an alternative to the dominant approaches discussed above that, on the whole, do not account for the role of structural societal issues in chronic pain. Scholars

in these disciplines have argued against the continued dominance of dualistic biomedical thinking, and called for more focus on phenomenology, meaning and narrative in both conceptualising and addressing chronic pain (Bendelow & Williams, 1995). More recently, Zajacova and colleagues (2021) highlighted the role of structural influences on prevalence of chronic pain, proposing that the increased incidence of pain and pain-related disability reflected political and economic forces such as retrenchment of the welfare state and wider inequalities. Cognitive scientists have argued against the continued dominance of brain-focussed theories of cognition and perception, calling for a more embodied understanding that emphasises the action/s of bodies interacting with and in their environments (Gallagher, 2017; Stilwell & Harman, 2019). Predictive processing models have also accounted for the role of the environment in creating sensations and influencing perceptions such as vision and pain, thus challenging biomedicine's core tenet that pain is produced only because of tissue damage or pathological insult (Edwards et al., 2012; Tabor et al., 2017). These theories all offer different ways of thinking about pain as emergent and influenced by environmental, political, and relational factors.

2.7 Conclusion

In this chapter I have demonstrated the multiple epistemological assumptions underpinning thinking about pain and, following from that, about health care for those living with pain. These assumptions shape both how and why pain 'management' is thought about and presented then acted upon in practice and in policy. My focus has largely been on delineation across the different clinical professions involved and the varied disciplinary lenses they adopt in relation to pain. I expand on this in my findings (Chapter 6, pain

ontologies), turning to the more philosophical components underpinning different ways of thinking about and delivering pain care.

In sum, the different epistemological lenses that I have set out in this chapter, regarding how pain is known, present contested and messy knowledge and practice worlds. The orientation in clinical practice and research is nevertheless towards a 'singular' pain (different lenses to the 'same' phenomenon) or different way of knowing and therefore doing. In the next chapter I turn to review how different ways of knowing and supporting people living with pain relates to self-management of chronic pain.

Chapter 3: Self-management of chronic pain: a hermeneutic literature review

3.1 Introduction

In Chapter 2, I structured my review of the literature around an epistemological inquiry of chronic pain. I highlighted how differences in the ways that chronic pain is known affects how services for people living with chronic pain are conceptualised in policy and delivered in practice. One intervention that is frequently offered for chronic pain is '*self-management*'. The literature reporting self-management of chronic pain is large and diverse and incorporates widely disparate assumptions regarding what self-management *is*, and how it is understood and enacted. In this chapter, I present a brief overview of self-management in the context of chronic illness and its relevance to chronic pain. I explain my rationale for conducting a hermeneutic literature review and present my methods and findings. As well as providing more detail on how self-management discourse and storylines unfold in the literature, I summarise the paradigms and research traditions that researchers have adopted in this field. Finally, I discuss the assumptions and tensions that I have identified through the review and consider what these might mean for studying self-management of chronic pain.

3.2 Self-management of chronic illness

There are several descriptions of self-management in the academic literature. One of the most widely referenced is the Chronic Disease Self-Management Programme (CDSMP), a community-based group programme in the United States (US) providing self-management

education (Lorig & Holman, 1993; Lorig et al., 2010; Lorig et al., 1993). The programme focuses on improving individuals' coping skills and is underpinned by behaviour change theories – the thinking is that behaviours contribute to illness and disease, that they are easier to change than complex social circumstances or genetic predispositions and that defined behaviours (e.g., increased physical activity) are the endpoint of behavioural interventions (Michie & Johnston, 2012).

Evaluation of the CDSMP in the US has demonstrated improvements in self-efficacy, health status and health behaviours in people living with arthritis, stroke, and diabetes (Lorig et al., 2001; Wright et al., 2003). When transferred to the UK context, the outcomes for a range of chronic conditions were more modest with only small changes in self-efficacy and the use of cognitive behaviour therapy (Wright et al., 2003). Despite these outcomes, the Expert Patient Programme (EPP) in the UK was modelled on the CDSMP and offered to different groups of people with chronic conditions like diabetes and arthritis. Evaluation of the EPP showed that participation did not lead to the same type of improvements in health outcomes as the CDSMP. Looking beyond individual behaviour change issues, the differences in improvement were attributed to lack of engagement by the implementation team with patients and staff, failure to consider low health literacy or culturally patterned behaviours, lack of attention to the need for social support and a fragmented approach to the provision of health and social care (Greenhalgh, 2009; Kennedy et al., 2007). In short, there was more to consider when thinking about self-management programmes other than efficacy of behaviour change.

Self-management forms a cornerstone of UK health policy (Department of Health, 2001, 2005a, b, 2012; NHS England, 2014, 2019a), and is recommended as part of the overall management of many long-term conditions. The emphasis on self-management can be traced back to the NHS Plan published in 2000, which included a commitment to "*provide information services and support to individuals in relation to health promotion, disease prevention, self-care, rehabilitation and after care*" (Department of Health, 2000, 3). This commitment has been reinforced in subsequent policy. For example in 2007 the NHS and Social Care Long Term Conditions Model highlighted self-management as integral to improving services for people with long term conditions (Department of Health, 2005b). In 2014, the Five Year Forward View included an explicit goal to empower patients by investing in group-based education (NHS England, 2014). More recently, the NHS Long Term Plan (NHS England, 2019a) extended the commitment to self-management. None of these documents provide a definition of self-care or self-management. I explore the reasons for this, and policy perspectives of self-management of chronic pain more generally, in Chapter 8.

3.3 Methodological approach

I conducted a hermeneutic review with the aim of interrogating assumptions associated with self-management of chronic pain and bringing a different perspective to how meaning (and use) of self-management was constructed in the literature.

I came to hermeneutic review having first identified several reviews synthesising the literature on self-management of chronic pain from systematic reviews (Carnes et al., 2012;

Du & Yuan, 2010; Du et al., 2011; Miles et al., 2011), qualitative systematic reviews (Devan et al., 2018) and critical reviews (Jensen et al., 2003). I quickly realised that none of these attempted to unpack and explain underlying assumptions or meanings of self-management. Instead, they often reproduced the existing assumptions and descriptors of self-management held by the original study authors. As a result, it is unclear from the academic literature how self-management of chronic pain is understood, how it is delivered and who benefits from different forms of delivery.

I therefore sought to examine the key storylines around self-management of chronic pain in policy and in the literature asking; How is self-management of chronic pain characterised in the academic literature? And what kind of knowledge assumptions and research paradigms seem to lead to these characterisations of chronic pain assumptions? My focus was on developing a deep understanding of self-management of chronic pain, synthesising findings from studies on self-management of chronic pain from varied research traditions and tracing the use of the term 'self-management' of chronic pain and how it has been conceptualised in the academic literature and encoded into textual form.

A principle of the hermeneutic approach is to shift and move understanding through dialogic exchange (Boell & Cecez-Kecmanovic, 2014; McCaffrey et al., 2022). To achieve this, I applied Boell and Cecez-Kecmanovic's (2014) hermeneutic framework to my search and interpretive synthesis of the academic literature. Their framework consists of two interlinked hermeneutic circles with the first focussing on searching and acquisition of texts and the second on constructing new arguments through analysis and interpretation (see

Figure 1). Guided by this process, my review involved repeated and overlapping cycles of searching, sorting, selecting, and developing analysis and interpretation. As I followed this hermeneutic process, I synthesised the included papers into a table (Table 1) attending to the study populations, research paradigms stated (and my interpretation of them), self-management storylines and overall theoretical framings.

In the following sections, I provide additional detail relating to my search and acquisition of relevant literature, and analysis and interpretation. Given the iterative nature of the hermeneutic review process, rather than present this in formal sections relating to searching, reviewing, analysis and interpretation, I provide a narrative account of the overarching process that reflects the process of moving across different hermeneutic circles (Figure 1). Finally, I summarise my interpretive synthesis of the findings.

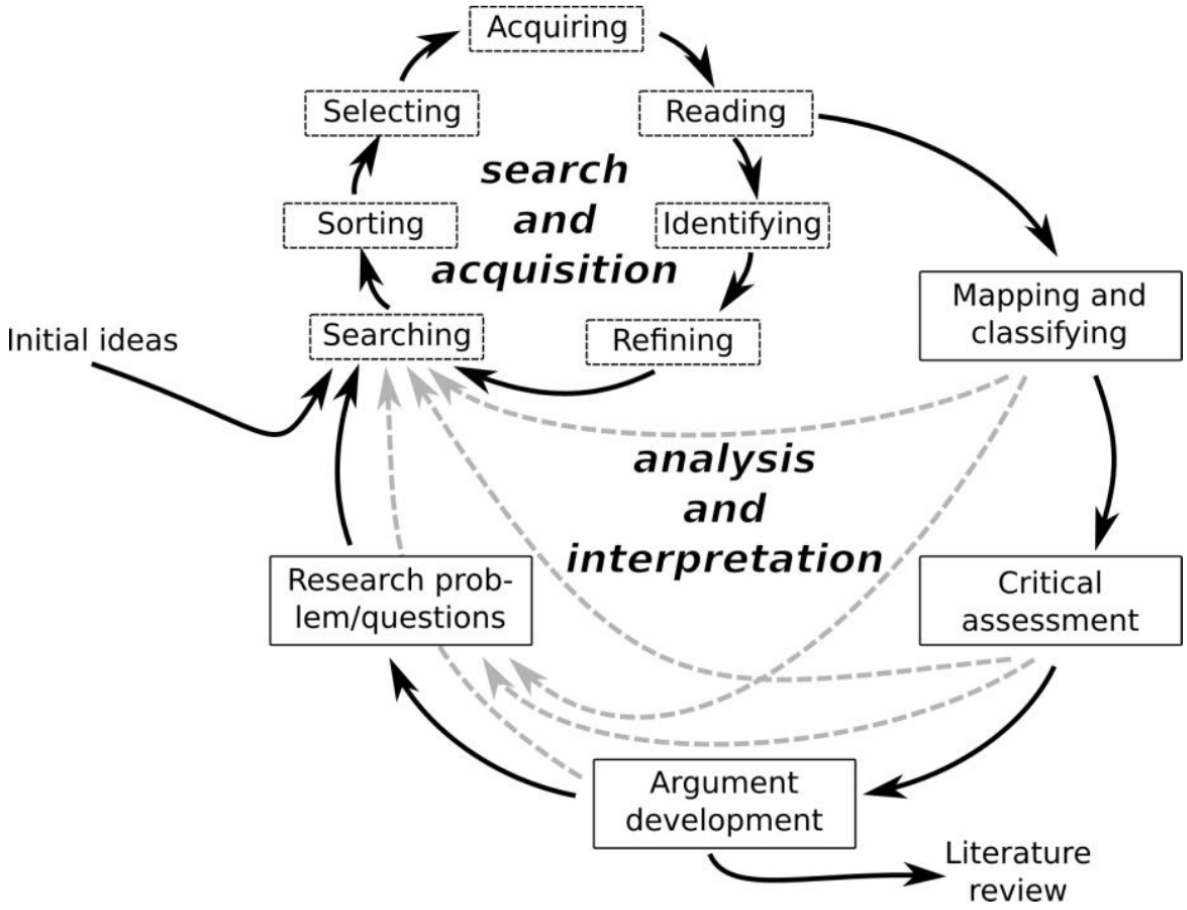


Figure 1: *Hermeneutic framework for literature review process (Boell & Cecez-Kecmanovic, 2014, 264)*[4]

3.4 Methods underpinning my hermeneutic review

I adopted a practical approach to searching for papers that would yield a workable amount of literature that I could analyse in-depth. The aim of a hermeneutic review is not to collect all of the relevant literature and summarise it, but is *"an understanding process that involves reading, critical engagement, argument development, and writing"* (Boell & Cecez-Kecmanovic, 2014, 261). In doing so, I focussed on tracing dominant understandings of self-

[4] Excerpted from A Hermeneutic Approach for Conducting Literature Reviews and Literature Searches by Boell, S. K., & Cecez-Kecmanovic, D., ©2014. Used with permission from Association for Information Systems, Atlanta, GA; 404-413-7445; www.aisnet.org. All rights reserved.

management of chronic pain. I conducted this review throughout the duration of my doctoral studies in parallel with my empirical research and writing (from October 2018 – June 2022). Starting with a few papers that I had identified in Chapter 2 which referenced self-management of chronic pain, I started citation tracking (by reviewing the reference lists and setting up alerts on Google Scholar, PubMed, CINAHL, PsycINFO and PEDro databases) and identified frequently referenced authors. I noted frequently used key words of *self-management, self-care, chronic pain, and persistent pain* used in these papers. I then searched PubMed, CINAHL, PsycINFO and PEDro databases (from October 2018 back to when their records began) using these multiple search terms. Many of the papers returned were either reviews of interventions or studies of the effectiveness of self-management.

I screened the returned titles and abstracts identifying papers that explicitly included ideas about self-management of chronic pain as their primary focus. I did not restrict the type of pain or presumed cause of pain, but rather selected papers that included self-management in the title or abstract in the first instance. I also selected papers that had multiple citations in Google scholar and PubMed (where most of the studies appeared to be indexed) as a proxy measure for importance. I continued to track citations through alert notifications and going through references of papers I had already identified both manually and electronically. I identified further papers through journal algorithm suggestions. I used EndNote reference management software to organise my review.

Boell & Cecez-Kecmanovic (2014) suggest that as well as identifying texts via the methods I have described above, that there is value in asking related stakeholders of papers they feel

have particular significance and relevance. My initial attempts to identify seminal papers through experienced clinical practitioners did not yield papers on self-management of chronic pain, but rather papers that outlined key concepts in pain management e.g. psychologically informed practice (Harding & Williams, 1995), effectiveness of interventions (Williams et al., 2012) or neurobiological explanations (Woolf, 2011). Many of these papers were resources for doing 'self-management' including books and linked websites and were not therefore included in the review but provided useful context for other elements of my research (e.g., the epistemological inquiry presented in Chapter 2).

Following initial reading and first interpretations, I filtered out papers from the same research teams reporting on the same data and those that used self-management in the key words, title or abstract, bit did not mention it again in the body of the paper, creating a data set of 34 academic papers for the first cycle.

I began by reading all the papers, familiarising myself with overall content and the different ways in which authors conceptualised and wrote about both self-management, generally and in relation to chronic pain. I then re-read the included papers, refining and re-interpreting initial ideas in context of new data from additional reading. This iterative process represents my dialogical interaction with the literature, continually interpreting, re-interpreting and casting a critical view to existing knowledge (Boell & Cecez-Kecmanovic, 2014). My analytic focus was guided by continually asking: "is this paper likely to *add meaning* to our emerging overview of the field?" (Greenhalgh et al., 2017, 2).

I worked iteratively with the 34 articles identified, using close analytic reading to identify and record relevant information about the research paradigm, study design, study population, assumptions about self-management and analytic theories or frameworks (see Table 1). I discussed initial categories with my supervisors in regular meetings and invited feedback on a series of drafts (initially descriptive, and over time more critical-analytic as my interpretations evolved). Additionally, I shared initial arguments with, and invited critique from, academic peers in departmental seminars, clinical peers in meetings and conferences, patients and the public in Patient and Public Involvement (PPI) group meetings and public presentations (McCaffrey et al., 2022). All of these discussions informed my ongoing interpretations.

At this point I noticed that many of the studies included thus far were mostly grounded in positivist paradigms and within behaviour change theory. My search strategy had not produced papers that explored self-management of chronic pain in more critical or interpretive ways. I therefore expanded the iterative search to consider papers that were more critical of the more dominant perspectives. Though not specifically referencing chronic pain, I found four social science papers (Fletcher et al., 2019; Kendall et al., 2011; Pickard & Rogers, 2012; Rogers et al., 2009) that provided more interpretive analyses of the notion of self-management of chronic pain. I included these as I further developed my analysis and argument, specifically in response to my second objective of tracing the use of the term self-management in academic literature.

I drew on Hajer's (2006) description of the storyline as a discursive construction to further focus my analysis. Storylines are *"condensed statements summarising complex narratives, used by people as 'short hand' in discussions"* (69). For example, '*self-management techniques*.' Storylines acted as a sensitising concept (suggesting directions in which to look) that informed my overall analysis and interpretation (Blumer, 1969). They reflected the perspectives that summarised and made sense of self-management of chronic pain. These storylines are continually changing and reflect the social-historical conditions in which they are used. I constructed a narrative synthesis in response to my review questions considering the theories, methods and arguments of each storyline and perspective.

***Table 1**: Overview of papers included in the hermeneutic review*

Author (s)	Research Paradigm	Study design	Study population	Self- Management storyline	Theory or framework	Citations Google Scholar
(LeFort et al., 1998)	Positivist-Behavioural Psychology	RCT 12-h Chronic Pain Self-Management Program (CPSMP) intervention group, or the 3-month wait-list control group -Psychometric questionnaires	110 Men and women over 18 with idiopathic chronic pain (3-6 months) Canada	CPSMP adapted from Lorig *Standardised,* nurse-led *psychoeducation* group programme • Complex intervention with multiple components • encourage individual participation and experimentation with various cognitive/ behavioural self-management techniques, and facilitate mutual support • low cost, resource allocation (one facilitator), alternative to inaccessible specialised pain clinics	Self-Help Model of Learned Response to Chronic Ill- ness Experience (Braden, 1990, 1993)	258
(Kerns & Rosenberg, 2000)	Positivist-Behavioural Psychology	Psychometric questionnaires before and after VA SM pain program to determine readiness to adopt a SM approach	109 chronic pain patients (4 months) USA Completers and non-completers	Self-management approach = psychological treatment • Reconceptualising pain problem as subject to personal control and mastery • Active problem solving • Modification of maladaptive and catastrophising idiosyncratic cognitions • complex intervention with multiple components • personal responsibility for pain control • engagement & adherence	Pain stages of change model	204
(Dijkstra et al., 2001)	Positivist-Behavioural Psychology	Psychometric questionnaire study assessing validity of readiness to change measure	321 patients with fibromyalgia Netherlands	Self-management = cognitive behavioural treatment • credibility of approach precondition to motivation to change • vs biomedical understandings • active in coping with their pain • control over pain • no descriptions of SM	Readiness to change model	100
(Jensen et al., 2003)	Positivist-Behavioural Psychology	Critical review: understanding motivational issues in pain coping. Research and clinical recommendations	n/a	Self-management therapies = cognitive behavioural & multi-disciplinary pain treatment • complex intervention not well defined • Altering coping behaviour and maintaining lifestyle changes • engagement and adherence • pain control • work of managing pain is done by patient • expert role in motivating patients • resistance as lack of motivation • 13 self-management behaviours listed	Preliminary motivational model of pain self-management	257

Author (s)	Research Paradigm	Study design	Study population	Self- Management storyline	Theory or framework	Citations Google Scholar
(Ersek et al., 2004)	Positivist-Behavioural Psychology	Study protocol for RCT comparing pain self-management training group intervention with education-only control condition Psychometric measures (outcomes)	273 adults over 65yrs with chronic (3 month) non-cancer pain living in retirement communities USA	Self-management = multimodal therapy • education, instruction & practice • physical and psychosocial pain coping skills • description of components of intervention • acknowledge other descriptions e.g., CBT, psycho education, educational, self-management • includes physical therapies • wellness-oriented pain management strategies • self-efficacy for managing pain • manual, relaxation tape, exercise band, hot cold packs (socio-material)	Not stated	49
(Blyth et al., 2005b)	Positivist-Epidemiology Statistics Behavioural	Population-based random digit dialling computer-assisted telephone survey Psychometric measures	474 adults with chronic pain (3 months) Australia	Self-management = strategies 'you' used to manage your pain • pre coded categories of SM • active behavioural e.g. exercise, work • active cognitive e.g. relaxation, meditation • passive behavioural e.g. diet, rest, hot packs • passive conventional medical e.g. medication, braces • active better than passive • outliers use of alternative practitioners had less disability • socioeconomic factors and context important • different from clinical best practice	Logistic regression modelling (statistics)	233
(Krein et al., 2007)	Positivist – Epidemiology Behavioural	Cross-sectional nationwide survey (VA) Psychometric measures	543 older patients, with chronic health conditions and chronic pain (6 months) USA	Self-management = exercising regularly, taking medications and, following an eating plan as recommended by doctors • self-efficacy predicts adherence • appropriate targeting important for resource constrained settings	Linear regression (statistics) Self-efficacy	74
(Ersek et al., 2008)	Positivist-Behavioural Psychology Statistical inference	RCT comparing pain self-management training group intervention with education-only control condition Psychometric measures (outcomes)	256 adults over 65yrs with chronic (3 month) non-cancer pain living in	Self-management = multimodal therapy • education, instruction & practice • physical and psychosocial pain coping skills • description of components of intervention • exercise • peer support • self-efficacy for managing pain • manual, relaxation tape, exercise band,	Not stated	109

Author (s)	Research Paradigm	Study design	Study population	Self- Management storyline	Theory or framework	Citations Google Scholar
			retirement communities USA	hot cold packs (socio-material) • Personalised • follow up calls • No difference between groups on primary outcome • SM not enough, need more support		
(Reid et al., 2008)	Positivist-Experimental Statistical inference	Review article synthesising the scientific literature on self-management strategies for pain due to musculoskeletal disorders	27 articles reporting outcomes for older adults (over 65) with chronic pain deliverable in community settings	SM holds substantial promise for pain in older adults • altering behavioural, cognitive and emotional responses to pain • education about pain • relaxation • problem solving • communication skills • delivered in community settings • yoga, massage, tai chi, music, aquatic • groups • exercise • multiple interventions described • differing efficacy • safer than medicines • low cost • community based	EBM	124
(Bair et al., 2009)	Positivist – Qualitative Behavioural Psychology	Qualitative study using focus group methodology – thematic content analysis to identify patient- perceived barriers and facilitators to self-management of chronic musculoskeletal pain.	18 adults with chronic MSK pain (3 months) comorbid depression after their participation in a RCT (6 session SM program) (USA)	SM is a treatment modality • "the ability to manage the symptoms, treatment, physical and psychosocial consequences and life-style changes inherent in living with a chronic condition" • teach skills to manage own pain • engage with providers • increase confidence • self-efficacy • make lifestyle changes • active • pain interferes with SM • not medication only • with support • barriers and facilitators identified • elements of self-management	Social cognitive theory	233
(Crowe et al., 2010)	Positivist – Qualitative Nursing (stated interpretive)	Qualitative study using semi-structured interviews	64 adults with chronic low back pain (3 months) and their health care professionals (15) (NZ)	Self-management from first person perspective • medication, exercise, heat • medical compliance with medications • low impact exercise learned from physiotherapists or peers • pacing • environmental awareness • diversional activities • getting on with it • trial and error • sceptical of biomedicine Self-management from HCP perspective • core strengthening exercises • prescribing medication	Self-agency model of self-management	112

Author (s)	Research Paradigm	Study design	Study population	Self- Management storyline	Theory or framework	Citations Google Scholar
(May, 2010)	Positivist – Epidemiology	Topical review including systematic reviews and meta-analyses	Studies on SM of OA and chronic low back pain	Self-management is essential to prevent overwhelming health services • Not offering SM is negligent • continuum from autonomous self-care to collaboration between patients and clinicians • programmes are heterogenous • small effect sizes of interventions • exercise • a philosophy • lack of congruence between pts and clinicians • changing physical activity • education • self-efficacy	EBM	101
(Du et al., 2011)	Positivist-	Systematic review and meta-analysis of SM programmes (RCT's)	Adults Chronic MSK pain (3 months)	SM or self-care • self-efficacy • self-monitoring • goal setting • decision making • problem solving • self-tailoring • partnership with hcp and patient • community based • close to home • affordable NOT biofeedback • relaxation therapies • exercise • group therapy on own	EBM Self-efficacy theory	185
(Miles et al., 2011)	Positivist- Statistical	Systematic review of RCTs to summarise evidence of predictors, mediators and moderators (sub-group analysis)	Chronic MSK pain	SM = non-pharmacological • multi-component interventions • at least 2 components • psychological (behavioural or cognitive therapy) • mind-body therapies (relaxation, meditation, or guided imagery) • physical activity (any form of exercise) • lifestyle (dietary advice and sleep management) • medical education (on medication use) • goal to improve health status or quality of life	EBM SCT Self-efficacy theory	109
(Carnes et al., 2012)	Positivist-	Systematic review and meta-analysis of RCTs to examine the effectiveness of different components within multicomponent SM courses	Adults Chronic MSK pain (3 months)	SM = structured, taught or self-taught • distinct components • aimed at patients • teaching skills • goal to improve health status or quality of life • at least 2 components • psychological (behavioural or cognitive therapy) • mind-body therapies (relaxation, meditation or guided imagery) • physical activity (any form of exercise) • lifestyle (dietary advice and sleep management) • pain education (understanding condition and medication) • expert led groups better NOT single or passive interventions	EBM Cochrane	133

Author (s)	Research Paradigm	Study design	Study population	Self- Management storyline	Theory or framework	Citations Google Scholar
(Ruehlman et al., 2012)	Positivist-Psychology	RCT evaluation of online Chronic Pain Management Programme (including SM components)	305 adults with chronic pain (USA)	SM contemporary approach • online CPMP self-directed and self-paced • education • skills and motivational strategies • self-guided symptom management supported by tech (e.g. calendar) • available for as long as needed No additional detail of SM component in program description	CBT (in part)	144
(Boyers et al., 2013)	Positivist -	Systematic review of RCTs to assess cost effectiveness of SM strategies	Older people (0ver 65) with chronic pain (3 months)	SM is cheaper than usual care • Empowering pts to take control • improve QOL • has different meanings • consensus definition • single or combined approach • minimise impact of chronic pain • home based exercise • multi-modal • supplemented/supported • cost effectiveness and cost containment vs usual care • health care usage	QALY health economics	45
(Mann et al., 2013)	Positivist – Behavioural Psychology	Review article of SM interventions in chronic pain groups	Adults with chronic pain (3 months)	SM variety of interventions • expert led • Stanford model • CBT • ACT • managing medical interventions • targets self-efficacy • manage symptoms • teaching pain management skills • separate from exercise • consistency important • individualised • referrals on	Social cognitive theory (self-efficacy) Trans theoretical model of change	58
(Nicholas et al., 2013)	Positivist – Behavioural Psychology Experimental	RCT of pain self-management group, exercise attention control and usual care	141 Adults aged over 65 with chronic pain (Australia)	SM is active not passive • CBT principles • Expert led • high dose/intensive • integration of activities/exercises and psychological skills better than exercise alone • self-monitoring • homework • goal-setting- problem solving • dealing with pain flare-ups • functional tasks • talk on medication •	CBT	118
(Kawi, 2014)	Positivist – Qualitative Nursing	Qualitative content analysis of open-ended survey questions to evaluate SM, SMS, and functional ability	110 participants with chronic low back pain (USA)	SM vs self-management support • SM taking medications and maintaining physical activity • making wise decisions • lifestyle changes • heat and cold • rest and relaxation • SMS prescribing medicines, providing	Chronic care model	41

Author (s)	Research Paradigm	Study design	Study population	Self- Management storyline	Theory or framework	Citations Google Scholar
				other treatments and encouragement • Stanford model • SMS to activate patients • decreased health costs		
(Lee et al., 2014)	Positivist -	Systematic review and consensus by subject matter experts on active self-care complementary and integrative medicine		SM can be performed by individuals on own following training • meditation/mindfulness • relaxation • biofeedback • guided imagery/self-hypnosis • autogenic training • laughter therapy, self-therapeutic touch/self-reiki, faith healing/prayer, mental healing – no papers returned • commonly used • poor evidence for making recommendations • reduced use of health care services	Patient-centred care EBM	73
(Schofield et al., 2014)	Positivist – Participatory collaboration	Collaborative lay-user review of older adults' pain self-management materials	Seven older adults with an interest in pain management and self help	SM the daily participation of patients to manage and control their symptoms • active management • minimise impact of chronic pain • single or combined approach • self-taught or expert led • definition co-produced by reviewers • books, magazines, websites, leaflets, CDs and tapes • mode design more important than content • choice and flexibility	Co-design	6
(Stewart et al., 2014)	Post positivist	Concept analysis to develop a theoretical definition of persistent pain SM	Older adults	SM has different meanings • is multidimensional process • personal development • active individuals • symptom response and symptom control • perceived need and ability to manage pain • with support from others • COMPLEX • multiple events & features • theoretical definition proposed	Rogers evolutionary model Grounded theory	23
(Keogh et al., 2015)	Positivist-Behavioural psychology	Review of behaviour change theory to promote SM	Adults with CLBP or OA	SM is a behaviour required for adherence with HCP advice • No description • references Lorig • SM is adopting behaviour change techniques	Behaviour Change Theory (BCT)	55
(Bourgault et al., 2015)	Positivist-Behavioural psychology	RCT of SM intervention in fibromyalgia	Adults with FMS	SM managing symptoms • psycho education• CBT • exercise	CBT	41
(Machado et al., 2016)	Positivist-	Systematic review of Smartphone apps for SM of LBP against NICE guidelines	LBP	SM unsupervised exercise, booklets and online education • patients being proactive to manage and monitor their own health •	EBM	81

Author (s)	Research Paradigm	Study design	Study population	Self- Management storyline	Theory or framework	Citations Google Scholar
(Pearce et al., 2016)	Positivist	Multi-stage process; MDT expert workshop; consensus exercises; systematic overview of literature • systematically extracted components, categorised into core components	969 RCTs examining 14 diverse long-term conditions	SM not sole responsibility of person • collaborative approach • on-going **support** • SM support complex, multi-faceted interventions, includes training for professionals, resources, flexible access to advice and information • patient activation	Non stated	126
(Taylor et al., 2016)	Positivist-Behavioural psychology	2 systematic reviews to inform SM course content and delivery style. Qualitative study and RCT of SM intervention delivered over 3 days	Adults with chronic MSK pain (UK)	SM is cost effective over existing pain SM programmes • Lay and HCP delivered • extensive descriptor including manual of included interventions • grounded in behavioural psychology	BCT CBT/ACT Theory of planned behaviour MRC Complex Interventions	21
(Gordon et al., 2017)	Positivist-Practice based	Qualitative study in primary care • focus groups (18) with patients and HCPs barriers and facilitators to facilitation and adoption of SM	54 patients, 38 HCPs, 9 carers	SM initially taught by HCPs or learned by an individual • to minimise impact of chronic pain • broad range of ongoing daily efforts people make to improve well-being • failure to find a cure • more than just a prescription	None	30
(Hutting et al., 2017)	Positivist-Behavioural psychology	Mixed methods evaluation of an RCT of a SM programme and e health module	31 Employees with complaints of the arm, neck or Shoulder (Netherlands)	SM not described • references Lorig and Barlow (unclear which approach is being studied) • individual behaviour change	Behaviour Change Social Cognitive Theory	11
(Devan et al., 2018)	Positivist – behavioural psychology Limited interpretation with thematic synthesis	Meta-synthesis of qualitative studies • CASP quality assessment	Adults (over 16) with chronic pain (3 months)	SM individual ability to manage • active •self-efficacy • self-monitoring • goal setting • action planning • problem solving • partnership with HCP • pacing •relaxation • cognitive behavioural strategies • counselling • ergonomic advice • enablers and barriers • collaborative with family, friends, work environment • pain as part of 'self'	Social cognitive theory CBT EBM (Cochrane)	39

Author (s)	Research Paradigm	Study design	Study population	Self- Management storyline	Theory or framework	Citations Google Scholar
(Elbers et al., 2018)	Positivist-Behavioural psychology	Systematic review and meta-analysis of RCTs comparing SM interventions with control • classify against BCTs	Chronic MSK pain	SM is ability to manage symptoms, treatment and consequences related to ones condition • references Lorig and Barlow • to self-regulate • generic skills and competencies • large variation in content • behavioural adjustment • problem-solving • decision making • resource utilization • partnership with HCP • taking action	Behaviour Change Theory EBM	21
(Van de Velde et al., 2019)	Positivist – Health promotion	Concept analysis • Qualitative data from literature review to discover defining attributes, antecedents and consequences • In-depth analysis to reach consensus, create clarity and eliminate ambiguity of SM • triangulation, saturation	Multiple chronic health conditions	SM lacks clarity as a concept • should be included in conceptualisations of 'health'• no consensus on meaning • operationalised in different ways • different definitions • different outcome measures • should be researched in greater depth • identify 10 attributes; person oriented, person-environment-oriented and summarising attributes • many require individual capacity and personal responsibility • attribute 9 includes 5 personal skills • examples of a model case, a borderline case and a contrary case of a 'weak' self-manager • self-efficacy and health literacy as antecedents	Biopsychosocial model	88
(Williams et al., 2020)	Positivist-Behavioural psychology EBM	Cochrane systematic review of RCTs	Adults with chronic pain (excl headache)	SM not described • SM promoted through behaviour change • SM skills	EBM (Cochrane) Behavioural psychology	1045
(Kendall et al., 2011)	Interpretive	Conceptual review of the concept of self-management • Drawing on a number of research projects by the authors	n/a	SM involves navigating and responding to myriad of information & experiences • organic and dynamic • In policy and practice SM is; cost cutting mechanism • domain of health professional experts • SM as emancipation when individuals supported to do so • assumptions about SM impinge on health equity • shifted from a verb to a noun (nominalisation) • historical, social and political meanings hidden	Sociology	132

Author (s)	Research Paradigm	Study design	Study population	Self- Management storyline	Theory or framework	Citations Google Scholar
(Fletcher et al., 2019)	Interpretive	Secondary analysis of interview and focus group data	37 stroke survivors and 9 health care professionals and commissioners (UK)	SM ambiguous, multifaceted and contentious • adopted and advocated • interpreted in different ways • aspects of power influence multiple identities of SM • highly nuanced and complex • fluctuates depending on structures, routines of an individual	Foucauldian theoretical lens	16
(Pickard & Rogers, 2012)	Interpretive – Phenomenology (Merleau-Ponty)	Qualitative data from interviews • explore embodied self-awareness & everyday practices	Patients with multi-morbidities (UK)	Self-care is an embodied practice grounded in context • Knowledge as doing vs EPP (SM) is dualist separating mind & body • state sponsored patient action at core • containing costs and supporting demand management • biomedical, specialised & reductionist • valorises cognitive practices	Lived body paradigm Medical sociology	72
(Rogers et al., 2009)	Interpretive	Policy review and analysis of qualitative data from research on Expert Patient Programme	Policy documents, (UK)	SM shift from patient rights to individual responsibility • transmission of ideology and rhetoric into SM skills training (religiosity) • influenced by problems with fiscal resources and shift away from welfare state • delegated work • formulaic, protocol based • shift from collectivism to individualism	Social policy	71

3.4.1 Assumptions

A key overarching finding is that self-management in the context of chronic pain is rarely defined. Rather it is often taken for granted as a requirement of and integral to chronic pain management. Research is directed towards identifying barriers and facilitators to self-management (Bair et al., 2009; Blyth et al., 2005a; Gordon et al., 2017; Keogh et al., 2015), or evaluating the effectiveness of specific interventions (Du et al., 2017; Ersek et al., 2004, 2008; LeFort et al., 1998; Taylor et al., 2016) or identifying patient characteristics that make a 'good' self-manager (Devan et al., 2018; Kerns & Rosenberg, 2000), without any agreement on what self-management *is*. It is common for different services and practitioners to understand and describe self-management in different ways (Carnes et al., 2012).

3.4.2 Paradigms

Overwhelmingly, the research included in this review was grounded in a positivist paradigm (often without explicitly stating this) that assumed that self-management was a single unified concept. The methods used reflected these knowledge assumptions, with many studies adopting experimental designs such as randomised trials, systematic reviews of randomised trials and meta-analysis of quantitative data generated from both. Studies that used qualitative methods were rare and broadly aligned with a realist ontology (positivist paradigm) seeking out views from participants of the assumed singular and homogenous reality of self-management and were generally atheoretical. Papers drawing on qualitative data (e.g., Bair et al., 2009; Crowe et al., 2010; Gordon et al., 2017; Kawi, 2014), did not

question the underlying assumptions as to the nature of self-management in chronic pain instead adopting the superficial colloquial meaning of the term.

Crowe and colleagues (2010) stated that their choice of study design was employed to capture experience without relying on pre-determined categories. However, they used a semi-structured interview schedule with health care professionals that did not allow for alternative conceptions of self-management, assumed a self-evident meaning and, focussed on their perceptions of patients' ability to self-manage. Their stated analytic stance was an interpretive one, but it was unclear if they satisfied the conditions of interpretive paradigms. For example, they focused their content analysis on manifest content, identifying what was occurring on the surface and describing actions of the participants choosing not to attend to latent content as part of an interpretive process.

Critical perspectives that challenged a single interpretation were generally absent, further suggesting that perceptions of a universal way of self-managing chronic pain were uncontested in the literature. A single paper acknowledged that self-management of chronic pain has different meanings. Stewart et al (2014) used grounded theory methodology to examine the different meanings of self-management of chronic pain related to older adults. Following a concept analysis of the different meanings, they proposed a definition of self-management of chronic pain acknowledging the multidimensional components and conceptual complexity. Their proposed definition was not adopted by any of the other papers cited in this hermeneutic review. I did not identify any other interpretive or multiple understandings of self-management of chronic pain. This finding may reflect the absence of

specific reference to self-management literature by practitioners I encountered in my professional work.

I sought to include a wider range of perspectives on the meaning of self-management and extended my search to include literature not specific to chronic pain as I continued the iterative search. I limited this to selected papers that challenged the idea of a singular meaning of self-management in other health care conditions. I identified two detailed and extensive review papers that conceptualised self-management as complex and constituted of different meanings and/or components both using positivist methodologies to describe these different components. In a detailed structured and systematic concept analysis of the concept of self-management, Van de Velde et al (2019) used an eight-step concept analysis, including an in-depth analysis of literature across different chronic conditions to clarify the concept and resolve the many ambiguities associated with it. They reported on 10 attributes (many of which had additional domains) and recommended a revised definition of self-management that they hoped would lead to more consensus researching and reporting of self-management. They triangulated the findings from the literature with additional requests to researchers of included studies to critically read their findings and suggest further articles. They felt that this process ensured that they had discovered and described a consensus meaning of self-management. An earlier study by Pearce and colleagues (2016) focussed on the support people required to self-manage their long-term conditions. They conducted a review with the aim of unpacking and describing the components of self-management support for long term conditions. They produced a taxonomy of proposed components of what constitutes self-management support. None of the papers on self-

management of chronic pain included in this review referenced their proposed taxonomy or the definition proposed by Van de Velde (2019), suggesting limited utility of complex frameworks or taxonomies designed to simplify the notion of self-management of chronic pain.

3.4.3 Critical literature: a minor storyline

I found a small, but growing, critical literature on self-management reflecting a minor storyline. This largely focused on long term conditions (not specifically chronic pain), was policy focused, grounded in sociology, and questioned taken for granted assumptions underpinning perspectives on self-management using an interpretivist lens. I included four of these papers to my review to understand the broader meaning(s) of self-management outside chronic pain and summarise their main arguments before returning to papers specifically focussed on self-management of chronic pain. Kendall and colleagues (2011) reported their conceptual observations of self-management drawn from insights from varied projects they had been involved with. They discussed self-management in Australia including historical, socio-political, consumer (their term), practitioner and policy discourses and considered the tensions between them. They argued that self-management in its current iteration was the domain of expert health care professionals, with patients situated as passive recipients of benevolent advice; and that policy discourse was dominated by concerns about economic cost containment. They found that self-management had shifted from being understood as a verb describing actions to a pre-packaged noun, *"where the historical, social and political process meanings of the term have become hidden"* (95).

Fletcher et al (2019) conducted an interpretive secondary analysis of qualitative data drawn from interviews and focus groups with stroke survivors, health care professionals and service commissioners focussing on self-management in stroke rehabilitation. They used a Foucauldian perspective to explore how dynamics of power played out in the daily practice of stroke self-management. They identified different aspects of power that influenced how self-management was characterised and enacted, for example rhetorical power was mobilised to support *"realising cost-savings, reducing formal service provision, increasing patient influence in service design or improving patient choice"*(7). For them different forms of power were aligned with specific ways of enacting self-management with concerns around cost-containment being one driver of meaning. However, in contrast with the previous authors, cost containment was not the most dominant way of thinking of self-management. Instead, self-management in the context of stroke was a strategy for dealing with the long-term consequences of stroke. They concluded that self-management in stroke rehabilitation was a highly nuanced concept that fluctuates depending on an individual's structures and routines and influenced by dynamic issues including power.

Pickard and Rogers (2012) also argued that self-management (sometimes conflated with self-care) is not a single concept with a consensus view but rather a contingently understood and practiced phenomenon that varies based on underlying assumptions. Utilising a lived body conceptual paradigm, they conceptualise self-management of long-term conditions as an embodied practice grounded in context which in turn constitutes a form of knowledge otherwise not considered in more biomedical frameworks. The version of self-management espoused in the state sponsored Expert Patient Programme, they argue

is dualistic, separating mind and body, valorises cognitive practices and overly promotes economic concerns at the expense of lay forms of knowledge.

In a policy review of self-management and the Expert Patient Programme, Rogers and colleagues (2009) pushed for the recognition of more politically conscious understandings of the motives behind the popularity of personal responsibility and cost-containment framings of self-management. They noted a shift in framing of self-management from one of patient rights to one of individual responsibility which was then adopted with a type of religiosity that facilitated the transmission of ideology and rhetoric into the EPP. They connected the privileging of formulaic, protocol based and delegated work with a societal shift from collectivism to individualism. Both papers (Pickard & Rogers, 2012; Rogers et al., 2009) contrasted the lay practices of self-care and living that have long been part of a person's arsenal in living with chronic illness with the more professionally led structured programmes of self-management that are more commonly sanctioned perspectives on how people ought to live with chronic illness.

These papers highlighted that self-management is not solely concerned with individual behaviours, but also consists of meaningful practices undertaken within social contexts. The authors caution against uncritical adoption of state sponsored self-management with its focus on personal responsibility and alignment with economic concerns of containing costs for long term conditions. Lay-led forms of practicing self-care and self-management in multiple ways are promoted as useful alternatives to dominant state sponsored, often protocolised self-management.

This critical literature and its conclusions have not yet found their way into the mainstream professional context or academic studies of chronic pain management. I now turn to the dominant storylines apparent in the mainstream literature.

3.5 Dominant storylines about self-management

I identified three overarching and often overlapping storylines reflecting how self-management of chronic pain was understood and operationalized. As discussed above most of the literature drew on behavioural psychology and within that behaviour change theory though did not always explicitly report using conventions from that field. I separated out the storylines into 1) self-management as an intervention for people with chronic pain, 2) self-management as a predetermined set of desirable (and variable) behaviours and 3) self-management interventions as a cost-containment measure in the context of increasing chronic disease and demand for health care (see Table 2).

Table 2: *Self-management of chronic pain storylines*

Storyline	Synopsis	Papers
Self-management as an intervention	Mainly emphasized programs or groups that included many different components purported to impart the necessary skills to achieve self-management	(Boyers et al., 2013; Carnes et al., 2012; Crowe et al., 2010; Dijkstra et al., 2001; Elbers et al., 2018; Ersek et al., 2004, 2008; Jensen et al., 2003; Kawi, 2014; Kerns & Rosenberg, 2000; LeFort et al., 1998; Miles et al., 2011; Reid et al., 2008; Ruehlman et al., 2012; Schofield et al., 2014; Stewart et al., 2014; Taylor et al., 2016) **n=17**
Self-management as a set of behaviours	Different sets of behaviours required by individuals to manage their chronic pain	(Bair et al., 2009; Crowe et al., 2010; Devan et al., 2018; Dijkstra et al., 2001; Du et al., 2011; Ersek et al., 2004; Hutting et al., 2017; Jensen et al., 2003; Kawi, 2014; Keogh et al., 2015; Kerns & Rosenberg, 2000; Krein et al., 2007; Miles et al., 2011; Reid et al., 2008; Williams et al., 2020) **n=15**
Self-management as cost-containment	Successfully doing 'self-management' leads to a reduction in health care spending	(Boyers et al., 2013; Elbers et al., 2018; Kawi, 2014; Krein et al., 2007; Lee et al., 2014; LeFort et al., 1998; May, 2010; Reid et al., 2008; Ruehlman et al., 2012; Taylor et al., 2016) **n=10**

3.5.1 Self-management as an intervention

Conceptions of self-management as described and defined by Lorig and colleagues (Bodenheimer et al., 2002; Lorig, 2003; Lorig & Holman, 2003; Lorig et al., 2001) and Barlow and colleagues (Barlow et al., 2009; Barlow et al., 2002; Wright et al., 2003) were most common in papers included in my review. Both these groups conceptualise self-management of chronic pain as an educational and skills-based intervention and have been influential in design and evaluation of self-management programmes for chronic pain. I summarise their conceptualisation of self-management first before exploring how papers interpreted these descriptors in their use in the context of chronic pain.

Lorig acknowledges that *"self-management education is not well defined and is often confused with patient education or self-management support that helps manage their disease"*(2003, 699). She clarifies, that self-management consists of three tasks (medical, role, and emotional management) and six skills (problem solving, decision making, resource utilization, the formation of a patient–provider partnership, action planning, and self-tailoring) learned through a structured education programme (Lorig & Holman, 2003). Self-management is about imparting skills in the form of a behavioural intervention. Self-management is enacted by *"informed, activated patients in partnership with their physicians"* (Bodenheimer et al., 2002, 2469).

Barlow et al also note that self-management has different descriptors and definitions before setting out their own which focusses on individual ability and behaviour to utilise relevant skills:

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

Despite these two definitions emphasising different ideas of what a self-management intervention could be, papers referencing them sometimes incorrectly conflated them as referencing the same intervention. For example in their systematic review, Elbers and colleagues did not distinguish between different definitions and components of self-management programs, combining 20 heterogenous self-management intervention trials which included up to 18 different behaviour change techniques and concluding that *"generic self-management interventions have a marginal benefit for patients with chronic musculoskeletal pain"* (Elbers et al., 2018, 1577). Despite referencing both Lorig and Barlow, the subsequent interpretation of self-management was contrary to both their conceptions.

Other papers included in this hermeneutic review also presented self-management as a set of disparate tasks that formed the basis of interventions. Some authors referred to self-management as a multicomponent, complex intervention (Boyers et al., 2013; Ersek et al., 2004, 2008; Jensen et al., 2003; Kerns & Rosenberg, 2000; LeFort et al., 1998; Miles et al., 2011; Reid et al., 2008; Stewart et al., 2014). However, the constitutive components of the interventions were inconsistent and varied in terms of what was included or excluded. For example, some approaches included exercise and physical activity (Kawi, 2014; Miles et al., 2011; Taylor et al., 2016) whilst others did not (Ruehlman et al., 2012; Schofield et al.,

2014). Some papers made the distinction of self-management interventions as excluding biomedical approaches such as taking or prescribing medications (Dijkstra et al., 2001) and being a safer alternative to medications (Reid et al., 2008). There was a mix of interventions that included lay knowledge and delivery (Crowe et al., 2010; Taylor et al., 2016), and those that privileged expert knowledge and delivery from health care professionals (Carnes et al., 2012; Jensen et al., 2003).

Many authors either assumed the universality of self-management when describing their interventions or often, selected one of the more common descriptions or definitions of chronic pain. These well used descriptions included multiple notions of what constitutes self-management.

3.5.2 Self-management as a set of behaviours

Self-management was conceptualised by multiple authors as *a set of behaviours* required by individuals to manage the symptoms related to chronic pain. For example:

> *"Self-management is a behaviour or range of behaviours that require individual's to adhere to physiotherapist advice on suggested lifestyle changes."* (Keogh et al., 2015, 728)

Papers adopting this orientation presented patients as needing to have personal responsibility; acquiring skills and knowledge that allowed them to live with minimal support from the state and/or health care professionals. Aligned with behavioural psychology principles, desirable personal characteristics to enable personal control and mastery (Kerns & Rosenberg, 2000) included being active in coping with pain (Dijkstra et al.,

2001), motivation to take on the work of managing pain (Ersek et al., 2004; Jensen et al., 2003), adherence to expert recommendations from health care professionals (Krein et al., 2007), modulating cognitive and emotional responses to pain (Reid et al., 2008) and taking medication as prescribed (Crowe et al., 2010; Kawi, 2014). There was sometimes a distinction between so-called active (e.g., exercise) versus passive approaches (e.g., massage), with the latter considered a barrier to good, successful, and sustained self-management (Bair et al., 2009; Devan et al., 2018). There was a suggestion that not participating in the required behaviours would result in increased disability (Keogh et al., 2015). As well as being a set of behaviours, this storyline also privileged standardised psychometric questionnaires as tools with which to assess the outcome of interventions designed to engender the desirable behaviours. These questionnaires evaluated the extent to which participants in self-management programmes increased for example, their pain self- efficacy[5]. In this storyline increased self-efficacy was regarded a desirable characteristic of those considered successful at self-management (Devan et al., 2018; Du et al., 2011; Ersek et al., 2004; Hutting et al., 2017; Krein et al., 2007; Miles et al., 2011; Williams et al., 2020).

Many of the papers that discussed self-management of chronic pain as a desirable behavioural outcome, also used the term self-management when discussing the multimodal interventions offered to produce the desired set of behaviours.

[5] The extent to which people felt able to execute the behaviours required to cope with pain (Nicholas, 2007)

3.5.3 Self-management as cost-containment

The third storyline frequently leveraged to justify self-management approaches was based on the economic utility of these approaches in containing rising and unaffordable costs of health care in the face of rising prevalence of chronic pain, with increased disability and reduced availability of more effective treatments. Both group sessions and lay delivery were presented as viable cost-containment measures when compared to both usual care (Boyers et al., 2013; Kawi, 2014; Ruehlman et al., 2012) and existing costly pain management approaches (LeFort et al., 1998; Taylor et al., 2016). Additionally, patients continued application of the skills acquired from self-management interventions was considered to continue delivering savings based on reduced health care usage by alumni (Lee et al., 2014). May (2010) goes so far as to say that not offering self-management is negligent given the ongoing risk of services being overwhelmed by demand. In this storyline, self-management is presented as a modern solution to issues such as the absence of a medical cure for chronic pain, high levels of disability and distress and, stretched health care services.

3.6 Discussion

Self-management of chronic pain is often framed in the literature as an issue of personal responsibility associated with concepts such as resilience (Goubert & Trompetter, 2017), acceptance (McCracken & Vowles, 2014) and self-efficacy (Jackson et al., 2014). The focus is predominantly on individuals, with little attention to patients' lived experience. Through this lens of personal responsibility, patients 'choose' to attend appointments; they 'opt in' to pain management programmes and other interventions after the health care professional outlines available options (Knight et al., 2019). The expert or professional perspective is

disproportionately visible, and there is little consideration of patients' capacity to make choices nor of alternative modes of reasoning and practice 'beyond the clinic'. Certain practices performed by people living with chronic pain such as taking pain medication and receiving passive manual therapies, are not generally considered 'good' self-management. We know that people living with chronic pain would like better tailored and effective support to help them cope with their chronic pain in their everyday lives (Lennox Thompson et al., 2019; National Pain Audit, 2012). However, the dominant version of self-management put forward in the literature (and the different storylines within it) suggests a preference for 'active' approaches that demonstrate 'good' self-management.

In Chapter 2, I outlined the different epistemologies of pain (and chronic pain). Despite there being many different ways of knowing chronic pain and professionals, the academic literature on self-management of chronic pain was dominated by perspectives and concepts from behavioural psychology. Though ostensibly derived from a biomedical nursing paradigm espoused by Lorig and Barlow, self-management as used in relation to chronic pain has diverged from this dominant view common in other long-term illnesses. Instead of a lay delivered skills and education programme, the focus is on expert instruction from health care professionals who promote individual behaviour change. The interventions are varied and overwhelmingly suggest that self-management as done by individuals living with chronic pain offers a less expensive and low resource alternative to expensive alternatives. The outcomes of self-management interventions presented in this literature valorise cognitive principles and adherence to protocol driven, standardised and state-sponsored self-management.

It is unclear how the different kinds of knowledge presented in Chapter 2 are considered when offering support for those living with chronic pain. Despite the ethos espoused within the Biopsychosocial model to reject mind-body dualism, the dominant models of self-management of chronic pain, couched in the language and routines of behavioural psychology promote a focus on cognitive perspectives over lived, embodied and non-dualist ones. Though frequently described as complex interventions, they only offer a partial view of how self-management of chronic pain can be understood, achieved, and supported.

3.7 Conclusion

In this chapter I have presented findings from a hermeneutic review of the literature on self-management of chronic pain, showing that this literature is often contradictory and fails to acknowledge that there are different ways of understanding both chronic pain and self-management. What evidence there is tends to privilege expert perspectives. I found, through my hermeneutic literature review that self-management is broadly characterised in the academic literature as:

- an intervention
- a set of behaviours
- a cost containment measure

There are multiple assumptions embedded in how self-management of chronic pain is understood, mainly that there is a singular understanding of the concept. The papers included in this review did not question the underlying assumptions. Though a small literature exists that focuses on different aspects of the lived experience of self-management of chronic pain, most published qualitative research has a methodologically narrow focus, is descriptive, often atheoretical and embedded within biomedical

frameworks. Authors frequently adopt unclear meanings of self-management of chronic pain inadvertently encoding conflicting and overlapping storylines into new ones thus reifying an otherwise abstract concept into policy and practice.

To date, very little qualitative research has explored *how* people are self-managing their chronic pain both within and outside of mainstream services, adopting methods that take into account people's social context. There has been less of a focus understanding how people living with chronic pain who are *not* supported by specialist health care professionals working within technocratic health systems achieve self-management and how they can be better supported. In Chapter 4 I set out my methodological approach to researching chronic pain self-management, and my use of multiple qualitative methods to understand individuals' lived experiences of self-managing chronic pain, as well as the wider socio-political influences that shape those experiences.

Chapter 4: Researching self-management of chronic pain: methodological considerations and methods

4.1 Introduction

In this chapter I set out my methodological approach and detail the methods used in my study. To begin, I set out my research questions, aims and objectives. I then describe my methodological approach, which is grounded in an interpretive philosophy. This approach reflects my focus on patient perspectives on self-management of chronic pain, my interest in understanding individuals' lived experiences of self-managing chronic pain, and my appreciation of the wider socio-political influences that shape those experiences.

In the second part of the chapter, I describe the methods I used in my research, justify my choice of methods, and explain how and why these changed as this project progressed, including the impact of the Covid-19 pandemic. I present my approach to analysis *within* each phase of the study, my synthesis across them and use of relevant social theory. I describe the process of zooming out and in, moving from larger and smaller units of meaning as a key commitment in my methodological approach.

Guided by the principle of the hermeneutic circle (i.e., iteratively moving between the parts and the whole (Boell & Cecez-Kecmanovic, 2014)) I explain how my data collection, analysis and interpretation occurred recursively. Analysis was an iterative process that informed ongoing and additional data collection (e.g., refining the interview schedule, guiding the

collection of relevant documents). This weaving together of the threads of data collection and data analysis was central to my research practice.

I conclude with sections on ethics and governance for my study, and on reflexivity, setting out my approach to keeping a reflexive diary and the evolution and influence of my own views and perspectives on the research.

4.2 Research Questions, Aims and Objectives

My research focused on the experiences of people living with chronic pain who were not included in formal pain management services, asking:

1) How is 'self-management' accomplished by people living with chronic pain who have been excluded from (or have dropped out of) existing pain management services?
2) How can people who have been excluded from, or dropped out of pain management services be better supported in practice and through policy?

My aims were:

1. To identify and describe self-management of chronic pain by those who have been excluded from or dropped out of existing pain management services.
2. To understand how professionals decide who to refer and how to select patients for pain management services.
3. To understand how and to what extent the policy and organisational context shapes opportunities for self-management of chronic pain.

My objectives were:

1. At micro (individual lived experience) level: to understand the work of 'self-management' with a maximum variation sample of patients living with chronic pain who have been excluded from or dropped out of pain management services.
2. At meso (organisational context) level: to conduct a case study including health professionals and administrators (including managers) involved in pain management in order to understand the perspectives and practices that constitute 'self-management' of chronic pain.
3. At macro (national and wider social context) level: to identify and analyse a purposive sample of national policy documents relating to self-management and chronic pain and identify the extent to which policy supports (or otherwise) those who have typically been excluded from pain management services.

4.3 Methodological approach

I was interested in understanding individuals' lived experiences of self-managing and supporting self-management of chronic pain, with a focus on appreciating socio-material entanglements and relational aspects. This led me to adopt an interpretive philosophy, which views the social world as constructed in different ways by the people experiencing it (Inglis & Thorpe, 2013). This enabled me to embrace multiple and interacting perspectives on self-management of chronic pain.

As a practicing clinical physiotherapist, the prevailing epistemology in my discipline is broadly aligned with the empirical, positivist traditions of biomedicine (Nicholls, 2017). In the absence of a distinct applied disciplinary epistemology, I was guided by practice driven questions that lend themselves to thinking outside this positivist paradigm. I used an *interpretive description* approach, which amalgamates interdisciplinary perspectives, aims, histories, and methods under one umbrella with the aim of generating knowledge relevant for applied health contexts. Originally conceived for applied health research within nursing, the approach has been applied to other disciplinary applied health projects (Thorne, 2016). Interpretive description uses theory as a tool to think specifically about patient care (Thorne, 2016) which aligned with the aims and objectives of my research. I used it as an interdisciplinary lens guiding my methodological decisions, particularly when drawing on theories and tools not usually associated with my discipline (physiotherapy) or field (pain). Additionally, interpretive description accounts for the use of multiple theories to explain and make sense of research findings (Thorne, 2016), thus addressing the general absence of a single overarching theoretical framework guiding pain care (see Chapter 2).

To link the (micro level) lived experience of self-management of chronic pain with (meso level) organisational perspectives and (macro level) policy contributions, I drew on different theories that connected through their attention to socio-material entanglements whilst accounting for multiplicity. I drew on boundary work (Leigh Star, 2010), multiplicity (Graham, 2015; Mol, 2002) and assemblage theory (Buchanan, 2020; Deleuze & Guattari, 2013) to extend my first order interpretations and explain and situate my findings within existing theoretical work. Additionally, I drew on interpretive policy analysis (Wagenaar,

2014; Yanow, 2000), an umbrella approach concerned with how policies contribute to making meaning and shaping actions. Use of interpretive policy analysis enabled me to trace the contribution of policy on self-management of chronic pain as discussed in Chapter 8. I introduce each theory within the body of each chapter.

4.4 Study design

I wanted to better understand self-management of chronic pain as enacted in real life contexts and to produce a rich, detailed account of this. I therefore conducted an in-depth case study (named CHASM, an acronym for – CHronic pAin Self-Management) of the self-management of chronic pain combining (micro-level) interviews and observation of people living with chronic pain who have been excluded from or dropped out of pain management services, with (meso-level) interviews with health care professionals and managers and (macro-level) interviews with policy actors and analysis of policy documents. A single in-depth case study allowed me to tap into multiple subjective realities as experienced in a singular and unique setting (Simons, 2009; Stake, 1995).

4.5 Setting

Chronic pain in England - where my study was based - is routinely managed within (or at least with some oversight from) the health care system. The presence and accessibility of pain services is often locally determined depending on local providers, commissioners and populations (National Pain Audit, 2012; Royal College of General Practitioners, 2013). In addition, the processes dictating the transfer of referrals (e.g., from primary to secondary care) relies on the processes and systems in place between settings such as document

management systems and agreed care pathways. As such, my research lent itself to being applied within a particular geographical area. I focussed my case study on a single health care system (anonymised to 'the Shire'), allowing me to examine the phenomena of self-management of chronic pain as an intrinsic case and to study it in-depth in all its particularity (Stake, 1995; Thomas, 2015). While a single case, it was also a 'most likely' case (Flyvbjerg, 2006), exhibiting typical social organisation and depiction of self-management of chronic pain. In Chapter 3, I established that self-management of chronic pain was not a singular observable activity, practice or distinguishable narrative but was constituted of multiple interpretations and manifestations. Therefore, in clarifying 'what is "This" a case of?', I considered how self-management of chronic pain was "shaped and constituted through activity" (Langley, 2021, 254), attending to different institutional spheres and taken for granted assumptions. I introduce my case in Chapter 5, including further details of selection, negotiating access and data collection, and analysis.

To frame the boundaries of my case I drew on the work of Segar et al (2015), which uses a 3-dimensional lens that accounts for the more complex reality of case study research. These dimensions included: 1) local context (geography and location of services and, following restrictions from the global Covid-19 pandemic from March 2020, also including virtual sites), 2) local meaning and history (as constructed by research participants and organisational documents), and 3) national policy relevant to self-management.

In summary, my case study focused on self-management of chronic pain in the Shire, combining (micro-level) observation and interviews with patients living with chronic pain

who have been excluded from or dropped out of pain management services, with (meso-level) observations and interviews with health care professionals and managers and (macro-level) interviews with policy actors and analysis of relevant policy documents.

4.6 Sampling and data collection

I collected data over 18 months (December 2019 to June 2021) involving 30 participants (16 health care professionals and managers, 7 policy actors and 7 patients). Data sources are summarised in Table 3 and described in detail below.

Table 3**:** *Overview of multilevel data collection and analysis*

Study phases	Type and nature of data	First-order interpretation	Higher order interpretation
Meso-level study of organisational context of self-management of chronic pain	Audio-recorded interviews with 16 health professionals Documents relating to eligibility assessment and other guidance Researcher field notes, reflections and analytic memos	How actors (within formal services) understand pain management services and the support for self-management; insights into how services are organised and accessed; organisational routines around access to services	External social structures (such as standards and definitions of self-management of chronic pain); assumptions made during decision making processes; how and where different kinds of power and in/justice feature in the design and delivery of services/support; how health professionals work with different conceptions of self-management and multiple ontologies; boundary work
Micro level study of patients' lived experiences of self-management of chronic pain	Audio and/or video recorded initial and follow up interviews (up to 2 months apart) with 7 people living with chronic pain Emails and/or photographs depicting how participants experience, manage and cope with chronic pain in their everyday lives Ongoing field notes and home tours with 7 participants, spread over up to 5 visits over 6 months	What participants do in their daily lives in the presence of pain; their perceptions of self-management; what networks and resources people mobilise to enable them to live and cope with pain; what services (if any) they access, and why.	Lived experience of chronic pain self-management; daily tasks of living with pain; how and where different kinds of epistemic injustice and social power feature in people's experiences of chronic pain; agency to carry out tasks Forming and reforming assemblages
Macro level study of national-level policy relating to self-management of chronic pain	Audio-recorded interviews with 7 policy actors 13 national-level policy documents relating to self-management and chronic pain from 2000 onwards 8 symbolic artefacts (consisting of strategy documents, reports and websites)	Historical and policy drivers for the turn to self-management in chronic pain	Background to multi-level and integrated analysis; external social structures such as health policy and economic drivers; role of power in shaping discourses; interpretive communities and their discourses
Synthesis across all levels	Interview data (from micro, meso and macro levels) Researcher's reflective diary capturing thoughts and feelings whilst conducting research	The interaction between micro, meso and macro levels	External social structures; internal social structures; agency of actors; social power and justice; building complexity

4.6.1 Phase 1: Organisational context of self-management of chronic pain

I started out preliminary work mapping services for people living with pain in the Shire using publicly accessible resources and identified the main service providers in the county. In the first instance, I sought organisational permission via the relevant research and development office to approach members of staff. I identified staff involved in leading pain management services and working with them to map services and identify events where staff members congregate. I presented the research proposal at three of these events, leaving participant information sheets and contact details behind.

As a result of this process, I recruited 16 health care professionals and managers involved in planning and/or providing pain management services in the Shire who were engaged in (i) assessing eligibility for entry into services (as well as individual treatment options), and (ii) supporting patients with self-management of chronic pain (see Table 4). I used purposive, maximum variation sampling to ensure diversity in the type of workplace (i.e., hospital services, primary care and other (non-NHS) providers), clinical experience and disciplinary background. I sought variability in the services provided and in the staff groups (to reflect the kinds of influences on service provision set out in Chapter 2).

Narrative interviews (Reissman, 2008) were conducted face-to-face with staff at their usual place of work, via telephone or videoconference, and audio recorded (with consent). As part of the interview process, I asked participants to talk me through the decision-making processes to determine whether patients were suitable or eligible for their service/s and also invited participants to share relevant documents that they used in making these

decisions e.g., inclusion and exclusion criteria, service specifications, or other local or national guidance documents.

I identified staff at each site who were interested in acting as research champions. They supported the study by identifying patient and staff participants who met the inclusion criteria for their study site.

Table 4**:** *Overview of staff interviewees, their role and work setting (n=16)*

Participant Identifier	Professional Role	Work setting
1	Specialist Physiotherapist (Pain)	Hospital
2	GP Partner	Suburban
3	GP	Suburban
4	GP trainee ST	Rural practice
5	Consultant in Pain and anaesthesia	Hospital
6	Clinical Nurse Specialist (Pain)	Hospital
7	Specialist Physiotherapist (Pain)	Private contractor to NHS
8	Specialist Physiotherapist (MSK)	Private contractor to NHS
9	GP	Inner City
10	GP	Rural practice
12	GP	Inner City
13	Social Prescriber	Urban – multiple practices
14	Paramedic	Multiple
16	Clinical Psychologist	Hospital
17	GP clinical academic	Multiple
22	Occupational Therapist	Hospital

4.6.2 Phase 2: Patients' lived experience of self-management of chronic pain

Guided by my research questions, I deliberately chose to focus on patient participants who were not currently actively engaged with NHS commissioned pain management services, either by choice or due to not meeting relevant eligibility criteria (e.g., from the CCG or pain management service). Participants were recruited in part due to their involvement in NHS services and as such, I was guided by my ethics committee to refer to them as patients

(including in recruitment, information and consent paperwork). I put up recruitment posters in GP surgeries in the Shire (pre-pandemic) (see Appendix 2).

I adopted a two-pronged sampling approach:

1) Working with NHS services. I worked with staff in pain management services, secondary care services and GPs within the Shire to identify people who had been excluded from or dropped out of services over the previous 6 months. Staff at the study sites (identified in Phase 1, through local contacts and with support from the Clinical Research Network), identified patients either during routine consultations with a patient (GPs and non-pain management services) or in a follow up phone call (pain management services), and sought permission to pass contact details to me. My aim here was not to overburden patients who were already experiencing significant pain and may have been struggling with activities of daily living that many take for granted. Hence my focus on brief contact from the pain management service (e.g., a phone call from the research champion or administrator) and permission from the patient to provide contact details to the research team should individuals be interested in finding out more about the study. Working with pain management services, I contacted all of those who agreed, providing further information and an opportunity to ask questions (see section 4.10.1 on Informed Consent) and inviting them to participate in the study. I continued until (in combination with 2 below) I had achieved a sample of seven participants.

2) Following recommendations. As I identified participants, I used snowball sampling to identify other potential participants. This involved asking those already participating

in the study to discuss the study with their contacts and (if they secured interest from them) advising their contacts to make themselves known to me if they thought they would be interested in hearing about the study and consider participating.

I invited a purposive maximum variation sample of seven patients with chronic pain to participate in the study. I sought variation in age, gender, ethnicity, literacy, disability, language, and severity of pain. While variation in age, gender and chronic pain impact was achieved (see Table 5), variation in self-identified ethnicity was more limited than hoped for due to restrictions related to the Covid-19 pandemic in 2021 and 2022 when data collection took place. Several potential participants contacted via sampling method 1) above declined to participate due to varied concerns around e.g., sustaining employment, access to sufficient bandwidth, loss to follow up and access to interpreters.

I recruited seven patients aged 18 years and above with chronic pain, who were not accessing formal pain management services (commissioned by the local CCG at the time of recruitment), lived within the Shire County and were willing and able to give informed consent for participation in the study. I asked patients to self-identify as having chronic pain, defined in the patient facing materials as pain that persists or recurs for longer than three months. In line with ethics requirements (see section 4.9), for patients who made contact in response to public adverts, I confirmed eligibility on the phone or via email before taking informed consent. For patient participants identified by a health care professional (i.e., seeking permission to release contact details), I was guided by the clinical judgement of the referrer as to the suitability of patients to invite to participate in the study. Guided by advice from my research advisory group (see section 4.9 Ethics and governance) and in keeping

with diagnostic conventions, I excluded people who were experiencing chronic (or ongoing) pain from cancer and/or receiving palliative care at the time of recruitment as participating in this study may not have been appropriate with their receiving other care/treatment.

Table 5**:** *Overview of participant characteristics and contacts during the study*

Participant Identifier	**Pseudonym, age, gender, self-identified ethnicity**	**Chronic pain diagnosis/condition**	**Occupation/Living situation**	**Summary of contact**
24-1	John, 53, M, White British	Facial pain	Teacher With spouse in own home (terraced house)	Jan 2021 -June 2021 5 meetings/interviews over video including home tours and sharing of objects/images
25-2	Jessica, 61, F, White British	Unclear diagnosis, Rheumatoid Arthritis, Osteoarthritis, Fibromyalgia	Retired accountant With husband in own home (terraced house)	March 2021 – June 2021 3 meetings/interviews over video including home tours and sharing of objects/images via email
26-3	Michael, 55, M, White British	Shoulder pain, no diagnosis	Primary school teacher With wife and two kids in own home	March – June 2021 3 meetings/interviews over video including home tours
27-4	Clare, 72, F, White other	Chronic pain Back pain Nerve pain in both legs	Retired professional Alone in own home	March – April 2021 2 meetings over video, email correspondence and home tour
28-5	Max, 74, M, White British	Osteoporosis related back pain Parkinson's Disease Cancer survivor	Retired dentist With wife in own home	March – June 2021 3 meetings over video, limited email correspondence as "not very techy"
29-6	Sarah, 57, F, White British	'Regular' Arthritis in hands and feet	Administrator With spouse and son in own home	March – June 2021 3 meetings over video and email correspondence, recommended books
30-7	Phil, 39, M, White English	Abdominal pain Gastroparesis Parenteral nutrition	Unemployed due to ill health and pain (previous welder), receiving state benefits With mum and dad in council home	March – April 2021 2 meetings via telephone, no email address

I collected data over a 6-month period to understand how patients experienced self-management of their chronic pain. Once participants had consented to taking part in the study, I conducted:

1. An initial interview with participants, audio/video recorded (with consent). Interviews adopted a biographical narrative approach (Kaźmierska, 2004), asking participants to tell the story of their chronic pain in their own way and in their own words.
2. A home video tour (led by participants) using videoconferencing. I invited participants to show me any objects or spaces that were important to them in self-management of chronic pain, allowing me to elicit further participant views about living with (and in) pain. A home tour simulated the ethos of a go-along interview (Carpiano, 2009). My own and participants movements were restricted due to pandemic restrictions and a home tour provided insight into their day to day lives and generated observational data (Green & Thorogood, 2018).
3. Follow up unstructured interview between 1-2 months after the initial interview.
4. Additional unstructured interviews and informal meetings via videoconferencing or telephone.

I invited participants to take pictures, write email memos or record voice notes of their daily lives focusing on what they saw as relevant to how they lived with chronic pain. This provided a means for participants to narrate and depict their experiences of chronic pain. As I met with participants (n=7) on successive visits, I reviewed materials produced with them and used this to inform the content and direction of interviews, as well as subsequent analysis. At the outset of the study, I asked participants how they would like to keep in

touch in-between contact points and, was guided by them as to means (e.g., telephone, email) and frequency. One participant chose telephone contact as they did not have access to videoconferencing.

I met with my patient participants for between 2 and 5 months, conducting follow-up longitudinal interviews with all 7 (see Table 5) with ongoing email and/or telephone contact and follow up.

4.6.3 Phase 3: National-level policy relating to self-management of chronic pain

To appreciate the social context within which self-management of chronic pain was enacted, I set out to understand who was involved in shaping policy relevant to pain and how these policies were formed and implemented. This involved identifying both policy actors and relevant documents. I sought out policy actors who had contributed to, or had oversight of, the policy landscape involving self-management of chronic pan or other long-term conditions. I initially identified potential participants (involved in decision making relevant to pain management across organisational, regional, and national boundaries) through existing professional networks, my Research Advisory Group and, from introductions from research champions from Phase 2 (see section 4.7.1). I then used snowball sampling to identify other potential participants. This involved asking those already participating in the study to share details with their contacts and, if interested, to make themselves known to me.

Participants recommended relevant policy documents. Building from this and drawing additional documents from my search of the literature (see Chapters 3 and 8), I included

policy documents or texts from the year 2000 when self-management first gained prominence in UK health policy.

I recruited and conducted seven interviews with policy actors working across organisational, regional, and national boundaries (see Table 6). These interviews focused on understanding how self-management of chronic pain played out and influenced policy decisions and how, in turn, this impacted pain management services locally and nationally.

Table 6: *Overview of policy actor interviewees (n=7)*

Participant Identifier	Professional role	Scope of influence
11	Policy Implementation Manager	National/Regional
15	Policy Advisor	National/Global
18	Medical Director/Strategic Director	National/Cross sector
19	Professional Lead	Regional
20	Programme director/ Clinical Director	National
21	Policy Advisor	National/Cross sector
23	Policy Programme lead/Clinical Director	National

All interviews from Phases 1,2 and 3 were narrative in approach and supported by a topic guide (see Appendix 3) which provided a loose outline of my areas of enquiry and a selection of possible follow-up questions. Interviews were audio recorded (with consent) and transcribed verbatim by a university approved transcriber. Transcription included all the words spoken by interviewee and interviewer, with attention to significant hesitations, exclamations of emotion (e.g., laughter) and long pauses.

In total, I identified 13 policy documents relating to self-management and chronic pain. Policy means different things to different people: when I started thinking about policy as relevant to self-management and chronic pain, I was guided by the work of Lowri and

Ginsburg to think of it as the things that governments do to translate their political vision into reality, e.g., *"…an officially expressed intention backed by a sanction, which can be a reward or a punishment."* (1996: 607). As such, I limited my initial search and analysis of policy relevant documents to those produced by the UK government and state institutions (e.g., NHS England, Department of Health, Public Health England). I included 13 policy documents (selected due to their relevance to self-management of chronic pain or service planning in the NHS more broadly) in my policy analysis (see Table 7). My initial analysis involved identifying references to self-management and chronic pain, attending to language that contributed to the meaning of policy in this field and to key descriptors and definitions around self-management. I then used this to generate a narrative account of what these formal policy documents said (and did not say) about the meaning/s of self-management of chronic pain.

Table 7: *Overview of policy documents included in documentary analysis*[6]

Policy document
Department of Health. (2000). *The NHS Plan: a plan for investment, a plan for reform*
Department of Health. (2001). *The Expert Patient: A New Approach to Chronic Disease Management for the 21st Century*
Department of Health. (2005a). *Self care – A real choice: Self care support – A practical option*
Department of Health. (2005b). *Supporting People with Long Term Conditions: An NHS and Social Care Model to support local innovation and integration*
Department of Health. (2012). *Long Term Conditions Compendium of Information: Third Edition*
NHS England. (2014). *NHS Five Year Forward View*
Health Education England. (2018). *Musculoskeletal core capabilities framework for first point of contact practitioners*.
NHS England. (2019a). *The NHS Long Term Plan*.
NHS England. (2019b). *NHS Long Term Plan Implementation Framework*
NHS England. (2019c). *Adult Specialised Pain Service Specification*.
Public Health England. (2019). *Musculoskeletal Health: A 5 year strategic framework for prevention across the lifecourse*.
Public Health England. (2020). *Chronic Pain in Adults 2017: Health Survey for England*
Department of Health and Social Care. (2022). *Joining up care for people, places and populations*.

As I progressed this documentary work, I continued to speak with policy actors with more experience of policy and extended my reading to more interpretive approaches to thinking

[6] I present an extension of this table with added analysis in Chapter 8

about and analysing policy (Shaw, 2010; Wagenaar, 2014; Yanow, 2000). This process increased my awareness of other interpretive perspectives that consider policy to be a messy and shifting conglomeration of things, e.g., "…a set of shifting, diverse, and contradictory responses to a spectrum of political interests." (Edelman, 1988, 16). This shifted my analytic lens to question *why* chronic pain appeared to be missing in the documents analysed to date and *where* else could differing perspectives available to decision makers be, "seek [ing] out the different spaces and places in which policies evolve and the kinds of data emerging from these" (Shaw & Eyre, 2019, 336).

I additionally identified eight strategy documents and objects (including but not limited to reports, websites, competency frameworks) produced by different interpretive communities involved in shaping chronic pain policy, what Yanow (2000) calls symbolic artefacts. These artefacts accommodate different meanings and embody discourses that act on the social world. I report on this additional analytic focus in Chapter 8 (section 8.4) along with my findings.

As with other phases of my research, I made contemporaneous field notes to record observations, reflections, and analytic memos as my policy analysis (of both interviews and documents) progressed.

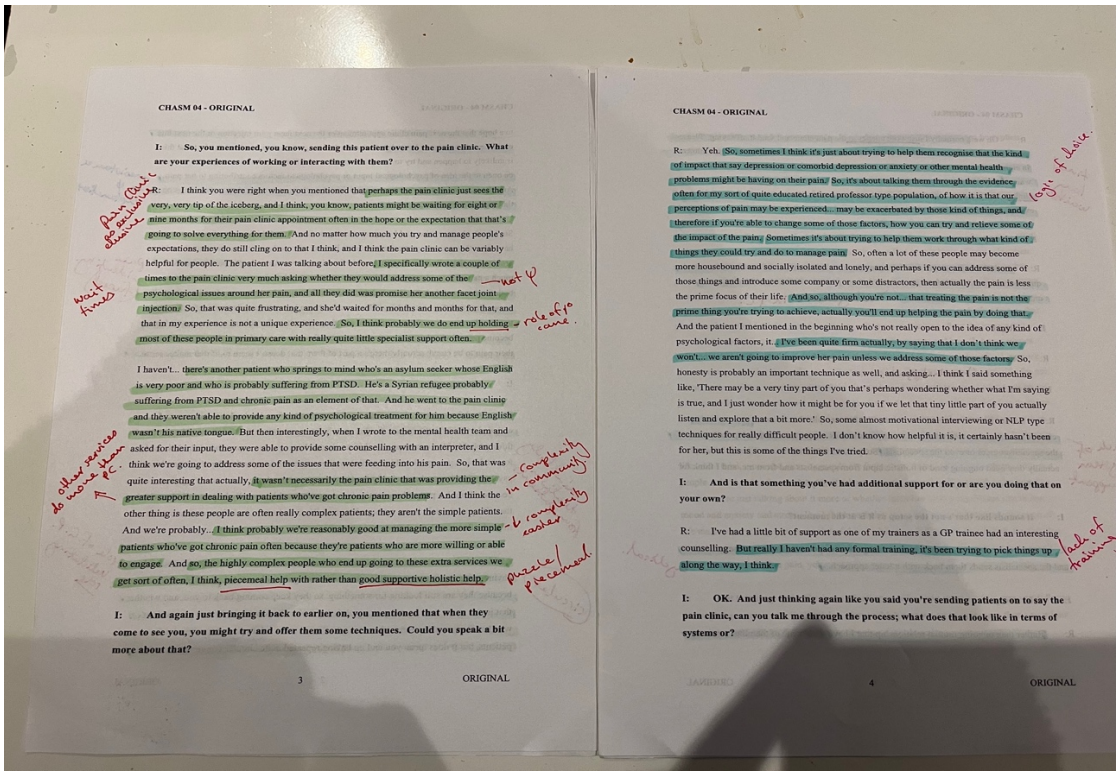
4.7 Approach to data analysis within each phase

I completed empirical data collection whilst simultaneously collecting, synthesising, and interpreting the literature on self-management of chronic pain, which, in turn, informed my

interpretive decisions during analysis (Thorne et al., 2004). I had already started analysis by the time I came to this more formal process.

I used an abductive approach to analysis (Tavory & Timmermans, 2014), enabling me to build a rich picture of self-management of chronic pain from multiple perspectives whilst being sensitive to local context and the influence of national policy. Abductive analysis takes into account a priori assumptions that researchers might bring into their interpretations of data, as well as drawing new and theoretical insights arising from inductively viewing the data. This approach fits well with my broad methodological approach of interpretive description (Thorne, 2016; Thorne et al., 2004).

I used MAXQDA software to organize and manage the data across the different phases of my research (i.e., transcripts, relevant correspondence from participants, field notes and documents). I started by close reading and re-reading of transcripts, whilst listening to audio/video recordings, highlighting interesting statements and making preliminary attempts at naming them, as well as making analytic memos. I initially started a process of open coding, line by line within the MAXQDA interface (see Appendix 4 for an example of this process), pulling out initial categories such as 'diagnosis', 'complexity' and 'multimorbidity'. However, I found these categories did not add any insight and I was simply pulling out and listing familiar words and phrases. This led me to move away from using the software platform and go back to *"alternative sorting options"* (Thorne, 2016, 161). This involved printing off hard copies of the transcripts, reading them alongside my field notes and making additional analytic memos in margins (Figure 2), on coloured post-it notes and then onto large A1 sized white boards (Figure 3).



CHASM 04 - ORIGINAL

I: So, you mentioned, you know, sending this patient over to the pain clinic. What are your experiences of working or interacting with them?

R: I think you were right when you mentioned that perhaps the pain clinic just sees the very, very tip of the iceberg, and I think, you know, patients might be waiting for eight or nine months for their pain clinic appointment often in the hope or the expectation that that's going to solve everything for them. And no matter how much you try and manage people's expectations, they do still cling on to that I think, and I think the pain clinic can be variably helpful for people. The patient I was talking about before, I specifically wrote a couple of times to the pain clinic very much asking whether they would address some of the psychological issues around her pain, and all they did was promise her another facet joint injection. So, that was quite frustrating, and she'd waited for months and months for that, and that in my experience is not a unique experience. So, I think probably we do end up holding most of these people in primary care with really quite little specialist support often.

I haven't... there's another patient who springs to mind who's an asylum seeker whose English is very poor and who is probably suffering from PTSD. He's a Syrian refugee probably suffering from PTSD and chronic pain as an element of that. And he went to the pain clinic and they weren't able to provide any kind of psychological treatment for him because English wasn't his native tongue. But then interestingly, when I wrote to the mental health team and asked for their input, they were able to provide some counselling with an interpreter, and I think we're going to address some of the issues that were feeding into his pain. So, that was quite interesting that actually, it wasn't necessarily the pain clinic that was providing the greater support in dealing with patients who've got chronic pain problems. And I think the other thing is these people are often really complex patients; they aren't the simple patients. And we're probably... I think probably we're reasonably good at managing the more simple patients who've got chronic pain often because they're patients who are more willing or able to engage. And so, the highly complex people who end up going to these extra services we get sort of often, I think, piecemeal help with rather than good supportive holistic help.

I: And again just bringing it back to earlier on, you mentioned that when they come to see you, you might try and offer them some techniques. Could you speak a bit more about that?

3 ORIGINAL

CHASM 04 - ORIGINAL

R: Yeh. So, sometimes I think it's just about trying to help them recognise that the kind of impact that say depression or comorbid depression or anxiety or other mental health problems might be having on their pain. So, it's about talking them through the evidence, often for my sort of quite educated retired professor type population, of how it is that our perceptions of pain may be experienced... may be exacerbated by those kind of things, and, therefore if you're able to change some of those factors, how you can try and relieve some of the impact of the pain. Sometimes it's about trying to help them work through what kind of things they could try and do to manage pain. So, often a lot of these people may become more housebound and socially isolated and lonely, and perhaps if you can address some of those things and introduce some company or some distractors, then actually the pain is less the prime focus of their life. And so, although you're not... that treating the pain is not the prime thing you're trying to achieve, actually you'll end up helping the pain by doing that. And the patient I mentioned in the beginning who's not really open to the idea of any kind of psychological factors, it... I've been quite firm actually, by saying that I don't think we won't... we aren't going to improve her pain unless we address some of those factors. So, honesty is probably an important technique as well, and asking... I think I said something like, 'There may be a very tiny part of you that's perhaps wondering whether what I'm saying is true, and I just wonder how it might be for you if we let that tiny little part of you actually listen and explore that a bit more.' So, some almost motivational interviewing or NLP type techniques for really difficult people. I don't know how helpful it is, it certainly hasn't been for her, but this is some of the things I've tried.

I: And is that something you've had additional support for or are you doing that on your own?

R: I've had a little bit of support as one of my trainers as a GP trainee had an interesting counselling. But really I haven't had any formal training, it's been trying to pick things up along the way, I think.

I: OK. And just thinking again like you said you're sending patients on to say the pain clinic, can you talk me through the process; what does that look like in terms of systems or?

4 ORIGINAL

***Figure 2*:** *Example of transcript with highlighted sections and analytic memos in margins*

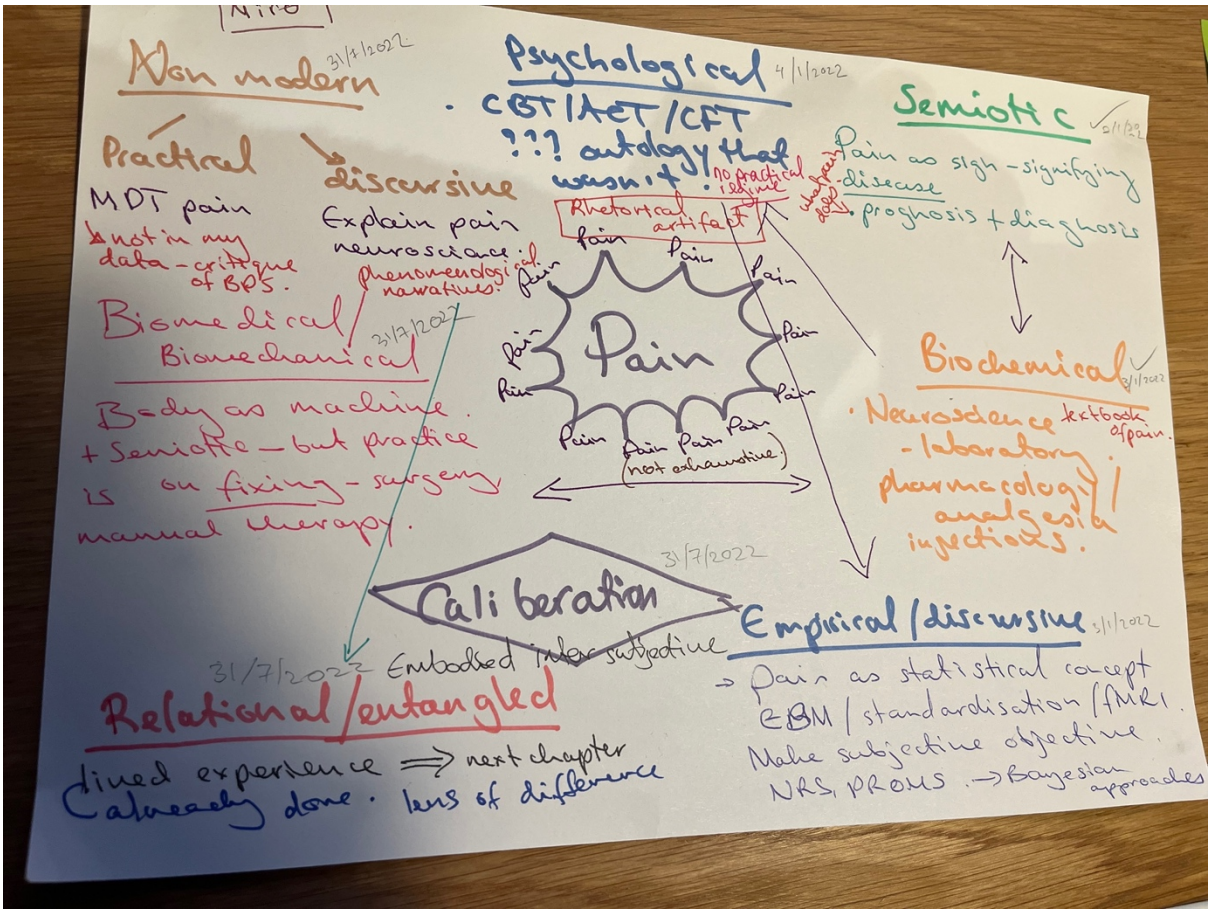


Figure 3: *Example of 'plugging in' theory to data as part of analysis and synthesis*

This more creative process helped me to start identifying thematic similarities. I made a conscious choice to resist highlighting familiar phrases and groupings, and started to attend to data extracts that detracted from my a priori understandings of self-management of chronic pain. I made note of memorable quotes by participants MAXQDA, then copied and pasted them into a word document with a location code (participant and transcript page numbers).

Guided by this process, I started developing analytic insights as I collected and reviewed initial data, refining this iteratively as/when I then collected further data. Early insights shaped my framing of my questions and influenced my line of questioning in subsequent interviews. Following my first interviews in Phase 1, I discussed my early insights with supervisors, testing out my early analytic thoughts. I structured them as what I call 'first order' interpretations, which included interpretive description of practitioners and (people with lived experience) that I followed through the policy analysis process. 'Second order' interpretations considered self-management of chronic pain as a whole drawing on social theory (e.g., boundary work within organisations (Leigh Star, 2010)) to explain my interpretations of these empirical findings.

As I proceeded with interviews and observations, I extended my analysis by drawing on existing theoretical perspectives. This process involved taking suggestions from my supervisors, participants and my own explorations/reading of relevant theory. I did not employ a single approach, but used an interpretive approach to reading the data while thinking with theory, making new connections and relationships among texts referred to as

'plugging in' (Youngblood Jackson & Mazzei, 2012). This involved selecting specific theoretical concepts that spoke most clearly to my evolving data analysis and weaving these together as my thesis unfolded.

Turning to the data collected with patient participants: I narrated the lives of each patient as a vignette using a mixture of free text "thick description", (Geertz, 2000)), supplemented by photographs and other materials generated or suggested by participants (see Table 5). Vignettes provided rich accounts of the practical and sociocultural influences and multiple interdependencies shaping people's approaches to living with chronic pain. I paid attention both to how and to what extent participants perceived self-management as relevant to their lives. I then identified people's experiences of self-management within and across vignettes, teasing out examples that contributed to people's ideas about 'living well'. I report a selection of these vignettes in Chapter 7 along with analytic insights informed by social theory (e.g., how people continually adapt their socio-material relations in the form of assemblages, to enable living with (and in) pain (Buchanan, 2020)).

Turning to interviews with policy actors and with health professionals and managers in the Shire, I analysed this interview data in the same way, paying attention to different perspectives on self-management of chronic pain and how services do (or do not) support patients. I considered national and local documents as texts and working with them to build an account of how the wider policy context shaped how self-management of chronic pain is enacted. Guided by interpretive policy analysis (Yanow, 2000), I extended analysis to identify key discourses shaping policy and debate around self-management of chronic pain. I took discourses to be "analyses of texts…orientated towards broad-ranging ideological

explorations of how particular texts achieve their effects" (Green & Thorogood, 2018, 219). In the analytic process, I identified discourses by focussing on how self-management of chronic pain was being framed by the various parties in the texts they produced, their symbolic artefacts (Yanow, 2000). For example, the discourse around self-management being an intervention delivered by expert health care practitioners. I provide further detail of how I identified the various parties and their artefacts in Chapter 8.

4.8 Synthesising analysis across the phases of my study

To synthesise analysis across each phase, I searched for threads, continuities and discontinuities, tensions and ambiguities (within and across levels) regarding how self-management of chronic pain is achieved by people who are not supported by pain management services. To do this I compared data from documents with statements, actions and interpretations made by (meso and macro-level) actors, and paid close attention to the interaction between micro, meso and macro levels (Caldwell & Mays, 2012). I also drew on relevant theory (e.g., Mol's (2002) concept of the body multiple applied to pain) to extend analysis from initial first order interpretations of emerging findings (see Table 3).

As analysis and synthesis progressed, my original intention to describe what self-management looked like in practice shifted towards an exploration of assumptions and how these assumptions played out in a complex and continually adaptive system. I adopted a reflexive approach that involved 'zooming in and out' of my data, a process which occurred whilst continuing to collect data. Following storylines across different phases and types of data, and tracing back to where the idea of self-management came from, what influenced the practice of self-management and what this looked like on the ground.

4.9 Ethics and governance

I applied for study sponsorship from the University of Oxford's Clinical Trials Research and Governance. The study was sponsored by the University of Oxford (Appendix 5). Ethical approval was given by London - Camberwell St Giles Research Ethics Committee on 1/10/2019. The reference number is 19/LO/1278 (Appendix 6). Health Research Authority approval was given on 1/10/2019 (Appendix 7). Capacity and capability approvals were provided by all participating sites. Minor amendments to the protocol were approved by the sponsor on 17/3/2020 and 13/11/2022 to accommodate for changed procedures due to the Covid-19 pandemic (Appendix 8). Identifying sites and securing local governance approvals was supported by the local Clinical Research Network where this study was adopted as a portfolio study.

My research methods (e.g., home tour, observations, and recorded interviews) raised potential ethical issues around privacy, confidentiality and anonymity and the relationship between researcher and participants. For instance, I asked people if I could spend extended time with them at home, which may have been potentially onerous for some. Being mindful of this, I scheduled interviews at participants' convenience, ensured breaks as required and was guided by participants as to the frequency and mode of contact that I had with them. All participants were also free to stop or reschedule interviews or withdraw from the study at any time.

Maintaining anonymity for those in (sometimes unique) policy roles, could potentially be difficult as the small number involved could allow readers to identify participants despite

anonymising using pseudonyms. I countered this by keeping my descriptions of participant's job titles relatively broad e.g., National Policy actor and avoiding the use of distinctive illustrative quotes that may reveal or suggest their identities. I also chose to anonymise my case study site to maintain anonymity for participants involved in meso level interviews. The case is typical for a town or city with a university teaching hospital providing health services, aligned with a local higher education institute e.g., university or college.

I convened a research advisory group in September 2019 including clinicians, academics, and lay members with experience of living with chronic pain to support the conduct of the study. Unfortunately, due to the impact of the Covid-19 pandemic (work pressures, shielding and illness) this group did not meet again after the first meeting. Its function was instead taken up by my academic and clinical supervisory team who supported ethical methodological improvisation within the scope of the project's regulatory approvals. The overarching ethical principle with which I engaged involved developing and maintaining a mature and productive relationship with the participants, enabling on-going negotiation about their participation in the study and permission to withdraw from the study. Ethical issues were a recurring agenda item in supervision and given as much discussion time as needed.

I recruited and met regularly (via videoconferencing) with a patient and public involvement (PPI) group. The group consisted of seven members in total who were invited in their capacity as patients or carers with experience of chronic pain. Three members were invited from a register in the university's database of public contributors and the other four were recommended by the research champions identified in Phase 1. Between five to seven

members attended each meeting which occurred twice a year. All members of the group received terms of reference and outlines of their roles including terms of remuneration. Members of the group received payment for their time of up to £30 an hour as recommended by national guidance (National Institute for Health Research, 2022). Payment was in the form of vouchers from the retailer of their choice. The PPI group supported my application for NHS ethics approval for the study, and capacity and capability assessments, by reviewing early drafts and commenting and co-producing lay summaries. I presented my early findings to the group and received valuable input into how my approach to analysis and theory could be practically meaningful for people living with pain. Speaking to the group about social theory gave me the opportunity to refine my thinking and to communicate ideas with a lay audience. For example, they supported the technique I adopted from Fox (2011) to depict assemblages as a horizontal list in Chapter 7.

4.9.1 Informed Consent

Participant Information Sheets (Appendix 9) and versions of the Informed Consent forms (initially written pre-pandemic, and then verbal in light of in-pandemic restrictions with sponsor and ethical committee approval) were presented to the participants detailing the exact nature of the study, what it involved, and any risks involved in taking part (Appendix 10). It was clearly stated that participants were free to withdraw from the study at any time for any reason without prejudice to their future care or employment, and with no obligation to give the reason for withdrawal. No participants withdrew from the study.

I sought approval from each participating study site, prior to approaching staff about the study. Staff and policy actor participants (Phase 1 and 3) were given up to 7 working days to

consider the information, and the opportunity to ask questions to decide whether they would participate in the study. Informed consent was taken at the start of the interview (written and signed for face-to-face interviews and verbal for remote interviews).

Patient participants (phase 2) were allowed as much time as wished (at least 7 days) to consider the information they received about the study, ask questions and, if they wished, speak with their GP or other independent parties, to help them decide whether they wanted to participate in the study. Interviews were arranged at a convenient time for participants (via telephone or email). During our initial meeting, verbal consent to participate in the study was taken and we discussed the extent of their involvement in the study. As set out above, I recognised that the level of engagement in the study would vary across participants with some actively participating in several interviews and taking me on virtual home tours, others participating in a single initial interview and follow up. I also recognised that, for some people, how they wanted to engage would change throughout the study. To address this, I built flexibility into the study, agreeing an initial plan with each participant and revisiting this with them at each meeting to review and make any changes, as needed. To avoid overburdening patients, I reviewed participation in the study regularly with each participant, seeking verbal consent at each meeting.

All participants received an email copy of the consent form (initialled, signed and dated by me) for their records. The original signed form was filed securely with other study materials.

4.10 Reflexivity and positionality

As discussed in Chapter 1, I was and continue to be embedded in the pain management professional community occupying clinical, strategic, educational, and operational roles. I brought these insider perspectives and local knowledge into my research thus situating myself as an informed researcher. My positionality shaped my interest in self-management of chronic pain and my previous experiences influenced how I came to my research questions, epistemology and resultant methodology. I adopted the position of participant observer trying to understand my topic from within (Thomas, 2015). While this identity was helpful in recruiting my case study sites and participants, as well as in negotiating access to the field, I was also aware of my power position relative to different participants throughout my research. For instance, as a clinician with unequal institutional power relative to people living with chronic pain, as a peer when interacting with staff participants, as a relatively powerless researcher when conducting 'elite' interviews[7] with policy actors and, as a racially minoritized black woman interacting within majority white spaces.

I made contemporaneous field notes to record observations, reflections and analytic memos throughout the research process taking note of where (and how) my perspectives outside my researcher role contributed to my research practice and analysis. I also kept a reflexive diary to encourage my awareness of analytic 'closeness' and 'distance' from my data and to foster my ability to treat the data theoretically rather than unduly privilege a health professional lens (Green & Thorogood, 2018). Parts of this diary included regular observations from my clinical work, specifically drawn from weekly multidisciplinary

[7] Interviews with those who are relatively more powerful than the interviewer (Green & Thorogood, 2018, 136)

meetings that I attended. I include an extract from my diary below, showing how I started to adopt a more critical view to the received wisdom and assumptions within my work as a physiotherapist and orient me towards more sociological thinking:

> *I found that, the focus of the conversation was almost entirely on personal responsibility and resilience. When I asked about structural issues that may have been contributing to this current presentation, I did not feel that anyone was with me on this. So, I thought I would spend the next few weeks attending to the discussions around complex patients with opioid dependence through a 'sensitising' lens of personal responsibility vs socio-cultural explanations. I will not limit myself to just these lenses but will also note other interesting themes*. (Extract from reflexive diary, May 2019).

I have sought to continue this reflexive process throughout my research. To this end I write reflexively throughout my thesis, adopting first person language and inserting myself into the data through my writing and reflections.

4.11 Summary and conclusion

In this chapter, I have set out my aims, research questions and objectives alongside my methodological approach which is grounded in an interpretive paradigm and guided by an interpretive description approach which seeks to focus the object of study on applied health matters. I have discussed the interdisciplinary underpinnings and theory that guided my research design, data collection and later analysis. I have given a detailed and reflexive account of how I carried out my research, including use of an intrinsic case study to examine the process of self-management of chronic pain at macro (national policy), meso (organisational) and micro (patient and practitioner) levels.

I now turn to present my findings. In the next chapter, Chapter 5, I present the overall case study of self-management of chronic pain in the Shire attending to how different actors conceive and work with the concept. In Chapter 6, I focus on how multiple ontologies of pain are enacted throughout the Shire. Chapter 7 turns to the experiences of those living with chronic pain and shows how they do so through embodied and subjective socio-material entanglements. Finally, in Chapter 8, I account for how macro level influences have (and continue to shape) the reality of how self-management of chronic pain is conceived and enacted in the English National Health Service.

Chapter 5: Complexity in pain management

5.1 Introduction

In this chapter, I introduce my case study of the self-management of chronic pain located in a single county in the south of England (which I refer to as 'the Shire'). I provide a detailed account of services that offer support for people living with chronic pain. These include services formally commissioned as pain management services and those not formally commissioned (as pain services) but offering services for people living with pain. I return to John's narrative throughout the chapter, grounding my account of self-management of chronic pain within patient experience. Drawing on data from documents, narrative interviews, and observation of healthcare sites, I argue that chronic pain is experienced and managed within a complex adaptive system. A complex adaptive system is "a collection of individual agents with freedom to act in ways that are not always totally predictable, and whose actions are interconnected so that one agent's actions changes the context for other agents" (Plsek & Greenhalgh, 2001, 625). In this case study, it is a system exposed to repeated rounds of technocratic re-organisation, driven by a neoliberal political agenda. The actors within the system respond by retaining and reforming informal, relational professional networks that bypass and 'work around' externally imposed, more formal 'care pathways' in order to continue providing *care.* I introduce a range of sensitising concepts (Blumer, 1969), to inform my analysis and examine the tensions between the linear, top-down operational models that tend to dominate the Shire's health care system and the hidden, more complex, relational and distributed ways of working that characterise the everyday practice of professionals working in pain management and the experiences of

patients. I highlight how the complex and multidimensional nature of chronic pain is variably dealt with within these structures and how this complexity is accounted for. I conclude by proposing that self-management in the Shire can be conceptualised as a boundary concept (Allen, 2009) that serves as a place holder for different meanings, many of which have been under-explored. I will unpack these further in Chapter 6,7 and 8.

5.2 The Shire: a case of self-management of chronic pain

My research is concerned with a specific case of self-management of chronic pain in the Shire. Most hospital and community services in the NHS in England are commissioned by local clinical commissioning groups (CCGs), that determine what services are available locally[8]. CCGs are groups of GP practices (including patient representatives), managers and other health professionals who are tasked with planning and commissioning services for their specific locality and, in my case, for the residents of the Shire.

As I was designing my research, I anticipated that the case would have a fixed boundary (both geographical and administrative), around those services formally commissioned by the Shire CCG which broadly aligned with county boundaries. While conducting fieldwork, it became clear that this was only partially true. Although many of the services I was interested in were situated within a specific geographical area, the boundaries were porous. Patients did not always stick within these boundaries when choosing and accessing services for pain. Professionals moved between services within and outside the county, often working in dual roles as the configuration of services changed in response to different

[8] CCGs have now been disbanded but this was the case at the time of conducting this research

readings of both local and national policy directives. This made it difficult to define clear and distinct case boundaries. I therefore chose to focus on how *this* particular geography of the Shire organises self-management of chronic pain as planned, whilst recognising this movement of actors back and forth across the boundaries. As set out in Chapter 4, I approached this through a 3-dimensional lens, attending to the local context of where services were located (geography), the local history of service reorganisation and wider policy change, whilst following instances of self-management of chronic pain across space and time (Segar et al., 2015).

My focus was on how people who have been excluded from or dropped out of pain management services self-manage their chronic pain. People living with pain often seek support from multiple people and places (Breivik et al., 2006; Burke et al., 2018), including NHS commissioned services (I will call these 'formal services') as well as other sources of support that are not formally recognised as pain management services (I discuss some of these differences in Chapter 2). I chose to focus on the Shire as it provided a pragmatic, geographical area where formal pain management services are commissioned by a single clinical commissioning group and provided by a small number of providers with mixed public and private provision. The pathways into and through these formal services are locally determined and shaped by organisational practices and norms. There is also varied provision for pain management by the independent and charitable sector. I included these services in my case study only where they formed part of the NHS commissioned formal services. My insights into the kinds of support provided by informal services were gained through interviews and observation of people living with chronic pain (see Chapter 7).

The Shire offered a multi-level case study of self-management of chronic pain, enabling me to appreciate individual experience, organisational context (including operational procedures shaping access to pain management services), and relevant national policy. The formal configuration of NHS pain management services in the Shire share many features with NHS provision in other parts of the UK. For example services include: medically-led pain clinics located in secondary care with limited involvement from professionals of other disciplines; pain rehabilitation programmes run by physiotherapists or psychologists (or both) located in community and secondary care (National Pain Audit, 2012).

5.3 The cartography of pain care in the Shire

The Shire has a population of approximately 700,000, one third of whom live in rural areas. Despite relative affluence, there are pockets of poverty and deprivation in both rural and urban areas. There is a growing homeless population concentrated in more urban areas. There is a higher proportion of older people across all areas compared to the national average. The main city in the Shire is home to three higher education institutions resulting in a high term-time student population. The main NHS Trust – Foundation NHS Trust (a large acute teaching Trust) provides many essential services. Many of the hospital sites are located in the city, so many of the county's residents travel long distances to access secondary care. Health and care providers also offer services in the north of the county at one of the hospital sites. Community services are provided by a mix of NHS, social services, local county council, voluntary and private providers across the county.

There are a number of services at Foundation NHS Trust (a pseudonym) for people experiencing pain. The majority of hospital services (e.g., orthopaedics) target treatment at

the underlying pathological diagnosis contributing to pain. People with chronic 'primary' pain, where the focus is on treating or managing the pain itself rather than managing pain as a symptom of an underlying condition (Smith et al., 2019) are supported by two pain services each with slightly different treatment approaches. These formal pain management services are largely located within the two acute hospitals, both of which can be found in the county's main city (see Figure 4 for a fictionalised map representing the different services).

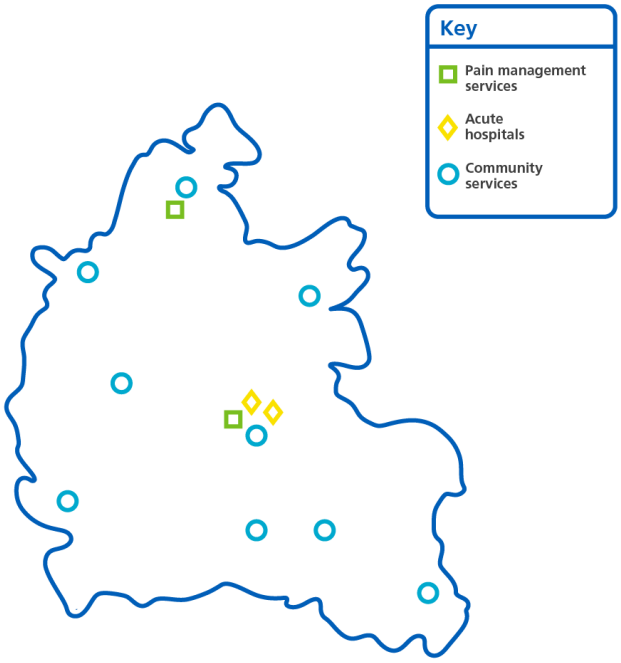


***Figure 4: Fictionalised** Map of the Shire County Pain Management Services*

People living in the South-East, West and North of the county, were further away from these formal pain services than those in the rest of the county. In terms of national, formally recognised, dedicated pain management services: the National Pain Audit mapped pain management services in England and Wales from 2010 – 2012 (National Pain Audit, 2012), and identified only a single pain management clinic in the Shire, run by Foundation NHS

Trust. This was a similar finding in many areas of both England and Wales. This clinic (Pain Management Centre) is an established pain management provider for the county, but other services are also available including a second, rehabilitation focussed service (Pain Rehabilitation Unit). The national audit only included the medically led NHS services providing pain treatment approaches and excluded other models of service provision (as discussed in Chapter 2) though it is not clear how this was decided (National Pain Audit, 2012).

In this chapter, I will foreground patients' lived experiences of self-management of chronic pain whilst also contextualising these experiences by juxtaposing them with accounts offered by service providers. To do this, I introduce John whose experience of chronic pain illustrates the challenges of negotiating access to pain management in the Shire.

5.4 Negotiating access to pain management in the Shire

In this section I highlight *how* people living with pain, who (like John) have struggled to access formal specialist pain service support, do 'self-management'. I outline the differing and changing preferences for the type of care people living with pain may have, from biomedical approaches centred on diagnosis and care in the first instance to more psychosocial support over time.

John is a 50-year-old white British man who works as a secondary school teacher. He lives with his partner in the city and enjoys walking in nature, listening, and making music and reading. He is also a big football fan and has been following his club for over 40 years. He is very close to his family and regularly brings them up in our conversations. John has had pain

in his face, front teeth, and jaw since 2006 following a routine dental procedure (a filling for a cavity). Following his visit to the dentist, the pain did not ease as expected:

> *"I think it was... I think the pain... the pain's actually been worse after the treatment than it ever was before it, is my view at the moment"*

He had started taking prescription and over-the-counter medications to help with the pain and continued to do so as he waited for the problem to resolve. At a routine follow up appointment later in the year, his primary-care dentist was alarmed at John's ongoing pain issues and, as he describes in the extract below, he was then referred to see an oral surgeon for a specialist opinion:

> *"Yeh, I mean I went to my dentist after the first two operations with a list of exactly how many painkillers I was taking and that was the first time I saw him look really worried and that was what led to the initial... sorry, I'm pedalling back a bit in my story, but that's what led me to get to oral surgery."*

The oral surgeon gave John a diagnosis of *atypical odontolgia and/or atypical facial pain*[9] and advised him to continue to take his painkillers, which he did. There was no specific treatment for the pain as his investigations did not reveal any new or significant pathology that could have been causing it. He then saw a second oral surgeon in 2008 who confirmed the diagnosis and referred him to the Pain Management Centre[10] at Foundation NHS Trust for further specialist pain treatment. This encounter stuck in John's mind as he remembers the language the clinician used in particular detail:

[9] Atypical odontalgia also known as atypical facial pain is characterized by chronic pain in a tooth or teeth, or where teeth have been extracted where there is no dental cause identified for ongoing pain problems (Merskey & Bogduk, 1994).

[10] I provide a more detailed description of the Pain Management Centre service in section 5.4.1

> *"But eventually, one of the oral surgeons, I think the second one I saw at Foundation NHS Trust, said that 'this was ridiculous' [i.e. John's second referral], were his exact words; it wasn't a... 'yeh, I know that makes you feel a bit strange' but I kind of get where he was coming from. In other words, there was nothing he could do surgically, so why on earth was yet, another oral surgeon.... So, he was quite plain speaking, but I think sometimes that's kind of an advantage really. And I think that was the first time that I came out of an appointment and was in tears because it was a recognition that I needed help and some kind of light I suppose that would..."*

John was relieved at this acknowledgement of his suffering and looked forward to receiving much needed help with his pain, what he described as *"some kind of breakthrough in terms of treatment"*. People experiencing chronic pain often have a strong desire for a medical diagnosis as this legitimises their largely unseen concerns and is seen to be the first step in finding a biomedical treatment and/or cure (Toye et al., 2017). However, it would take three years from his initial pain and subsequent diagnosis, before John had his first appointment at the Pain Management Centre in 2009. Once he was under their care, he continued to receive fragmented and delayed care, within the service, he continues:

> *"But yeh, I ended up seeing... the same consultant twice actually; there was a big gap between first seeing the consultant. And there was some psychology backup then as well as seeing the consultant, pain consultant twice. I had two sessions with the pain psychologist, which at that stage were just sort of little interviews; there was no group work attached to that, it was just..."*

Long waits are common for specialist pain management services (Breivik et al., 2013) and people waiting for chronic pain care experience severe pain symptoms, increased psychological distress, disruption to their quality of life and increases in their medication dose and strength (Burke et al., 2018). John's experience reflects these findings though he

attributed his experience of delays in accessing treatment to the complexity of his condition saying, for instance, that pain is just so *"difficult to treat"*.

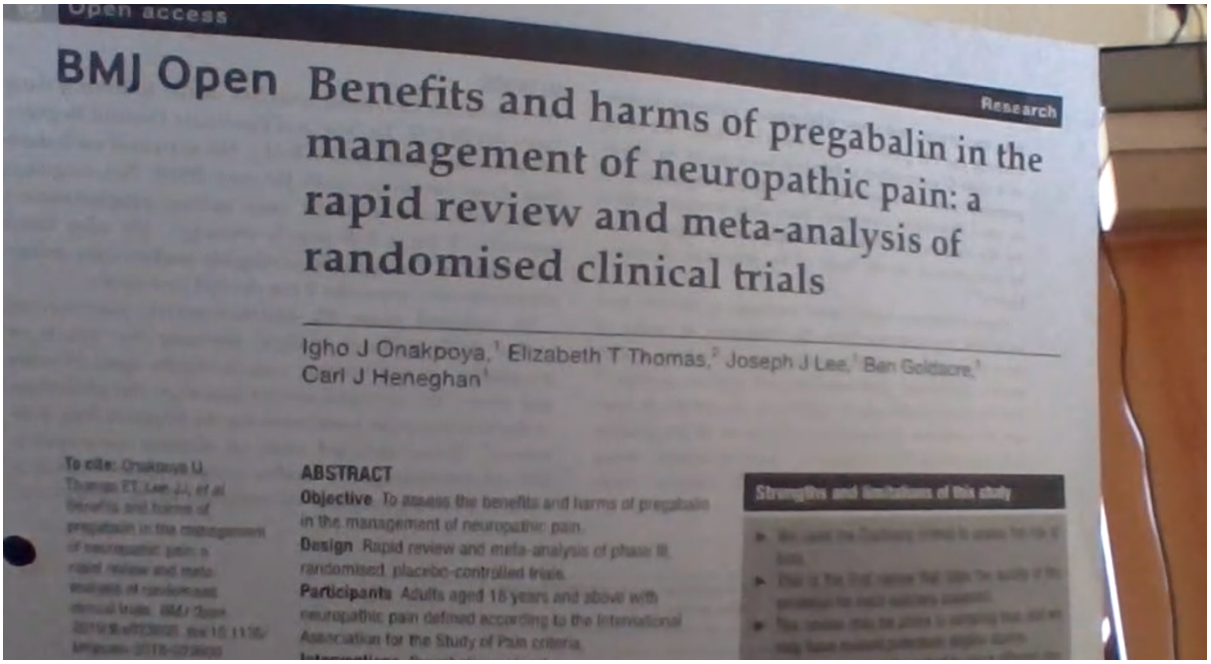
In the first few years after the onset of his pain, John was focussed on finding a medical resolution for his pain. He saw the pain consultant as the key professional to support him. The psychologist on the other hand, was *"backup"* and did *"just sort of little interviews"*. John found living with pain to be burdensome. He had to constantly monitor his pain and try to keep on top of it by limiting his activities (including work and hobbies) and taking his medication. He took up all the offers of help or support that came his way. His life was disrupted by the unpredictability of pain. He tried to describe his symptoms to me by drawing on more common and familiar experiences, but these attempts seemed to be inadequate. He hesitated and his speech faltered as he started and restarted his sentences. He switched to the medical diagnosis and language as if that offered more certainty in describing his pain:

> *"So, I found that the kind of... so, the type of pain, it feels a little bit, when it starts, as if you've bashed what we colloquially call the funny bone - you know, when you get that sort of... So, I describe it as a twinge, but it's not a spasm in the sense that my mouth's moving, you know, it just feels like that kind of sensation. So, I started to talk about a diagnosis, so atypical odontalgia and probably neuropathic in origin. So, that diagnosis with the neuropathic bit in, kind of ties in with this generally nerve sensation, I guess. But then it eventually, if that goes unchecked, in other words if I don't stop or I don't take painkillers or maybe a bit of both, that eventually leads to burning pain, which means I'm basically out of action. I can't... I certainly can't work; I pretty much can't do anything else. Music's probably my biggest... well it is my biggest hobby and I can't even listen to music when it's at its worst; I don't know what to do with myself when it's at its worst."*

John has been reliant on painkillers since the onset of his pain in 2006, with clinicians prescribing different regimes in the hope of managing the pain better. He knows how the different drugs are supposed to work and has become aware more recently of the risks and harms of being on controlled drugs for his now long-term pain. After reading in a newspaper article that Gabapentin and Pregabalin[11] had serious side effects and were considered problematic and potentially addictive, he started to do his own research about drugs (see Figure 5) and talked with his GP about his concerns. He asked friends who worked in research to help him identify high quality research that would backup his own experiences of side-effects. He was not confident that his testimony alone would be believed. Despite his ongoing concerns about medicines he did notice a slight improvement in his symptoms when he was switched from Gabapentin to Pregabalin in 2019 by his GP:

> *"So, in terms of treatment, I was started on Gabapentin by one of the oral surgeons actually; that's how I first started being given Gabapentin. So, that probably happened about 2009ish, I guess. So, I've been on drugs for it since then. Relatively recently I've switched to Pregabalin and my experience is that that has... has led to some improvement. So, it was when I first saw the consultant back in 2009, again I think... I think even at that stage Pregabalin was around, so it was seen as a potential one to switch to. And I don't know what took us so long, or me so long, in thinking I ought to try another one, but actually I've had probably about a year and a half now on... fully on Pregabalin. There was a few months where I switched where the dose was titrated up for the Pregabalin and down for Gabapentin as they evened out. So, I think even while that was happening, I noticed a difference."*

[11] Gabapentin and Pregabalin are medicines that were originally used as anti-convulsant agents for conditions such as epilepsy. They are recommended to treat specific cases of nerve pain (also called neuropathic pain) and in 2019, the UK government classified them as Class C drugs due to concerns around misuse, addiction, and increased mortality (Mathieson et al., 2020).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Research

Benefits and harms of pregabalin in the management of neuropathic pain: a rapid review and meta-analysis of randomised clinical trials

Igho J Onakpoya,[1] Elizabeth T Thomas,[2] Joseph J Lee,[1] Ben Goldacre,[1] Carl J Heneghan[1]

ABSTRACT

Objective To assess the benefits and harms of pregabalin in the management of neuropathic pain.

Design Rapid review and meta-analysis of phase III, randomised, placebo-controlled trials.

Participants Adults aged 18 years and above with neuropathic pain defined according to the International Association for the Study of Pain criteria.

Strengths and limitations of this study

Figure 5: *Screen shot of academic paper on harms of Pregabalin that John used to support his case against having it prescribed (from online interview).*

Since his initial interaction with the Pain Management Centre in 2009 and the appointment with the pain consultant, John spent 10 years *without* specialist support for his pain, self-managing by default. He worked with his GP to up-titrate the doses of his medication to get on top of his pain. He repeatedly asked for another referral back to the Pain Management Centre, again hoping for treatment that would resolve his pain. He was told by his GPs that this was not possible as he did not meet the criteria for a new referral, namely that he be on the maximum available dose of his medication:

> *"And at the time I found it a little bit disappointing that the two GPs said that I should be on the top dose for Pregabalin before I have a referral to the pain clinic, which at the time I just thought, 'Oh, well OK, it's just a kind of... just a stage I have to go through.' And I could see their reasoning at that stage, but what I found really surprising is eventually, out of that further two consultants appointments, so roughly*

ten years apart and it's 2019, I think when I saw... 2018/19, yeh, it's about a ten year gap, they then started at the pain clinic to have these group sessions, which sounded really positive to me because I hadn't really spoken to anyone else with chronic pain really, I guess."

John's next interaction with the pain clinic came 10 years after his first encounter. By then his prescription for Pregabalin had reached the full dose of 600mg a day. By his account this qualified him for a re-referral back to the Pain Management Centre. I found no written evidence for this requirement in referral documents and criteria for being seen at the Pain Management Centre. Clinical staff at the Centre assured me this had never been their policy. However, the idea that specialist pain clinics are a 'last resort' is commonly held and is related to long held biomedical conceptions that pain is a symptom and therefore a referral is only indicated when nothing else can be done (Nicholas, 2004).

John's expectation and hope at the time was that his medication dose would be lowered, and he would be offered alternative treatments though he was unclear what these could be. In a meta-ethnography exploring the experience of living with chronic pain, Toye et al found that in time, people with chronic pain often decided to *"end the quest for the holy grail"* (2017, 9) of diagnosis and cure and instead shifted to a stance of living with pain. John appears to have been in the process of making this shift, seeking to reduce his reliance on medication and seeking to work with a psychologist to manage the impact the pain was having on his mood. He had also heard from colleagues about group programmes for pain and was interested in attending these as he had not met anyone else who experienced pain quite like he did. John attended a single group programme session at the Pain Management Centre before these were cancelled due to the Covid-19 pandemic restrictions in early 2020.

He continued to wait for the service to reorganise provision of the hoped-for group programmes. However, the service opted to convert group programmes to what they called 'guided self-management' using standardised materials and psychologist support via the telephone. In advance of any appointments, John had already found a list of resources on the Pain Management Centre's public website and bought two books which he began to work through on his own (see Figure 6).

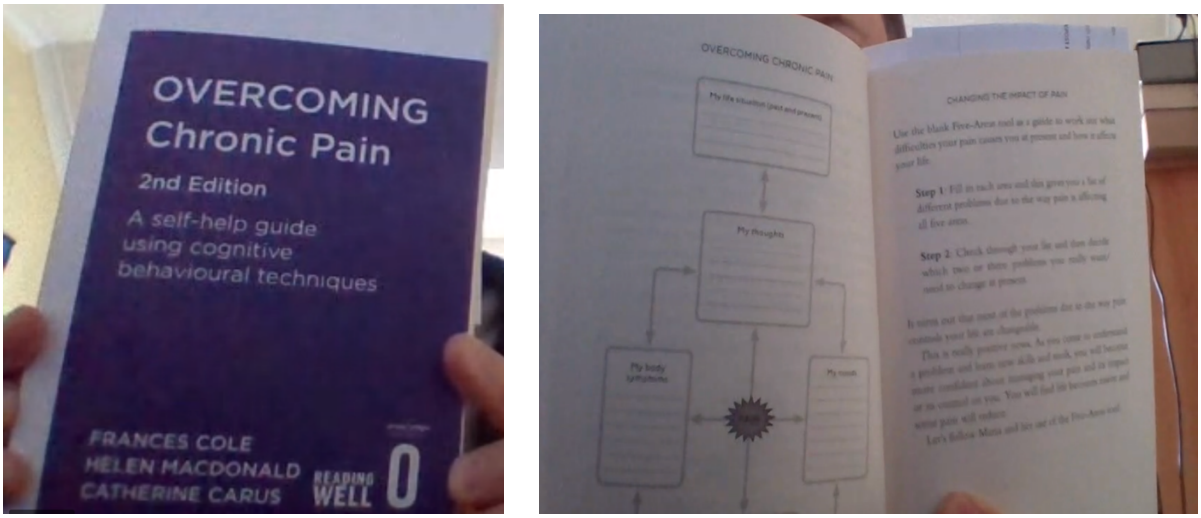

Figure 6: *Screen shot of main workbook used at Pain Management Centre that John had been working through (from online interview).*

John completed six weekly telephone consultations, including homework tasks between sessions. During his psychology sessions, he had continued to ask the about his continued use of high dose Pregabalin and each time, been advised to speak to his GP about reduction. Though his sessions with the psychologist had been helpful as he said, in helping him *"live well with pain"*, he remained uncertain about what to do about his medication and was planning to ask to have a review with the pain consultant. Contrast John's experience with this view from a psychologist at the Pain Management Centre:

> *"I suppose... because I think self-management is important for most of our patients, probably everybody. So, probably the only times where we wouldn't see somebody are when they are very clearly asking for medical intervention and aren't interested in seeing or sort of thinking about self-management, or where, I suppose where people are already doing a lot of self-management and it doesn't feel like we can kind of helpfully add anything." (Psychologist, 16)*

Gaining access to specialist pain management services does not necessarily mean that patients will have a good outcome regarding their pain. Different clinics employ a variety of delivery models and methods to assess their effectiveness (Nicholas, 2004). Many use psychometric measures evaluating e.g., pain interference, psychological functioning, and disability. Based on such measures, patients attending a specialist pain clinic in London, only 41% of patients reported at least a moderate subjective improvement (Shah et al., 2015). Knight et al (2019) in their paper reviewing the destination of patients referred to a tertiary level pain clinic found that 47% were discharged following assessment and before receiving any treatment. Reasons given included, patients not being ready for the approach offered or having complex psychological concerns that needed to be addressed before pain management.

John did much hidden work that enabled him to live with pain, between brief episodes of interacting with pain management services. Though this work was not always acknowledged, his preparatory work positioned him to advocate for a referral and to present himself as a good candidate for the service. He was already familiar with the more formalised work required of him by the service prior to attending his psychology sessions. John encountered different healthcare professionals tasked with helping him with pain. The professionals and the services they worked in, held particular and sometimes differing views

of John's pain which did not necessarily align with his own ways of knowing his pain. As such, John could be said to have experienced epistemic injustice. Fricker (2009) posits, that a person experiences epistemic injustice when they are wronged in their capacity as a knower. The configuration of services in the Shire did not allow for John's particular way of knowing pain that included evolving biomedical and psychosocial notions and as a result, did not afford him the opportunity to access *both* types of pain care though they were available. His hidden self-management work was not afforded the same significance as the formalised version of self-management he carried out with the psychologist. This was not a deliberate injustice perpetrated by individual health professionals attributing a lower level of credibility to patient testimonies, (what Fricker further distinguishes as *testimonial injustice*). Instead, this account of epistemic injustice is aligned with Fricker's concept of *hermeneutical injustice*, where the structural aspects of a system lead to a collective shortfall in shared conceptual resources and in this case contribute to inadvertent harms to those seeking pain care.

I have used John's case to foreground the experience of living with chronic pain and the challenges faced when seeking care in a system that is not well understood and where pathways to care are unclear. I have highlighted some of the issues in terms of gatekeeping into services. I now turn to the organisation and delivery of pain care in the Shire, exploring how different conceptualisations of - and assumptions about - pain influence service provision and the potential impact this has on those seeking care.

5.5 The epistemic organisation of pain services

Pain management services in Shire were broadly organised around distinct epistemic communities with explicit connections with particular disciplinary and scientific knowledge and practices. Epistemic communities are formed by networks of experts, creating knowledge (Haas, 1992) and generating discourses that shape service delivery (Wagner et al., 2019). Though these epistemic communities were broadly organised around services with common goals and were co-located in shared spaces, the boundary between them was not an organisational unit, but rather a set of ideas and practices that were aligned with how services were organised. Below, I use the organisational unit as a starting point from which to explore the work these epistemic communities delivered.

5.5.1 The Pain Management Centre

The Pain Management Centre is a medically led clinic that has been running in different iterations for 30 years. It is recognised regionally by clinicians as a centre offering often pioneering care for people experiencing both acute post-surgical and chronic pain. From its inception in 1970 when it focused primarily on pain relief for post-surgical pain, it developed minimally invasive pain management interventions, such as continuous epidurals for post-operative pain and injections for chronic pain. The stated purpose of the service is providing care for those with complex chronic pain conditions. Their public facing website does not foreground the more medically focussed treatments, instead stating:

> *"Chronic pain remains difficult to treat with no easy solutions. What we do now is to support patients to cope with their pain and to have a good quality of life despite their pain, using exercise and self-management."*

The main site is at the city centre hospital with an additional satellite clinic in the north of the county offering a limited range of pain consultant sessions, about once per week. The Pain Management Centre is staffed by six pain consultants (some of whom have dual roles in anaesthetics and inpatient pain), two part-time pain clinical psychologists and two specialist pain nurses (also working in the inpatient pain teams delivering care for post-operative patients) (see Figure 7).

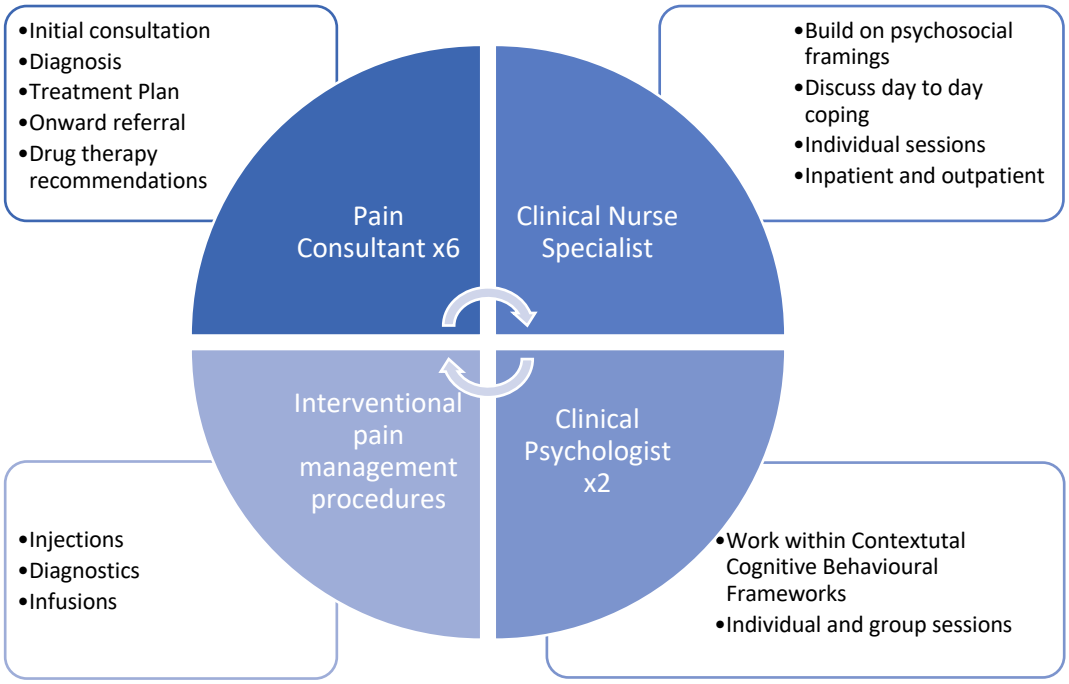

Figure 7: *Graphical representation of my interpretation of the Pain Management Centre roles and how they interact*

All referrals to the Pain Management Centre (including GP referrals) come through a single point of access triage service run by Pain Ltd (an NHS commissioned private provider)[12].

[12] I provide further detail about this service in section 5.6 below

New patients to the service first meet with one of the consultants for an assessment, following which, they may receive a diagnosis and explanation of their symptoms, further investigations, and a treatment plan. These explanations usually adopt neurophysiological terminology (grounded in biomedical understandings), to try help patients understand that pain may persist in the absence of obvious tissue damage. Pain consultants make suggestions for medication management via letter to the GP who takes on the prescribing work. They may suggest and conduct minimally invasive pain procedures such as injections for pain relief. Any new prescriptions or changes to existing regimes are sent to the referring GP via letter to action. The pain consultant role here appears to be focussed on symptom relief or symptom management using traditional biomedical tools.

Patients also meet with a psychologist and nurse on the same day for further assessment of the impact of chronic pain attending to more psychosocial concerns. Information leaflets and appointment letters for the centre state that patients may expect to be in the centre for "between one and six hours" for these multidisciplinary assessments. They are also asked to "allow one hour to find a parking place". There are plans to address this attendance burden for patients by running multidisciplinary assessments with all three professionals in the room at the same time.

The psychologists are concerned with supporting patients to understand and address the psychological impact of living with chronic pain, mostly drawing on contextual cognitive behavioural models (McCracken et al., 2007). They play an important role in framing any treatment or intervention for long-term management and introducing what they describe as "self-management approaches". The Pain Management Centre started offering a psychology

led group programme in late 2019. It is guided by the principles of a pain management programme (British Pain Society, 2013) but does not include a physical rehabilitation component nor the support of physiotherapy or occupational therapy. The focus is on providing an environment for peer support along with psychology treatment. Part of the drive to develop group programmes was to manage the increasing demand for psychology support as the clinic moved away from its historic roots of interventional pain medicine and drug driven approaches. Psychology capacity was recently increased with the recruitment of a part-time psychologist in recognition of the complex psychological issues that patients presented with. One of the psychologists also works in the Pain Rehabilitation Unit (see section 5.5.2 below). Historically, the Pain Management Centre did not offer psychology services or group programmes. There were plans to have the specialist pain nurses contribute further to the group programme – delivering more of the content as a specialist nurse said *"on much more of a fifty/fifty basis",* making it more multidisciplinary. She described the programme:

> *"what we tend to do is the first two sessions are very kind of probably more scientific based, so the nurses do a lot more talking on pain mechanisms and what is chronic pain, what's acute pain and helping them to understand that. And then as we progress through, you know, through the programme, we'll do things like relaxation practice, a lot of self-compassion talk; we might do some CBT based like little exercises." (Nurse 6)*

The centre runs two nurse-led follow up clinics with capacity to see eight patients a week along with pain education sessions supporting up to 24 patients a month. Patients are invited to attend either of these following their initial consultant appointment. The

specialist nurses also work in the acute post-surgical inpatient pain team rotating between services every six months, allowing them to apply their expertise in the different settings.

> *"So, when we're doing the inpatients it's very much a post-surgical, although we do get acute and chronic patients coming through emergency departments, so there is always a little bit of that self-management side that can kind of infiltrate into that side of my job because if you've got someone sitting in an acute bed when there's nothing on a scan, they... you sometimes need them to understand that, you know, we can't do something here but let's talk about what you... we can, you know, do for you at home." (Nurse 6)*

Psychology and nurse participants equated their work with the concept of self-management, and this was reflected in the materials and documents they referenced and used in their practice. Self-management was seen as an approach that needed to be skilfully presented to patients.

> *"... they're not going to just take that on board in one meeting; you have to build it up and gain their trust and talk to them, and that's the side that I absolutely thrive off that; I love it." (Nurse 5)*

The detail of what constitutes self-management was unclear and seemed to encapsulate a range of ideas and practices including what this nurse refers to as *"extra things…like relaxation, self-compassion"*. Like John, the specialist nurses appear to separate their work between scientific based explanations and medical treatments, and self-management and psychology referred to above as *"little exercises and extra things"*. The psychologists saw their work within specific psychological models as *doing* self-management work or offering self-management support. They achieved this by using tools such as manuals and books (see e.g., Figure 6) to guide patients through specific topics and tasks and collecting extensive

psychometric data to evaluate the effectiveness of their standardised interventions. The use of these standardised tools in turn appears to have then reified this particular conception of self-management within the Pain Management Centre as both, shorthand for psychological interventions and of the desired outcome for patients.

In a case study of care pathway development, Allen (2009) argued that the looseness or imprecision of care pathways allowed them to be inscribed as *boundary objects* which facilitated communication, cooperation and collaboration between groups where tensions exist in how care is offered, taken up and managed. The loose descriptions allowed different actors to apply their own specific meanings to concepts whilst keeping the appearance of some level of agreement. In doing so, members of different groups were able to work around or even gloss over disagreements and tensions. In this case, self-management of chronic pain acts as a *boundary object* that though used ubiquitously by participants in this study, held different meanings for different professional groups working together. The doctors, nurses and psychologists all talk about self-management but, they apply different meanings to the term. Self-management here is open to interpretive flexibility and allows these groups to work together without consensus, all aspects of boundary objects (Leigh Star, 2010).

The psychologists practice involved utilising relatively structured sessions couched in modernist perspectives for understanding the mind. They did not bring up or directly deal with issues of the body e.g., exercise, contrary to the service website suggesting this was part of self-management. The nurses practice appeared to adopt a more flexible position, often straddling both body-centric and psychological positions. They identified and worked

with patients who did not neatly fit into the other, often more routinised parts of the centre. One of the nurses describes this work:

> *"And then of course we've got all the voicemails and telephone calls, so if anyone's struggling at home we have a voicemail line that they're free to use as long as they're an active patient. So, they can email us, and they can call us, and it might just be, you know what, they've had a rubbish week, they just want to tap in with someone to say, you know, just to calm down or just to ask a question. So, the... we tend to ring them back and we do ring them back within twenty four to forty eight hours as long as it's not a weekend, and then, you know, sometimes you could be talking to them, you know, five minutes; other times I've spoken to people on the phone for thirty minutes, you know, so it's not a formal kind of nurse appointment but it's just a point of contact in case they feel like they're just, you know, no-one's listening." (Nurse 6)*

The participants working in the Pain Management Centre and their public facing materials suggested that the service offered a range of treatment options for patients of varying complexity and the option to work with a multidisciplinary team using biopsychosocial principles. This specialist nurse reflected:

> *"I think we have the opportunity to really like really invest time into getting people into coming to speak to us about things that aren't just about diagnostic procedures and having injections. I think there's a massive shift now from where it was, but even from… in my… beginning of my, you know, nine years to now, our focus is so much less on just sticking a needle in and hoping for the best. It's more about like the whole person and that holistic kind of approach." (Nurse 5)*

This was not view of others in the system. Participants within general practice were critical of what they saw as an overly biomedical orientation and reliance on increasingly problematic medicines and held a different view of the service perhaps reflecting the most

recent history of the service. Those working outside hospital services recalled varied experiences in their interaction with the Pain Management Centre with mixed experiences of support from the clinic. There were some critics of the perceived inaccessibility of the specialist service to more complex patients who clinicians found difficult to support in primary care, with a local GP describing an example of how they had to work around the service to access care for their patient:

> *"…there's another patient who springs to mind who's an asylum seeker whose English is very poor…He's a Syrian refugee probably suffering from PTSD and chronic pain as an element of that. And he went to the pain clinic and they weren't able to provide any kind of psychological treatment for him because English wasn't his native tongue. But then interestingly, when I wrote to the mental health team and asked for their input, they were able to provide some counselling with an interpreter, and I think we're going to address some of the issues that were feeding into his pain. So, that was quite interesting that actually, it wasn't necessarily the pain clinic that was providing the greater support in dealing with patients who've got chronic pain problems. And I think the other thing is these people are often really complex patients; they aren't the simple patients. And we're probably... I think probably we're reasonably good at managing the more simple patients who've got chronic pain often because they're patients who are more willing or able to engage. And so, the highly complex people who end up going to these extra services we get sort of often, I think, piecemeal help with rather than good supportive holistic help." (General Practitioner 4)*

The resignation that the GP quoted above expressed in relation to their Syrian patient reflected broader concerns that the Pain Management Centre was not able to offer any additional support beyond the work already being offered in primary care, and without the problem of long waiting lists, unmet expectations of pain relief from patients, and variable outcomes. GPs in the Shire often worked within their own networks and with non- specialist

pain services to ensure more timely and tailored support for their patients with chronic pain. I explore some of these other services in section 5.5.4. Overall, external perception was that the Pain Management Centre worked with drug-driven approaches, that were inadequate in supporting patients experiencing chronic pain and living within complex environments. The service aspires to move to a more holistic way of providing care grounded in the biopsychosocial model but has been unable to overcome the underlying, largely Cartesian mind-body thinking around pain that underpins their disciplinary traditions (I give an overview of these models in Chapter 2). This thinking has contributed to patients, who don't fit well into either mind or body categories being inadvertently excluded from receiving pain management there.

5.5.2 Pain Rehabilitation Unit

The Pain Rehabilitation Unit at Foundation NHS Trust offers multidisciplinary pain management rehabilitation to individuals and groups at one of the city centre hospital sites and is delivered by a team of specialist physiotherapists and a psychologist, supported by a rehabilitation assistant, a disability employment advisor and administration. The service also runs a small range of services (e.g., group rehabilitation) at a site in the north of the county but this has been limited due to staff availability. People that live in the far west and south of the Shire sometimes choose to attend pain rehabilitation services in neighbouring counties (though high demand for these services can mean waiting times in excess of one year). The rehabilitation unit is located on a different site from the Pain Management Centre and has a separate managerial structure located within therapy services at Foundation NHS Trust.

The unit is described on their public website as offering pain care that attends more to *"the psychological aspect of living with long term pain, …rather than just a more tissue focused model."* Much of their work is focussed on delivering recommended evidence-based pain care in the form of pain programmes as recommended by professional standards (British Pain Society, 2013; Faculty of Pain Medicine, 2020a). These programmes deliver psychologically informed rehabilitation drawing largely from psychological models applying contextual cognitive behavioural therapy frameworks (McCracken et al., 2007), with a recent additional focus on Acceptance and Commitment Therapy and Compassion Focussed Therapy (McCracken, 2021).

The service had evolved from earlier iterations in the early 2000's when it was a physiotherapy-led physical rehabilitation programme for patients with back pain where the assumption was that chronic pain was linked to disused and deconditioned bodies and would improve with exercise-based rehabilitation. The emergence of more integrated ways of understanding pain within Engel's broader biopsychosocial model (Engel, 1977) encouraged physiotherapists to incorporate psychological perspectives into their work (Harding & Williams, 1995). This specialist physiotherapist recalls:

> *I thought it would be really good if we could get a psychologist and then do like a traditional pain management programme where you'd have physio and psychology. And as well as the physio led programmes that we were already doing, because I knew then that we get good outcomes in the physio led programmes, but we don't... what is not as good is the people that are more complex, psychologically needed some psychological input. (Physiotherapist 1)*

The inclusion of a psychologist in the service shifted the physiotherapists work to using more specific psychological models such as Acceptance and Commitment Therapy. The psychologist was involved in supporting the rehabilitation team, using these models within clinical supervision around patients with more complex psychological needs leading to the physiotherapists reporting increased confidence in working with these patients. The service started collecting psychometric data to evaluate the effectiveness of their interventions and continued to adapt the treatment offered, guided by the increasing complexity of patients, their diagnoses, referral sources and wider policy recommendations e.g., National Institute for Clinical Excellence (NICE) – and continue to do so. Part of this shift was driven by the wider reorganisation of pain, orthopaedic and rheumatology services in Shire in 2015 which I detail further in section 5.6 below.

Referrals into the rehabilitation unit came mainly from within other clinical services at Foundation NHS Trust with a small number from the single point of access at Pain Ltd. New patients to the service were assessed by a specialist physiotherapist (with a small number being triaged directly to psychology once the referral is received). Following the initial assessment, options in the clinical pathway included *"a pain management programme, one to one sessions, advice on self-management, recommendations to the GP/rehabilitation team or referral to other mental health services"*. One specialist physiotherapist explained why they might not include patients in the groups:

> *"It might be somebody who finds groups very difficult due to anxiety, it might be people who don't want to work with people of the opposite gender, it might be language problems, it could be that there are other psychological barriers to working in a group". (Physiotherapist 1)*

Uptake and attendance of the group programmes was variable. Patients often dropped out or failed to attend sessions. The service had made efforts to understand reasons for this by following up non-attendances with a telephone call to patients. Reasons for attrition included limited access to parking and public transport to their city centre location, and patients not agreeing with the psychological focus of their work and absence of pain symptom management. This is in contrast with the psychological support that local GPs felt was required from specialist pain services. The rehabilitation unit recognised that patients with complex psychological issues referred to them might find it challenging to enter the service and had tried to support them where possible with one of the physiotherapists explaining:

> *"We have had patients with really severe anxiety that we have had to go and meet in their car in the carpark and gradually grade them into coming into the building, and I think those sort of patients wouldn't necessarily get help in other places." (Physiotherapist 1)*

This physiotherapist uses *"grade"* referring to the term "graded exposure" that is used to gradually re-introduce people to previously feared activities, in this case, *"coming into the building"*. Like at the Pain Management Centre, staff at the Pain Rehabilitation Unit were cognisant of the gaps in service provision for specialist pain management and the differences in the types of care they offered. The services did not appear to interact formally in their shared care of patients with one consultant who referred to both services reflecting:

> *"I think actually that relationship could be better, but it's a great service and it's the main Shire pain management programme; we don't have a separate one, so it's a great thing to do. But they are very physio and musculoskeletal focused, so it would*

be nice one day to have a similar type thing for headache or for abdo pain or for patients who don't quite fit into that group really." (Consultant 5)

This is in contrast to the *"seamless link between other diagnostic and treatment services"* portrayed in the public facing website for the Pain Rehabilitation Unit. The Pain Rehabilitation Unit service delivery was largely aligned with behavioural psychology principles with the broader aim of facilitating movement and function in the presence of pain, actively not focussing on pain relief. As with the Pain Management Centre, there are indications that some patients do not fit into this service either. There is a discrepancy between the formal representations of pain management services in the Shire as neatly bounded, pathway driven and clearly connected, and the more complex messy reality of continually adapting, yet siloed services delivered by different epistemic communities I encountered.

5.5.3 Inpatient pain team

Patients who are admitted to any of Foundation NHS Trust hospitals may meet the acute inpatient pain team. This team was not a part of formally commissioned pain management services in the Shire but played a part in supporting patients where they fell through the gaps of existing service provision. The team included specialist pain nurses and anaesthetists who supported pain management, though not all were required to complete pain speciality training and did not fall under the umbrella of formalised specialist pain management services (National Pain Audit, 2012). Rather than specifically managing chronic pain, this team was focussed on symptom control and alleviation related to acute injury or surgery during hospital stays. They also used medication and minimally invasive pain procedures as interventions but framed this work in terms of pain relief rather than pain or self-

management terms. The lead consultant for this service had worked with both acute and chronic pain patients for several years though not formally as a chronic pain consultant at the Pain Management Centre. They had strategic and clinical leadership roles at Foundation NHS Trust and had historical understanding of the wider pain management landscape in the Shire.

They had been running what they called, an "unofficial *outpatient* opioid reduction clinic" (once a month) for patients taking high doses of opioid analgesia, considered to be more than 120mg of the oral morphine equivalent of any opioid containing medicine (Levy et al., 2020). These patients were identified by the acute inpatient pain team during hospital admissions where the pain that had been difficult to control post-surgery, with increased use of opioid analgesia. Pain consultants at the Pain Management Centre could also book their patients directly into this clinic for support in reducing their opioids. It was unclear why the pain consultants had not taken on this work given their expertise and the stated remit of the Pain Management Centre. This service was not formally commissioned by the CCG as part of the formal pain management offer in the Shire so did not accept GP referrals through the single point of access at Pain Ltd. Work had been ongoing since 2017 to formally have the service recognised as a provider of opioid reduction and addiction services, secure funding to support adequate staffing and to open it up to referrals e.g., from local GPs who are currently unable to refer patients. The consultant explains:

> *"So, it's a bit of a pity we don't yet have the resources to see patients referred directly from primary care on high dose opioids, but at least the way it's set up at the moment it means that these patients have had a really good review by a chronic pain consultant to exclude anything else to make sure that the management plan is set up*

and so, when they come and see me to talk about opioids we're not talking about their whole pain management, we're just now parking that and looking very specifically at their opioid management." (Consultant 5)

This consultant was involved in reorganising the local pain service on a small scale to support patients who would otherwise fall through the net and who did not *fit* well into any of the existing services. Their role interacting and relating across different settings allowed them to bridge these gaps in formal pain management provision in the Shire. Long (2013) class this type of actor within a healthcare network or organisation as *boundary spanners*. They enable collaboration, support knowledge transfer, and create opportunities for innovative ideas. The boundary spanner consultant facilitated and enabled this work by distilling the distributed specialist expertise into formal tools (such as a spreadsheet that supported opioid conversions and set out planned dose reductions for different medicines) that themselves are used to perform boundary work e.g., allowing GPs to take on the difficult task of gradually reducing opioid prescribing without specialist support. The specialist nurses working across the inpatient pain team and the Pain Management Centre also did boundary work as they held dual roles across services (acute and chronic pain), allowing them to introduce small changes into the system e.g., bringing discussion of medications into the psychology group programmes that previously did not address medication concerns. In John's case, access to these boundary spanners might have allowed him to get support in reducing his medications.

5.5.4 "Little pockets of pain management in the Shire"

There are other services that provide care for people experiencing pain in the Shire, but they are not recognised formally within the system as offering specialist pain management.

In Chapter 2, I explored how the different ways that pain is conceptualised often leads to pain being treated in a variety of services though these distinctions are not always recognised or named accordingly. Looking at the wider data set for the study and across all the patient narratives (which I present in Chapter 7), there were a range of other services that participants used and referred to, especially when they could not get access to dedicated pain management services. John pointed out that the reason he went back to the dental service for a second referral, was because their public facing website stated that support for pain management was available, though it turns out, not in a way that was helpful for him. He also had weekly appointments with the community pharmacy to pick up his prescriptions of controlled drugs and often had helpful conversations with the pharmacist about his pain medicines. His GP had the responsibility for managing the weekly pain medicine prescription and regularly reviewed John's pain care.

Whilst conducting fieldwork, I was invited to attend and observe a meeting organised by the acute pain consultant. The meeting invitation explained that this was open to anyone working as a healthcare professional seeing patients with chronic pain and pain researchers to discuss developments in the field and make connections to support each other. The network had grown over seven years and had attendees from community pharmacy, community psychiatry, substance misuse, dentistry, neurology, gynaecology, general practice, and the pain services at Foundation NHS Trust. The chair of this meeting referred to the congregation as *"little pockets of pain management".* This meeting was an opportunity for people working in pain to connect, discuss challenging cases and to facilitate referrals to those who had expertise in aspects of pain management and to form a different epistemic community.

A social prescriber working in a rural community explained that in her experience, many of her clients experiencing pain attributed it to getting older and were not looking for diagnoses or treatment but rather support with the impact of pain on their social lives:

> *"...we have to remember that…the medical side of somebody's life is just the tip of the iceberg that, you know, they've usually got so much experience, so many gifts and skills and, you know, the things that they've done in their lives and the things that they've coped with." (Social Prescriber 13)*

This framing eschews a biomedical understanding of pain, instead focussing on working with people to access services and more general activities that they identify as potentially helpful.

These *"little pockets of pain management"* demonstrate that chronic pain in the Shire was managed within a relational network of services that were not formally recognised as providers of pain care, alongside the recognised pain management services. These relational networks formed an epistemic community that seemed better able to support patients who might not fit and therefore access the formal pain services.

5.6 Disruption and re-ordering boundary work

There have been significant changes in the organisation of services in the CCG area in the past five years which has impacted on pain management provision in the Shire. In 2015, the CCG carried out a review specifically of musculoskeletal services with a view to addressing long waits, containing costs and improving the patient experience. A new model of integrated service provision for musculoskeletal (MSK) conditions (including a large

proportion of chronic pain) was proposed. Following a competitive tender process, Pain Ltd, a private company that provides NHS services, was awarded the contract for MSK services in 2017.

The incumbent NHS providers, Foundation NHS Trust, did not participate in the tender process as they deemed the financial envelope insufficient to fulfil the service specification. They had worked with commissioners to shape the service specification to include meaningful pain management services that reflected the needs of all pain patients, and not just MSK conditions. A pain consultant who was involved in these discussions reflected:

> *But there was also a push in the CCG to develop a community pain service which sounds great, but actually it became obvious during the... all the kind of meetings we had was that they saw this as a cheap way of providing pain services and that it would then be able to replace our tertiary level service. This wasn't seen as an extra good thing, this was a let's do a cheap and cheerful community pain service and that'll be fine. And I think one of the things they just did not understand was that if a patient's in pain that's never going to go away, sees someone who they don't trust and they don't believe in and they don't feel knows what they're talking about, you're just introducing another step before they're referred up to our service anyway. And so, we were quite keen to engage with sending our staff out into the community and maybe doing pain clinics out there, but that's really not what they wanted; they wanted someone to do a two-week course and be able to sort out chronic pain. It's very frustrating. (Consultant 5)*

The new service configuration moved many services including elements of orthopaedics and rheumatology out of secondary care and into a community setting. I have illustrated my interpretation of what the ideal service was supposed to offer based on interviews and publicly available documents from the Shire CCG (see Figure 8).

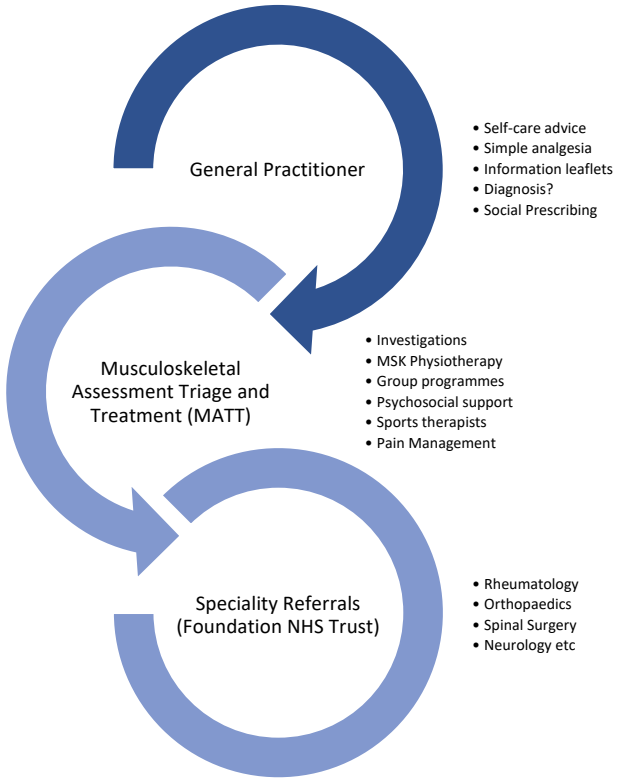

***Figure 8**: Ideal vision of commissioned pain management services*

There is now a requirement from commissioners that all referrals for pain management (from GPs, also consultant to consultant) go through a new musculoskeletal assessment triage and treatment (MATT) service run by Pain Ltd, with the aim of reducing unnecessary referrals into secondary care and offering local treatment alternatives.

Pain Ltd, though contracted to offer some form of pain management, has not been able to recruit the specialist staff to meet recommended service specifications as set out in the tender. Instead, it offers uni-disciplinary pain management support run by MSK physiotherapists offering *physical* rehabilitation. Despite the requirements of the new

service specification to provide some community pain management services, they continue to refer patients into secondary care pain management services at Foundation NHS Trust. The result of these changes is that, since 2019, there were two main provider organisations involved in providing formal pain management services in the Shire: Pain Ltd provides pain management to patients presenting with musculoskeletal pain in community settings, Foundation NHS Trust provides secondary specialist services for all types of pain.

Participants in this study were generally unclear about the role Pain Ltd had in providing formal pain management services, though broadly felt that they did not appear to offer the specialist pain services that had previously been accessible to patients. The public facing website for their services in the Shire indicated that they provided *"specialist assessments, a pain management programme and psychosocial support"*. A physiotherapist involved in triaging referrals at Pain Ltd confirmed that they ran a standardised group programme for chronic back pain that had been tested in a randomised control trial and implemented nationally (Lamb et al., 2010). They did not offer group programmes for other chronic pain conditions and did not have psychology, nursing or pain consultant staff members that she was aware of. Patients experiencing psychological distress were referred to local talking therapy services in the first instance. She was unsure about how to access services at Foundation NHS Trust, saying *"there's no clear pathway to be honest"*. Like other formal providers of formal pain management services in the Shire, there were cohorts of patients that did not fit into this service model for reasons the physiotherapist describes:

> *"It's not for them or they felt they were doing those things already or, you know, they were just told it was all in their head and nobody understood that or didn't have time." (MSK Physiotherapist 8)*

A series of case studies demonstrating some of their accomplishments were highlighted to me by a senior member of the Pain Ltd team. Many of the desirable outcomes showcased on Pain Ltd's website focussed on efficiency measures such as, *"Just 12% of referrals were sent to Acute Trusts for secondary care"*, *"imaging costs reduced drastically"*, and *"40% of patients self-care"*. Here, self-management is conceptualised as a successful cost-containment strategy suggesting that technocratic ways of doing self-management are privileged in this setting.

The reorganisation of musculoskeletal services in the Shire took away the hidden boundary work that was being done. What had developed informally as a set of services (delivered by different epistemic communities) that could be fit for purpose, even if they were not formally commissioned, was potentially dismantled and disrupted because the commissioners did not recognise the additional boundary work. At the time of concluding my study, musculoskeletal services (and still not pain services) remained an active work programme for the Shire CCG. Their annual report indicated overall satisfaction and that performance for Pain Ltd around triaging was *"exceeding targets"* but *"the remaining targets within the contract for getting patients into the services they need in the targeted time, is not yet being achieved".* Despite acknowledging that patients are still not accessing they treatment they need, the intervention to address this appeared focussed on changing clinician behaviour to *"improve GP understanding of service, to help avoid GP's trying to bypass our service and go straight to secondary care"*. However, the services at Pain Ltd did not sufficiently include many patients experiencing chronic pain and gaps in service provision remain.

Self-management of chronic pain in the context of the Shire was discursively constructed and held different meanings for different epistemic communities shaped in part by the underlying beliefs about the nature of pain. These different meanings entered the lexicon of the local health care system and over time and have been reified in response to efforts to streamline and formalise the pain care work done in different services. Reification of self-management was facilitated in part by the use of standardised tools (e.g., referral criteria, pathways, manuals, spreadsheets, websites) that themselves had generative power in facilitating the ongoing use of self-management as a boundary object. The formal tools distilled some of the complex tasks that constituted the work of managing chronic pain at a system level, but in doing so obscured further the hidden work performed by those outside these formal service structures (Berg, 1997). Self-management functioned as a boundary object allowing different epistemic communities of practice to ascribe their own meaning to their work despite underlying differences in their beliefs about the cause of pain thus avoiding conflict.

Ongoing reorganisation of the wider NHS administrative landscape including the formation of Integrated Care Systems and Primary Care Networks and the roll out of initiatives focussed on reforming the primary care workforce will likely impact on how pain care is delivered in the Shire. I explore these macro-level influences on the Shire in Chapter 8.

5.7 Conclusion

There were two types of system responses to the Shire's problem of how to best manage complex chronic pain. The first was the formal, top-down reorganisation of services

intended to fix existing problems in the pathway, redirecting resources and redesigning a new service. The second, an unplanned gradual growth of relational networks and boundary spanners creating *"little pockets of pain management"* and varied epistemic communities. Neither of these approaches appear to have addressed the problem of supporting those who have dropped out or have been excluded from pain management services in a replicable and sustainable way. John's experience showed that people living with pain continue to miss out on adequate pain care in the Shire, but the continued focus on reorganising and reordering services contingent on a linear understanding of how pain management works is unlikely to address this problem. In the next chapter, I will look further at the lived experience of people who had trouble accessing pain care and provide an account of self-management of chronic pain from their perspective.

Chapter 6: Doing and being: multiple ontologies of pain

6.1 Introduction

In this chapter, I propose that pain is multiple; it is not a single concern, condition, or category. Pain is experienced differently by different people and its meaning and expression cannot be stripped of context, power relations and history (Bourke, 2014). This orientation towards pain contrasts with normative standards and definitions (see Chapter 2) that reduce the complexity of pain to consensus-based definitions and taxonomies.

Annemarie Mol has argued that, as reality is constructed through *doings* (or practices) and *doings* can take many forms and iterations, reality is multiple (Mol, 1999). She demonstrated this thesis by identifying multiple ontologies of atherosclerosis (a vascular disease) through tracing medical practices across their sites of enactment (Mol, 2002). Drawing on this empirical philosophical work, Graham (2015) extends Mol's multiple ontologies analysis to pain medicine.

I begin by presenting a summary of these two explorations of multiple ontologies. I then discuss Graham's ontologies with reference to my case study of self-management of chronic pain. I extend this work to present eight ontologies of pain, illustrating sites of *"continuing ontological change and multiplicity"* (Graham, 2015, 65). In keeping with Mol's (1999) exhortation that *reality is done*, I focus on participant practices and performances of pain management as narrated by them and observed and interpreted my me.

Finally, I discuss the impact of ontological conflicts and show how staff participants worked through ontological calibration practices, to provide cross-disciplinary care. I conclude by proposing that raising awareness of multiple ontologies of pain might enable health care professionals to develop their own repertoires of practice in ways which may be more inclusive and that may limit the epistemic injustices that have typically dominated self-management of chronic pain to date.

6.2 Multiplicities in ontological perspectives

Before starting this research, I had never turned to issues of epistemology and ontology in my thinking about pain and pain management. Like most healthcare professionals I had accepted the common definitions of pain. I had never considered the proposition that reality, and thus pain, could be multiple. Some of the insights I present in this chapter are drawn from my own twenty-year immersion in clinical practice. Some emerged from stepping back and forth between clinical practice and research practice. It was sometimes difficult to separate practical wisdom (Tsoukas & Cummings, 1997) honed in clinical practice from insights developed as part of my research practice. My analysis led me to appreciate different versions of the story of pain playing out and being performed through participants' accounts of pain and self-management. This led me to ask 'how is self-management of chronic pain supported?' and, more fundamentally 'what *pain* and which *self* are being managed?'

6.2.1 Multiplicity

In *The Body Multiple* Mol argues that existing understandings of illness and disease, such as those accepted within the disciplines of medicine and sociology, maintain dualistic notions

of *subjects acting on objects*, thus perpetuating the notion that meaning and interpretation are of a singular, fixed reality. She observes that naturalistic disease has been the preserve of medicine, whilst illness and its subjectivity has been the preserve of sociology, anthropology, and other interpretive disciplines. Through a detailed ethnography of atherosclerosis conducted in a Dutch hospital, she counters that *"no object, no body, no disease, is singular"* (Mol, 2002, 6). Mol enquired about and attended to *practices* rather than thoughts in her interactions with participants. She elicited detailed, rich accounts of *how atherosclerosis was done* by different actors and in different places. She demonstrates multiple ontologies of atherosclerosis as enacted by patients, their families, doctors, laboratory technicians and others in their interactions with various objects and devices. She includes the material sites of enactment in order to *"escape the subject/object divide"* (Mol, 2002, 32). Her atherosclerоses (plural) were multiple and included clinical, pathological, social and anatomical *bodies*. She further explores how these multiple ontologies hang together and what happens when different versions of atherosclerosis are seemingly incompatible. Mol proposes that the threat of incommensurability between the multiple atherosclerоses leads to coordinating practices. Practices of upgrading, downgrading, addition and subtraction that lead to a coordinated singularity *"fused into a composite whole"* (Mol, 2002, 70).

6.2.2 Multiple ontologies of pain

In chapter two, I outlined the different ways of knowing pain and highlighted the difficulties in trying to seek agreement between different professional groups and different epistemological positions regarding pain and the practice of pain care. The International Association for The Study of Pain (IASP) has attempted to unify these conflicting positions by

providing definitions and extensive taxonomies of pain (International Association for the Study of Pain, 2004; Treede et al., 2019). Its seminal text on the classification of chronic pain, first published in 1986, has undergone three revisions and is regularly updated online (Merskey & Bogduk, 1994). It describes the detailed and often protracted work of multidisciplinary task forces to generate these descriptors. Some of the sticking points centred around the initial definition requiring a verbal report to describe pain, therefore excluding pain in non-verbal children, older people and animals and the ongoing linkage of pain with tissue damage. The association's most recent definition of pain is suggestive of multiple ontologies of pain and illustrates the attempts at unifying them:

> *"An unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage." (Raja et al., 2020, 7)*

The definition is accompanied by six key notes and etymology of the word pain for additional context. According to accounts of their deliberations, this definition now de-emphasises historic mind-body dualism (Raja et al., 2020) but critics have highlighted that it continues to couple the notion of pain with the notion of the damaged body (Graham, 2015); socio-cultural concepts remain minor footnotes to be considered as possibly contributing to the experience of pain (Stevens, 2021). The idea that there may be multiple ontologies of pain has not been explicitly considered by this body which represents the largest international pain management community. Recent attempts to provide alternative definitions of pain (Kiverstein et al., 2022; Moseley, 2007; Williams & Craig, 2016) have gained little traction by comparison and the IASP position on pain remains dominant. By implication this means that existing pain management practices offer at best partial responses to the problem(s) of pain, limited by which particular pain is being enacted,

defined, observed and managed. It leaves unattended those pains which are hidden, absent and unseen by virtue of their ontological invisibility.

In *The Politics of Pain Medicine*, Graham applies the theory of multiple ontologies to pain medicine by tracing ideas of pain historically (2015). Building on this ontological history of pain he then explores how a multi-professional group of pain clinicians, researchers, students and advocates (the Midwest Pain Group) talked about and enacted pain in their many practices. He argues that many areas of disciplinary and institutional disagreement are grounded in attempts to transcend the two-world problem[13] in medicine in what he calls 'calibrating practices'. He describes the tendency of members of the Midwest Pain Group to separate pain into subject/object and mind/body dichotomies with different members holding preferences for one or the other leading to disagreements, for example when discussing clinical cases and seeking to ascribe a cause. He explores and then presents the different calibrating practices that Midwest Pain Group members use to negotiate ontological differences, communicate effectively and enact a newer non-modern ontology. Graham describes his work as a rhetorical-ontological inquiry and explicitly aligns with Mol's work. For Graham:

> *"The theory of multiple ontologies…describes differently situated material activities that produce different objects…The reality you engage is determined by the kinds of actions you habitually perform and the material contexts in which you act." (Graham, 2015, 31)*

[13] The two-world problem in medicine refers to the persisting belief -originally proposed by French philosopher, René Descartes – that the mind and body are separate. In pain, this leads to practitioners aligning their practice, focusing either on the body or the mind. I have discussed this in previous chapters as mind-body dualism.

He makes a clear contrast with theories that describe epistemological differences that *'provide competing "perspectives" on a stable reality'* (Graham, 2015, 31). Under this view the definition of pain arrived at by IASP is an example of the latter; it assumes a singular stable reality which is differently understood by a range of actors. I explored the different epistemological perspectives on pain in Chapter 2. In this chapter, I draw on data from my case study of self-management of chronic pain (Chapter 5) to illustrate the multiple ontologies of pain that emerged and were enacted in the Shire. I present my interpretation of accounts of enacted instances -perspectives on practices- of Graham's six pain ontologies: semiotic, biochemical, empirical-discursive, cognitive behavioural, non-modern practical and non-modern discursive. I then discuss two further pain ontologies I identified, emerging from data in the Shire: biomechanical and embodied-intersubjective, that were *done* in my case study, illustrating sites of *"continuing ontological change and multiplicity"* (Graham, 2015, 65). I focus on each of these in turn below and present a tabular representation of my findings in Table 8.

Table 8: *Overview of multiple pain ontologies, their key features and practical regimes*

Pain Ontology	Key features & practical regimes	Locating accounts of practical regimes in the Shire
Semiotic (Biomedical - traditional)	Pain as a sign signifying underlying disease; aids diagnosis & prognosis; pain = damage; reliable indicator; proportional	Common amongst doctors both GPs and pain specialists
Biochemical (Biomedical-contemporary; biopsychosocial)	Pain objectified; the object of study; neurone doctrine; neural pathways of transmission; pain as nociception; neural encoding; pharmacology	Most common explanatory framing in pain specialist services; pain clinicians and researchers; some GPs aware but not practicing
Empirical-discursive (Biomedical-contemporary; statistical)	*Evidence* based medicine; statistical accounts; standardised; make pain objective, visible & disciplined; observation & experiment; medical gaze; neuroimaging; pain scales	Common amongst GP partners, hybrid clinician managers in pain services; Justification for services to commissioners; evaluation practices; guidelines; policymakers
Cognitive behavioural	Psychological impact of pain; changing relationship with pain; coping; living with pain; standardised protocols; fidelity	Within specialist pain services; community MSK services; physiotherapists; books; manuals; websites
Non-modern practical (Biopsychosocial; hybrid)	Multi-professional and multi-disciplinary working; boundary work; calibrating practices	Self-management as a boundary object (chapter 5) Not evident in the Shire
Non-modern discursive (Biopsychosocial; hybrid)	Pain management theory Phenomenological narratives	Within specialist pain services
Biomechanical (Biomedical – anatomy; biomechanics)	Body as a machine; practice related to fixing broken machine	Amongst physiotherapists; in people living with pain (chapter 7)
Embodied intersubjective	Holding uncertainty; not diagnosis or meaning focussed; comfortable with mysteries and doubts; open; moveable	Social prescribers; GPs; policymakers (chapter 8)

6.2.3 Semiotic ontology: pain as an indexical sign

Medicine - and specifically pain medicine - has had to rely on pain as an indexical sign in order to guide diagnosis and prognosis, particularly in the absence of objective or laboratory tests (Graham, 2015). In semiotics, indexical signs infer a causal relationship between the sign (in this case pain) and the meaning of the sign (underlying disease) (Kugelmann, 2003). Pain is considered a relatively accurate and reliable indicator of what is happening in the body. The difficulty is that assessment of pain can only ever be based on the subjective reporting of the person experiencing it. Pain defies attempts to render this inherent subjectivity of experience into objective, visible, measurable proxies. Paradoxically, despite the reliance on language to make pain visible to others, people experiencing pain often struggle to adequately express their private and personal experiences, the so called *inexpressibility* of pain (Scarry, 1985). In part, this arises from a lack of collective shared linguistic resource to enable this expressibility (and by implication, its understanding), leading the sufferer to experience a form of epistemic injustice which Fricker describes as 'hermeneutical injustice' (2009). The classifications and reclassifications of pain in its many forms (e.g., Raja et al., 2020) demonstrate the continued attempts to know pain through language, without a detailed consideration and understanding of the semiotic practices that they are engaging in.

The problem of unreliable narrators i.e., patient's whose subjective reports do not match up with observable tissue injury of pathology drove attempts to render subjective pain into objective, quantifiable measures of pain to guide treatment. One advocacy group - led by pain doctors - sought to respond to this challenge by campaigning for pain to be considered 'the fifth vital sign', along with other measurable signs such as blood pressure, respiratory

rate and temperature (Max et al., 1995). The success of the campaign is reflected in widespread use of numerical scores that assign numbers to verbal descriptors of pain and supports clinicians to assess the efficacy of pharmacological treatment. Criticisms of these pain scores have argued that they hide complex idiosyncratic meanings and are more reflective of patient attempts to construct meanings (Williams et al., 2000). The movement received much traction and was initially lauded as improving patients' access to pain relief. Later it was subject to criticism, the suggestion being that it contributed to the over-prescription of opioids and the ongoing crisis that has since plagued the USA in particular (Levy et al., 2018b). The increased visibility of so-called 'objective' pain was associated with the discourse that pain was under treated, and physicians were encouraged to prescribe increasingly higher doses of opioids to control it.

Diagnosing disease on the basis of pain was an ongoing concern for many healthcare practitioners in the Shire. This proved problematic. Take the example of this physiotherapy manager who described how diagnoses were frequently disputed and reassigned with what were considered more appropriate diagnoses:

> *"They were patients that would be given the diagnosis of functional disorders. But when we saw them we thought they were more like chronic back pain or chronic shoulder pain or whatever." (Physiotherapist 1)*

A diagnosis of functional neurological disorder is considered by some as a pejorative one akin (for some) to fictitious, or 'medically unexplained' disorders (Edwards et al., 2012; Launer, 2009). The physiotherapist here offers up a supposedly more accurate and acceptable diagnosis, couched in the descriptive terms that locates the pain in the body

though they do not make an assessment as to the cause. Chronic pain stands in, semiotically for more medically derived diagnoses (Kugelmann, 2003).

In the Shire, medical doctors were more likely to view pain as a sign. For example, in the extract below, an experienced GP, struggled with the idea that pain could be present without a previously undiagnosed condition. In doing so, they at best challenge, and at worst disbelieve, the subjective report of pain from some patients:

> *"And chronic pain, some might say it's fibromyalgia, but I think something... pain... yeh, labels of certain diseases, I don't want to give people because it then might be an excuse to feel that actually I'm sick with something with a name and therefore I can't function. And probably with the time I've been a GP some of the people who have had that label in the past have had other diagnoses. One person had hyperparathyroidism with hypercalcemia, which presents with chronic pain. Another one eventually had rheumatoid arthritis developed... diagnosed. And yeah, there may be a sub-section of people with chronic pain who are actually suffering from non-diagnosed disease which, if it was found, could be treated. Unfortunately, by the time it's diagnosed then they are addicted to painkillers. So, maybe reflecting on some of the cases has made me cynical or maybe it's made me wary of too easily giving a diagnosis. And I think when I was a much younger GP, people who had chronic pain, I just ended up giving them one painkiller after another after another." (General Practitioner 3)*

This GP demonstrates a commitment to a semiotic ontology of pain, opting to continue the search for a medical diagnosis that they could apply their skills to resolving. They are aware of the perils of relying only on opioids but seem at a loss as to what else can be done.

Diagnoses have social power. They shape practice and confer social approval for the sick, dictating what health care services a person is entitled to and receives (Rosenberg, 2002). A diagnosis driven approach to chronic pain can contribute to poor and more negative experiences of healthcare for people who have an unclear or contested diagnosis, like Fibromyalgia (Doebl et al., 2022). Fibromyalgia is a broad diagnosis for people who, as well as experiencing widespread body pain, also report cognitive problems e.g. trouble concentrating, poor sleep, and fatigue (Clauw, 2014). Traditional tests such as blood tests and imaging, are often negative or inconclusive with limited objective indicators to support a specific medical diagnosis. The diagnosis is usually given only after multiple investigations and after the exclusion of medically *known* causes. There have been concerted efforts to identify and characterise pathological processes that explain this condition in medical terms, usually via neuroimaging (see e.g., Chinn et al., 2016) or physical examination of trigger points in muscles (Clauw, 2014). Doing so, risks perpetuating further epistemic injustice by failing to give credence to alternative explanations that patients may hold, associating their pain to personal and social meanings e.g., bereavement or relationship breakdown (Carel & Kidd, 2014; Kleinman, 1988).

When enacting a semiotic ontology of pain, health care practitioners appeared unable to witness that which did not signify a medically *known* disease that they could treat. Having a diagnosis of Fibromyalgia in this case seems to signify not having a real condition that merits care. *"No one wants to look after the fibro patient"* (Doebl et al., 2020, 1716). In the Shire, when the quest for diagnosis rooted in semiotic ontology was thwarted, practitioners who ascribed to this ontology appeared rudderless and struggled with the idea of 'doing nothing' biomedical. In contrast, those not invested in a semiotic ontology, could work in the

absence of a diagnosis, and focus instead on interventions and practices not couched in causal biomedical understandings. I will discuss some of these other ways of doing and their associated ontologies in section 6.9 below.

6.2.4 Biochemical ontology: the neuron doctrine

Technological advances in medicine in the 19th and 20th centuries have provided healthcare practitioners access to opportunities to further specify the causes of disease and sickness. Laboratory tests allow the detailed examination of the biochemically constituted body and have increased confidence in the underlying mechanisms that cause disease as well as opportunities and agents to treat them (Rosenberg, 2002). Antibiotics, for example, have altered the reality of having an illness caused by bacteria from an often life-threatening condition, to a treatable and survivable one. With pain conditions, the exposition of the nervous system via high tech microscopic examination allowed scientists to declare that there were now neurophysiological substrates for the hitherto elusive subjective pain experience (Melzack & Wall, 1965). These discoveries, rooted in basic sciences and an understanding of the minutiae of biochemical processes, including identifying receptors that corresponded to known inflammatory substrates, offered great promise for the development of new pain killing drugs (e.g., Woolf, 2011). Advances in basic neuroscience in animal models offered up alternative explanations for pain that persisted in the absence of known inflammatory substrates (identified by increasingly more sophisticated blood tests) associated with tissue damage. Central sensitisation, where neurons remain excitable and continue to send neuronal signals to the central nervous system, in the absence of peripheral stimuli, has been proposed as a way to explain chronic pain (Arendt-Nielsen et al., 2018; Latremoliere & Woolf, 2009).

The discovery of possible biochemical substrates for subjective pain reports potentially resolved the 'problem' of chronic pain and was aligned with a different pain ontology. I discussed this in more detail in Chapter 2.6.3. A biochemical ontology that focussed on diagnosis of previously unseen and unknowable pain problems. *"No longer was pain primarily a semiotic phenomenon; pain itself now became an object of study"* (Graham, 2015, 47). The biochemical pain ontology is firmly aligned with modernist thinking exemplified by the enlightenment period though its insights and practices only became prominent in the 20th century. Specific disease concepts are relatively modern and reflect wider structural societal changes towards more *"technical, specialised, and bureaucratized"* modes of doing and practicing medicine (Rosenberg (2002, 237).

Designating pain as a disease in its own right as well as retaining its status as a symptom of other underlying biomedically defined conditions has led to further legitimising chronic pain beyond semiotic understandings, previously difficult to explain (Treede et al., 2019). There is now a significant community linking basic, cognitive and clinical pain sciences under the establishment of pain neuroscience or the *"neuron doctrine"* (Graham, 2015, 51). This powerful community has at its core the biochemical pain ontology and includes neurobiological correlates of mental health, suffering and psychological aspects of pain. Within this, there are those that continue to focus on the *objective*, peripheral body, and those that have moved to explore the *subjectivities* of pain by locating their gaze to the brain and more central nervous system mind work (Rubin, 2018). This work includes neuroimaging as a highly technical method of visualising previously unseen pain conditions.

In the Shire, the biochemical ontology was as apparent as the semiotic one with practitioners often discussing utility or disutility of different medication as a way of confirming or disconfirming diagnoses. This is unsurprising as both these pain ontologies align with modern views of biomedicine. Practitioners regularly reverted to neuroscientific explanations of pain, especially in the absence of clearly diagnosed tissue-based explanations. Many often spoke of ‘‘explaining pain’’ as a shorthand for explanations rooted in biochemical ontology. The link between the lab and the clinic was also an explicit one with a number of more specialist staff having done work with basic and experimental neuroscience colleagues thus ensuring the knowledge transfer of this ontology from bench to bedside. This pain consultant explained:

> *“ …we've been doing very basic science related research, could also see how that may translate into clinical services and also they could actually talk to people to help them recruit patients and things like that really, and we could then find out what the new things were on the horizon from a research point of view.”* ***(Pain Consultant 5)***

Interventional pain management practices rooted in the biochemical ontology included prescription of powerful opioid medication and the provision of facet joint injections, targeted at neural tissue (nerves) with the expectation that the pharmacological agents introduced would work to arrest the source of pain. The promise of this ontology and its potential to explain complexity of pain conditions, inclusive of both body and mind, was not fully realised when viewed from primary care practitioners in the Shire who remained sceptical of its explanatory power. Speaking about one of her complex patients with chronic pain, one GP expressed her frustration at how the specialist service continued to provide ineffectual interventions whilst failing to address key issues in her patient’s life:

> *"The patient I was talking about before, I specifically wrote a couple of times to the pain clinic very much asking whether they would address some of the psychological issues around her pain, and all they did was promise her another facet joint injection. So, that was quite frustrating, and she'd waited for months and months for that, and that in my experience is not a unique experience. So, I think probably we do end up holding most of these people in primary care with really quite little specialist support often." (General Practitioner 4)*

Despite her apparent authority and position of power as a GP, this extract shows how she too experiences epistemic injustice: her request for psychological support for her patient is disregarded in the face of the more dominant ontology in place that prioritises the neuron doctrine. This particular GPs' experience reflects that of many of those also working in primary care where *"models of pain produced in the laboratory are not necessarily meant to be applied to the complex, clinical population"* (Rubin, 2018, 70).

6.2.5 Empirical-Discursive Ontology: pain as statistical construct

The empirical-discursive ontology was born out of a wider shift in medicine from *"clinical art to empirical medicine"* that similarly influenced the biochemical ontology (Graham, 2015, 54). It is situated within the wider discourse of Evidence Based Medicine (EBM). EBM is *"the conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients"* (Sackett, 1997, 3). Though initially presented as an amalgamation of clinical expertise, empirical research evidence and individual patient preferences, current applications of EBM have elevated the use of systemic population evidence over the other two constitutive elements (Greenhalgh et al., 2014). It is the latter conception of EBM that is aligned with Graham's empirical-discursive ontology of pain with an emphasis on observational and empirical sciences in what he calls a *"metaphysics of pain*

as statistical construct" (Graham, 2015, 55). As randomised controlled trials and EBM - with their focus on observable events- became more ubiquitous in medicine, so too did the requirement to render the subjectiveness of pain into standardised objective forms that could be manipulated and understood through a statistical lens. Disciplines that developed alongside and counter to biomedicine have, in a quest for legitimacy, adopted the statistical tools of EBM to demonstrate efficacy of their interventions. Ostensibly designed to be used in trials, empirical outcome measures for evaluating pain interventions are now common place with, for instance, the British Pain Society and Faculty of Pain Medicine producing detailed guidance on their selection, implementation and interpretation for clinical practice (Faculty of Pain Medicine, 2019). This guidance explicitly draws from recommendations for conducting randomised clinical trials in chronic pain and is then extrapolated to complex clinical populations (Dworkin et al., 2005).

The objective parameters that rendered biochemical pain real and trustworthy in technical scientific terms, cannot be applied to real-life patients (Rubin, 2018). Additionally, pain cannot be studied and pain interventions evaluated within EBM parameters without being quantifiable. The discourse and practice of EBM has led to the production of formal tools to evaluate pain, which in turn have been absorbed into clinical pain management and become representations (and evaluative) of that practice. Practitioners in pain management continually tailor their interventions to ensure favourable outcomes on these same measures (Wilson, 2017). Berg (1997) speaks of these material artefacts as 'maps' that discursively mark out the terrain of existing models of practice, recursively influencing each other to produce new distributed work practices. In pain management, the turn to

measuring or 'mapping' pain has affected the 'terrain' of pain management by producing models of care, pathways, programmes and networks that reflect the tools themselves.

Graham discusses practices as *representational* of empirical artefacts (Graham, 2015). In the Shire, the formal tools of EBM acted in a generative way, contributing to how pain management was *done*. Specifically, the forms were used as screening tools to 'sift' and 'manage' patients into and *out* of specialist services:

> *"So, we ended up by working out whether we could use GAD-7 for anxiety or PHQ-9 for depression to actually have a better bar of who actually would benefit more from psychology. Because the other thing of course was the psychology service being quite small was completely overwhelmed by a huge number of referrals because most of our patients with chronic pain do need that support." (Pain Consultant 5)*

The GAD-7 and the PHQ-9 that the pain management consultant refers to are formal tools used to screen for psychological conditions and assess outcomes of different interventions. Their use has been co-opted into pain management as an indicator of suitability for treatment (Faculty of Pain Medicine, 2019). High scores are considered indicative of depression and anxiety, would usually preclude attendance on rehabilitation group programmes and are suggestive of poor outcomes for pain management interventions. Paradoxically, when viewed through an empirical-discursive ontological lens, those who might be most requiring of pain care, may be ineligible to receive it (as disabling pain is most associated with poorer psychological functioning).

In the Shire, this outcome data generated through the use of 'tools' also had rhetorical power, in that empirical data held sway with purchasers and commissioners of pain services.

Many practitioners with managerial responsibilities used the language of EBM to justify the continued existence of their services. In this extract, a service manager repeatedly refers to outcomes demonstrating just how embedded and pervasive the empirical-discursive ontology was in the Shire:

> *"I did a comparison of our hospital with all the other…hospitals about the numbers of patients attending and how many went to programmes and was able to demonstrate that we were able to see more patients than some services that had a higher level of staffing, and our outcomes are good, I feel, which I sort of benchmarked against the national pain audit outcomes, and also published outcomes for kind of gold standard centres."* ***(Physiotherapist/Service manager 1)***

The success of the service was benchmarked against a much wider, decontextualised population and little was said about locally experiencing clinicians or individual patient views. Pain management was done in and through objects that reproduce and strengthen the empirical-discursive ontology of pain. I will explore the implications of the role of this dominance in disciplining the self in Chapter 8.

6.2.6 Cognitive behavioural ontology

> *" We live in an era when many people believe – as a basic, unexamined foundation of thought – that pain comes divided into separate types: physical and mental (Morris, 1991, 9).*

Morris argues that this myth - *"the myth of two pains"* – is exactly that, a myth. He explains that its persistence is grounded in historic notions of mind and body being separate (Cartesian mind and body dualism) and thus capable of producing different pains. He goes on to say that our commitment to it prevents us from seeing and acknowledging their

interdependence as exemplified by many chronic pain conditions (Morris, 1991). My own experience of clinical pain management would seemingly corroborate the existence of this myth, for there is no shortage of psychological discourse, or of psychological practitioners (pain psychologists) in the field working alongside colleagues to support those with complex chronic pain purportedly experiencing psychological pain. However, in naming and evidencing his cognitive-behavioural ontology of pain, Graham found that though common in pain management discourse, a psychological ontology of pain was absent in practice. He goes further in describing this elusive ontology as *"the ontology that wasn't"* (Graham, 2015, 61).

The absence of an observable *"practical regime of engagement"* (Graham, 2015, 64) with a psychological ontology was also notable in the Shire. Though there were multiple references to psychology and psychological care from different practitioners, these were related to either the psychological impacts of having pain or the practices of those working with a cognitive behavioural ontology. Take the following example from a physiotherapist who does not reference psychological pain as a pain that exists 'in its own right', but rather as a facet of living with or coping with the pain, the language of Graham's cognitive behavioural ontology:

> *"I was interested in the psychological aspect of living with long term pain, and rather than just a more tissue focused model." (Physiotherapist 1)*

Extending this, a second physiotherapist describes having taken on the mantle of what is referred to as psychologically informed practice grounded in cognitive-behavioural

understandings (Wilson et al., 2017), and offering what the first physiotherapist expressed a desire for:

> *"They're physiotherapists but bringing in a psychological framework for supervision, a space very much on acceptance and commitment therapy to shape supervision framework really, so I've just started that. In terms of my role, again I suppose the same applies for the pain education group that we run, that we run that with psychological well-being practitioners, and I'm there again to help support them and give them the confidence to run an interactive group rather than that didactic group that's being run that something's more interactive and, you know, really sort of gets the shared experience from those patients sat in the group really and helps use their... that was bringing out their ideas; it was helping them use a different way or working really, so I suppose there's that."* ***(Physiotherapist 7)***

In her recounting of the practice of this psychological practice, this second physiotherapist describes regimes more aligned with the 'pain education' of the biochemical ontology and explicitly, the 'acceptance and commitment therapy' of the cognitive-behavioural ontology[14]. The absence of a *practical* psychological ontology of pain may explain, in part, the epistemic injustice experienced by the GP in section 6.4 above. The reported work of pain psychologists in the Shire, associated with rendering subjective emotions into objective and quantifiable metrics through the use of forms and outcome measures, is more aligned with the empirical-discursive ontology of pain. They do not aim for psychological pain reduction, but rather to support patients to live well despite pain and to meet distal bureaucratic objectives set at a distance from the immediacy of the clinical encounter e.g., by clinical guidelines:

[14] Acceptance and commitment therapy is part of the so-called third wave of cognitive behavioural therapies, both of which have become standard psychological treatment models for chronic pain (Wilson et al., 2017).

> *"I talk to people a lot about how, you know, chronic pain is often not very treatable in the sense that we can't kind of take away pain or fix it, but that there all sorts of ways of living better with it. And I guess practically, the sorts of things that I spend a lot of time talking to people about are pacing and how people manage their activity levels and the impact that has on pain."* ***Clinical Psychologist (Pain) 16***

These selective accounts of the work done by some practitioners along with additional data from service websites, patient information leaflets and the manuals, protocols and books that guided practice within both specialist pain and community MSK services, supports situating the work that pain psychologists did in the Shire within empirical-discursive and cognitive-behavioural ontologies. A phrase common across these data was *"overcoming chronic pain"* and *"living well despite pain"*.

6.2.7 Nonmodern (practical and discursive) ontologies: the biopsychosocial approach

Grounded in data from his empirical ethnography of the practices of the Midwest Pain Group, Graham argues that there were new revolutionary nonmodern pain ontologies that for him, overcome the two-world problem so embedded in Cartesian dualism (Graham, 2015). He argues that "postmodernism's rejection of positivism/modernism does not so much deconstruct the two-world problem as it does reify it" by privileging subjective over objective (Graham, 2015, 18). Graham posits that a *non*modern ontology truly accounts for 'both worlds' engaging with both objective and subjective constructs or realities. He distinguishes these two ontologies as nonmodern practical and nonmodern discursive, presenting their practical regimes together as falling under a hybrid, biopsychosocial approach. Engel proposed the biopsychosocial model as a counter to the hegemonic

biomedical model in medicine which he regarded as overly reliant on bodily notions of illness and failed to account for psychological and social aspects (Engel, 1977)[15].

Practitioners in the Shire freely and frequently referenced the biopsychosocial model as their working model for pain management, in line with convention in the wider pain management community (e.g., British Pain Society, 2013; Treede et al., 2019). It is widely acknowledged in the academic literature (see Chapter 2) that complex and chronic pain is managed better by multi-professional or multidisciplinary teams with the skills to address different aspects of pain (Breivik et al., 2008; Burke et al., 2018). However, staffing such teams is not always possible (for instance, due to differential societal and professional beliefs about pain and its causation, and funding models) and there are differences in provision across health systems. In the UK, multidisciplinary care is considered the gold standard, but the disciplinary make up, availability and accessibility is inconsistent (National Pain Audit, 2012).

I highlight these global differences as Graham's empirical ethnography of the Midwest Pain Group where he observed the nonmodern-practical and nonmodern-discursive ontologies, was carried out in the United States (the other ontologies were derived from an examination of historical texts). The nonmodern-practical ontology was observed in relation to the practice of multimodal (also known as multidisciplinary) pain management, where different disciplines apply their own unique approaches to shared patients who access the self-organised network of practitioners, regulators and researchers that is the Midwest Pain

[15] I presented details of the model and how it is applied in pain management in Chapter 2.4

Group. The descriptions of the Midwest Pain Group offered by Graham suggest that though participants were seeking more cohesive ways to work together, the work was still distributed within a system (the US healthcare system) that maintained and reproduced dualism in its formal configurations. The practices of ontological calibration could not be done inside the system. Instead, the Midwest Pain Group relied on ephemera; transitory spaces they created to facilitate the creation of nonmodern-discursive ontological practices such as discussing and exploring different perspectives before returning to the fixed spaces to enact their learning separately. Arguably the data presented in the ethnography did not demonstrate an embedded non-modern practical ontology beyond those related to making diagnoses.

The nonmodern-discursive ontology references multimodal pain management theory (Graham, 2015) which values shared work both within and in between disciplines where individual professional identities are blurred and the shared regimes (including with patients) are constituted discursively, practically and phenomenologically (Choi & Pak, 2006; Giusti et al., 2017). Drawing on Graham's description of the nonmodern practices of the Midwest Pain Group, my professional experience of multidisciplinary working as captured in my reflexive diary and multimodal pain management and rehabilitation theory from the academic literature, I turned to the Shire to see if - and if so how - this nonmodern ontology was done. As with descriptions of the Midwest Pain Group, I did *not* find exemplars of the nonmodern-practical ontology. Like the Midwest Pain Group, various practitioners and researchers in the Shire sought to meet in temporarily assembled spaces (e.g., the practical network meeting described in Chapter 5) thus enacting the practical regimes of the nonmodern-discursive ontology. There were many instances of practitioners describing

attempts to work in this way and attend to multiple (biopsychosocial) pain realities, for example from one of the GPs:

> *"Normally, I would try and work out the analgesic ladder for pain as well as trying to address any of the other things that could be worsening that. So, their low mood or their anxiety or trying to help get them some support through the social prescribing service or the Citizen's Advice, or whatever, the stressful life setup. And it depends on the person really and talking to them about what it is they're trying to achieve and what it is that they're expecting, and think will happen about when you say we're not willing, let's ask the pain clinic to see."* ***(GP 4)***

In contrast to the Midwest Pain Group that used networks to provide practical multimodal pain care, non-pain specialist practitioners in the Shire relied on individual patients to source the care, albeit with judicious signposting, advocating, and negotiating. Patients played a crucial part in forming, deconstructing (when no longer required) and continually reforming the spaces they need. (I say more about this process in Chapter 7). Graham did not clarify the role of the patient in the nonmodern-practical ontology perhaps reflecting the differences in the healthcare system the Midwest Pain Group was in. Turning to the nonmodern-discursive ontology, I found clear accounts from healthcare practitioners making clear efforts to attend to subjective aspects of their patients. For instance, take the following example from a pain nurse who describes making a concerted effort to acknowledge and make space for phenomenological concerns:

> *"I think we have the opportunity to really like really invest time into getting people into coming to speak to us about things that aren't just about diagnostic procedures and having injections. I think there's a massive shift now from where it was, but even from in my beginning of my, you know, nine years to now, our focus is so much less*

on just sticking a needle in and hoping for the best. It's more about like the whole person and that holistic kind of approach." ***(Nurse Specialist 6)***

Much of this discursive effort appeared to be constrained by the organisation of services along disciplinary hierarchies, the continued dominance of biochemical and semiotic ontologies and structural constraints around resource allocation for this different kind of pain care. In the Shire, the nonmodern-practical ontology, like the psychological ontology of pain were in fact rhetorical artefacts within pain care that did not have associated practical regimes, but rather existed nevertheless as powerful unexamined discourses.

6.2.8 Biomechanical ontology: the body-as-machine

Alongside the biomedically oriented semiotic, biochemical and to some extent, the empirical- discursive ontologies, I identified a conceptually different *biomechanical* ontology of pain. The semiotic and biochemical ontologies are rooted in enduring Cartesian notions about the separate nature of the mind and body. However, in contemporary medical practice, the construction of the body has expanded and incorporates multiple biological systems (e.g., the lymph, digestive, circulatory and immune systems) that interact variously producing both health and disease. These biomedical understandings are reflected in the various specialities and sub-specialities of medical practice.

As a physiotherapist, I do not recall these biomedical understandings informing my training in a meaningful way. I was trained to think of and act on the body in a mechanistic way. I trained in the UK in 2003 in one of the more traditional schools of physiotherapy at that time. On my first day, I was issued a real, half human skeleton to take home, assigned a

cadaver in the anatomy lab, and attended the first of many lectures in biomechanics. I remember having a preference for the engineering heavy textbooks that emphasised angles of pull for various muscles, pulleys and so-on. By the time I saw my first real patient (supervised), I had a well-formed idea of what the body was - a wonderful machine that responded to the laws of physics (and my manipulations) and could be mended if it broke. Such ideas are common in lay discourses and are evident in the use of phrases such as "slipped disc" "wear and tear" "putting your back out" and "strengthening your core" that are evocative and illustrative of the body-as-machine thinking. Many of these ideas have been shown not to reflect the complex reality of the biological human body (e.g., Lederman, 2010).

Thinking about the body *in pain* for my research, I was sensitised to seek out instances of how a painful body-as-machine was done in my data. In Cartesian terms, the painful body-as-machine is mostly detached from functional tasks and is not troubled with subjectivities. Though professionally aligned with biomedicine, scholars of physiotherapy have argued that the enduring pedagogy in the profession is one that is illustrative of machinic understandings of the human body.

> *"Physiotherapists are artisans of the body. And yet the physiotherapists' view of the body is quite limited; concerned largely with the body-as-machine (the idea that the body can be understood biomechanically, as a series of intersecting parts that can be repaired or replaced when they malfunction)."* (Nicholls, 2017, 121)

In the Shire, I identified this distinct biomechanical ontology of pain which Graham had not specifically considered. At its core this ontology is associated with the premise that the body

is a technical object with moving parts that can be fixed and thus relieved of pain caused by mechanical dysfunction and failure. This ontology was illustrated by the following accounts of past practice from physiotherapists reflecting on its lack of utility in management of chronic pain:

> *"I'm…not trying to fix everything all in one go and not trying to fix anything sometimes. I felt that helped me relieve the pressure off me because I guess I felt I'd been trained to fix people."* ***(MSK Specialist Physiotherapist 8)***

> *"But within eighteen months I was pretty disillusioned with physiotherapy, I thought, 'What on earth are we doing here really?' Because for me, there was a big paradox - you can have two people sat in front of you with what seemed to be the same signs and symptoms around a pain problem, and the two of them would react very differently to what you did. You know, some people you could just talk to them and they said, 'I feel so much better,' when they came back, and others you could throw all the modalities in the world that you were taught in those days and it wouldn't make a blind bit of difference, so I was really questioning what on earth I was doing really."* ***(Pain Specialist Physiotherapist 7)***

Accounts of similar enactment of the biomechanical ontology were rare amongst healthcare practitioners in the Shire, perhaps reflecting the focus on chronic pain rather than other types of pain. They were more common in both discourse and the practical regimes of people living with pain (see Chapter 7). These accounts suggest that the biomechanical ontology is fading amongst specialist pain practitioners who are slowly rejecting its meanings and practical regimes but enduring amongst those living with pain.

6.2.9 Embodied inter-subjective ontology

Before turning to the last pain ontology, I return once more to the Shire, this time looking to describe how (or even if) these multiple ontologies play out in the lives of practitioners. The multiple ontologies were not ascribed or confined to individual practitioners or disciplines. An individual could be party to several ontologies at the same time or be in dialogue with a colleague holding a different pain ontology and often hold shared uncertainty with their patients. Most of my participants were not cognisant of the possibility of multiple pains and as such were sometimes faced with the so-called 'incommensurability' problem where competing realities (ontologies) lack a common measure, because they use different concepts and methods to address different problems (Kuhn & Hacking, 2012).

Graham found that moving towards the nonmodern hybrid ontologies embracing the biopsychosocial approach worked for the Midwest Pain Group, united in rejecting Cartesian mind-body dualism (2015). However, critics of the biopsychosocial model of pain for instance have argued that, it fails to address or resolve the two-world problem (Stilwell & Harman, 2019), and as I also found, it is not *done* in practice but through discourse (Mescouto et al., 2020). Its adoption in preference to longstanding biomedical ontologies may result in surfacing disciplinary trouble as different stakeholders and practitioners assert their own priorities and interpret reality differently resulting in ontological conflict (Mol, 1999) (see e.g., Wilson et al., 2014). On an individual basis, practitioners may experience moral distress and dissatisfaction with the care they provide, and they may not have a way to integrate these seemingly disparate ontologies. For example:

> *"No, it doesn't work or this this isn't the right way, or this is the right way, you know, constantly in your mind, or in my mind, and so, is this right, isn't this right, why isn't*

this working, yes... do you know what I mean, constantly, and then in that there's sort of experience of trying to understand people I think. How I can help, because you feel helpless yourself as a clinician sometimes, and people sit, and cry and they sort of... so, sort of... I don't know, it's sad, you know, it really gets you, and feeling helpless to help them. That's not a nice feeling, but..." ***(Physiotherapist 8)***

In this account, the physiotherapist is struggling with reconciling these different ways of working and experiencing ontological conflict reflected in the elisions in their speech. It is not just patients experiencing hermeneutical injustice due to not possessing the conceptual resources to articulate their own experiences, it is also a professional struggle. Attempts to separate one ontology from the other or prioritise one over the other might create a site of ontological conflict. I present three separate accounts (two from a single practitioner) that for me, suggest a different way of working with multiple ontologies that includes an ability to oscillate between them and accommodate rather than attempt to dispel uncertainty.

"And I think a lot of people are very open to thinking about the impact that some of the social factors as well have same sorts of life stresses and how that exacerbates pain, poverty and the challenges of trying to deal with the issues around that." ***(GP trainee 4)***

And:

"I bumped into one of those patients in the street the other day and he gave me a huge hug and just said, 'How lovely to see you,' and I wonder if perhaps the benefit I offer is not really about the pain or treating the pain, the benefit is in the bearing witness to the pain. And we both know that I'm unlikely to make significant benefit or significant improvements in treating it, but at least I'm there watching how awful it is for him and trying; I haven't given up on him, and perhaps that's important for people. So, if you haven't got that then you stop engaging." ***(GP trainee 4)***

And:

> *"But we all address it... we all look at it through different eyes. So, I say to patients, 'I'm the occupational therapist. I work for the rheumatology team. You know, I'm going to tell you about the sorts of things that we can support you with today and whether you might need our services in the future. And we all look at you slightly differently and as occupational therapists, we're very interested in how does your arthritis affect what you do? What sorts of things are you finding that you're having problems with? Is there anything that we can support you with that?' Whereas obviously the doctors and... are looking at it through a medical eye, so it's interesting that pain gets... mentioned, but we all have different bits of it that we address it through."* ***(Occupational Therapist 22)***

Mol cautioned against discarding signs that were incompatible with a particular ontology and argues instead for addition as a *"powerful way of creating singularity"* moving away from seeking meaning and towards generating action (Mol, 2002, 69). Addition of these accounts uncovers an embodied action that is relational and inter-subjective and open and bears witness and supports. This embodied inter-subjective ontology generates liminal hotspots where multiple ontologies can articulate, and from which alternative ways of doing can emerge (Greco & Stenner, 2017).

The boundary work I encountered and presented in Chapter 5 served to maintain the disparate stable ontologies held within the service whilst enabling members of the pain multidisciplinary team to avoid conflict and disagreement. Arguably, patients such as John experienced the lack of accommodation of his own changing pain ontologies as unhelpful. The liminal hotspot could be a space of possibility, lack of judgement and of creative compassion, from which embodied social practices could take root/emerge,

The embodied inter-subjective ontology offers a hermeneutical resource that circumvents the need to solve the incommensurability and inexpressibility problems in pain. Practitioners gain from not having to make pain mean anything other than what their patients show up with; suspend judgement and offer to be a compassionate guide through available services. Though this approach may be challenging for those attached to a prior or conflicting ontological frame, doing nothing biomedical, behavioural or biomechanical may support their engagement with shared uncertainty without this necessarily being so problematic. The practical regime of this ontology being, fundamentally 'doing nothing' biomedically, behaviourally or biomechanically, but allowing space to do other supportive practices such as listening or signposting.

6.3 Conclusion

Building on work from Mol and Graham, I have used my empirical case study to extend what is currently known about the multiple ways that pain is done. I have focussed my insights from the Shire to outline eight multiple ontologies of pain. The two additional ontologies I have presented reflect the additional practices visible and available outside hospital settings (the Shire) and including my deeply embedded understanding of how physiotherapists view the body as machinic which shaped my interpretation. I have presented my analysis on the reasons for ontological conflict when these multiple realities are not recognised and the impact that these moments of incommensurability had on my participants. From my reading of these texts (including textual data from interview transcripts and documents), I conclude that pain and biomedical discourses are inextricably linked and biomedical ways of doing and being in pain remain extant. I have noted a hegemonic emphasis on the body as an object with limited attention to subjectivity and embodied subjectivity when it comes to

pain. I argue that an embodied inter-subjective ontology, allows healthcare professionals and their patients to work with uncertainty, by removing the requirement to have a single causal meaning for chronic pain. This presents a different way of doing and practicing pain care.

I will now turn to examining how pain management is *done* by those living with the condition. In doing so I seek to understand and surface, what realities (if any) are invisible or excluded. I attend to socio-material entanglements between the human self and non-human others and contrast these accounts with existing narrative accounts of pain.

Chapter 7: Assemblages of pain: unpacking the self in the self-management of chronic pain

7.1 Introduction

In this chapter, I turn to ask, "what can a painful body do?" Along with which self is being managed, I explore conceptions of the body that align with the multiple ontologies perspective introduced in Chapter 6. I draw on Deleuze and Guattari's (2013) work to map the multiple ways that people with painful bodies *did* pain in the Shire, using their conception of the assemblage[16] as a social formation that constitutes other complex socio-material configurations, to examine and explain how self-management of chronic pain is enacted. I focus specifically on how their concept of '*bodies-without-organs*' shapes an emergent and multiple ontology that aligns with how participants in my research lived with pain.

Deleuze and Guattari presented the body without organs as a metaphor summoning up an alternative conception of the human body as having more possibilities beyond the normative biological conventions. I begin by articulating my reading of Deleuze and Guattari's theoretical concepts before applying them to empirical data from the Shire, an approach for thinking with theory that some refer to as 'plugging in one text to another'[17] (Youngblood Jackson & Mazzei, 2012). I do this by illustrating ill-health and health assemblages relevant to participants' living and doing *with* pain, attending to assemblages

[16] The assemblage is more than the collection of things that its adjectival linguistic use infers. The analytic assemblage draws its purpose from desire which directs its actions.
[17] I cover this approach in more detail in Chapter 4

that contribute to *ill-health* and contrasting them with those that illustrate better health. I highlight instances of participants becoming-healthy through breaking and re-making relationships with people, discourses, places, and objects; and show how becoming-healthy is not a single, linear, or predictable process. I present instances of participants in *ill-health* assemblages seemingly shaped by the inclusion of medicalisation discourses and practices, which is contrary to current understandings of the role of medicine in supporting health. The post human orientation allowed me to explain how the embodied inter-subjective ontology I identified in The Shire (and presented in Chapter 6) was practically done.

My findings indicate that multiple assemblages constitute the 'self' in chronic pain. These assemblages are continually made and remade, including or excluding individual components, thus troubling prevalent notions of self-management as representing a singular ontology aligned with biomedical understandings of the body. Encounters with healthcare professionals sometimes contribute to ill-health making assemblages and people living with pain move towards forming becoming-healthy assemblages through entangled practices that exclude biomedical ways of doing. I conclude by demonstrating that the prevailing notion of 'self' in self-management of chronic pain is a misnomer that presupposes the human self as an independent actor removed from socio-material and cultural understandings.

7.2 Living with pain

There are many accounts of the subjective individual experience of living with chronic pain in the research literature and in narrative accounts of chronic pain. For instance, scholars have described how living with pain often leads to biographical disruption, where a person's

narrative about the future is ruptured by illness (Bury, 1982). A recent synthesis of findings from qualitative research concluded that people living with pain were torn apart from the world and themselves, had their pain invalidated and experienced a loss of credibility (Toye et al., 2021). There has also been some attention to what it means (and looks like) to live well with chronic pain. Reporting on a grounded theory study of people living with chronic pain, Lennox Thompson and colleagues (2019) found that living *well* requires what they refer to as an idiographic process of sensemaking that starts with seeing themselves as a person (rather than a patient), flexibly pursuing meaningful occupations, coping and making future plans. Working with patient researchers, Toye at al (2021) reported on a meta ethnography of qualitative studies focussed on the concept of recovery and presented their conceptual model of 'a healing journey'. They argue that living with chronic pain is *"an ongoing and iterating journey of healing rather than a final destination of recovery"* (10) where patients are able to reconnect to their personal selves, have their pain validated, are empowered, and have a sense of having a future. Conventional ways of thinking about chronic pain have not typically involved thinking of recovery. The focus instead (see Chapters 2, 5 and 6) has been on individuals coping with pain, changing cognitions and behaviour – related to Graham's (2015) cognitive-behavioural pain ontology, and managing the symptom of pain – linked to the biochemical pain ontology. Toye et al's paper presented a non-medical orientation of the meaning of recovery that also relies on individual agency and action for success.

The papers I've summarised above consider the lived experience of pain from phenomenological perspectives, however they give little attention to how the ideas they present can be practically operationalised by people situated in the world and in

relationships with others and environments. The phenomenological orientation is aligned with the non-modern discursive ontology I presented in Chapter 6.7. There has been some acknowledgement that people's reality of living with chronic pain is influenced by external relationships. For instance, early traumatic life-world experiences can be inscribed onto bodies leading to illness and pain in a demonstration of how external relationships can constitute pain through socio-cultural pathways of embodiment (Kirkengen, 2001). Additionally, people with pain sometimes experience hostile or adversarial interactions with healthcare professionals, particularly when there is no biomedically plausible explanation for their pain (Toye et al., 2017). Acceptance of accounts of invisible chronic pain can also be difficult for family members, leading to complicated home lives and sometimes a reduction in emotional and social support (Kempner, 2017). Phenomenological accounts of pain centre on human experience but do not account for wider socio-material contributions to the active prospect of living with pain *in* the world. I therefore sought an alternative theoretical lens to explain the accounts of practical regimes of people living with chronic pain in the Shire beyond the more well-known phenomenological perspectives.

Post-human perspectives allowed me to trouble the notion of the *self* when considering self-management in chronic pain and to expand other possibilities for those living with pain. Under this lens *"humans and their capacities are reconceived as continually being made and unmade across different encounters. This decentring of the autonomous subject creates space for analysing the interactions between human and non-human entities without privileging (or 'centring') one over the other"* (Gibson et al., 2021, 294). The self is continually constituted in entanglement with others, including objects, ideas, and people, to produce different embodied subjectivities.

I drew on assemblage theory as conceived by Deleuze and Guattari (2013) and interpreted by Buchanan (2020) to extend my analysis. I engaged specifically with their concepts of the body without organs, desire, territorialisation and the rhizome to illustrate my thinking. In the sections below, I begin by briefly explaining my reading of these concepts before 'plugging them in' to my data from the Shire to present and discuss the different productions of 'self' that lived with chronic pain.

7.3 What is an assemblage?

The tension between 'real' pain versus the 'perception' of pain is pervasive and enduring within the multidisciplinary pain management community with ongoing attempts to differentiate between them (Dale et al., 2019). Language and discourse around *mal*adaptive beliefs and unpalatable positions that people may hold regarding the cause and presentation of their pain are ubiquitous (e.g., Kempner, 2017; Werner & Malterud, 2003). As discussed in Chapters 2, 3 and 6, much of this language originated in behavioural psychology and is now embedded in formal health systems. The stories people may tell health care professionals about their pain are often considered by those same professionals, and/or the systems they work in, to be untrue and outside the established normative understandings of pain (Toye et al., 2018). This frequently results in an emphasis on 'correcting' these perceptions via pain education, underpinned by neurophysiological principles (Malfliet et al., 2018) or cognitive behavioural therapy (Tan et al., 2011).

Deleuze and Guattari's concept of the assemblage offers up a way of thinking of so-called maladaptive ways of living with chronic pain as being the reality for many people. An

assemblage is a relational working arrangement composed of multiple, heterogenous entities including ideas, human bodies, non-human objects, and discourses that are products of historical processes (Deleuze & Guattari, 2013). They are neither static nor malleable but possess *"tendencies toward both stasis and change as the abstract poles of a single continuum"* (Adkins, 2015, 13). The stable elements of an assemblage can be traced and the changeable ones mapped (Adkins, 2015). An assemblage is not merely a collection of things. An assemblage is produced by *desire,* which itself guides the selection of materials that go on to produce it (Buchanan, 2020); a process of production if you will. This creative desire motivates all living organisms and the assemblages they are a part of (Fox, 2011). The assemblages thus produced are real, and not an abstraction. When applied to thinking about living with chronic pain, an assemblage might comprise of an individual, their body and their social context all of which have the capacity to change depending on what tasks or goals need to be achieved (the desire).

The idea of self-management of chronic pain is suggestive of a stable hierarchical process by which people achieve a known end point in their living independently with pain. Patients are instructed by expert healthcare professionals on which knowledge and skills are best to achieve the state of self-management, with some approaches considered deficient (e.g., use of passive manual therapies- see Chapter 3). The cases and assemblages I present below (informed from my longitudinal involvement with seven people living with or in pain) suggest otherwise. I demonstrate how patient participants in my study made multiple, ongoing efforts at forming and reforming different assemblages which achieved different versions of self-management. The emergent 'self' was continually constituted and presented opportunities to become-other by making and breaking new connections.

Deleuze and Guattari use the metaphor of a *rhizome* to depict this process of becoming. *"Rhizomes do not propagate by way of clearly delineated hierarchies but by underground stems in which any part may send additional shoots upward, downward, or laterally. There is no hierarchy. There are no clear lines of descent."* (Adkins, 2015, 23). The rhizome allows multiple and heterogenous connections in keeping with the embodied action proposed by Mol (2002) and that I discussed in relation to the embodied inter-subjectivity ontology (see Chapter 6.9).

Through this lens, it is possible to see differently how and what a painful body can do that is removed from the binary value judgements inherent in the prevalent ways of thinking about self-management of chronic pain. Becoming *other* is made possible by becoming a *Body without Organs*.

7.4 Becoming a *Body without Organs*: living with chronic pain

Deleuze and Guattari's (2013) concept of a Body without Organs (BwO) represents a form of embodiment that includes the known biological body, yet is also expansively created by various assemblages. *"This approach de-centres the biological aspects of embodiment, while retaining biology and physicality as a (necessary but not privileged) component of the body"* (Fox, 2011, 360). The Body without Organs is not limited by an individual's organic biology or deterministic sociological explanations, but rather by the generative capacity of the assemblages available to them. The assemblages are continually formed and re-formed from a person's social and material relations and interactions (Fox, 2011). Thus, the Body without Organs has a greater capacity to do more even when in *ill-health* than the more constrained biomedicalised, organic body. It does so by making, resisting, and transforming

its relations. It *"may be thought of as a territory constantly contested and fought over. While the BwO is the site of cultural inscription, it is also the site of resistance and refusal, and is constructed and reconstructed (territorialized) continually"* (Fox, 2002, 352).

Deleuze and Guattari describe established processes and concepts as being territorialised into social practice, their disruption as deterritorialising and any subsequent movement away from them and towards different possibilities as reterritorialising (Buchanan, 2020). Stable and established ideas are embedded and therefore are difficult to move away from; they are territorialised into social relations and practices.

The Body without Organs is not the conventional body as it is known to modern biomedicine. That body is organic, localised and situated in biomedicine and is subject to the medical gaze to determine both illness and health. In my analysis, I trace, and map different Bodies without Organs as accounted by patient participants in my case study, rendering them visible by identifying and following the assemblages from which they potentially emerge and linking them with motivating desire.

7.5 What can a painful body do?

In Chapter 6, I presented the case of John, one of my case study participants. I return to John's case here, employing a Deleuzio-Guattarian lens to map out the assemblages evident through my analysis, and raising the question: *what can (and what does) a painful body do?* I additionally attend to what may be considered 'ill-health making' assemblages that produce what participants considered negative aspects of their health and, assemblages that reterritorialized them into more 'health-making' or 'becoming healthy' assemblages. In

doing so, I highlight that for different participants, there were multiple and varied ways of living with and in pain and that it was common for participants to experience both ill-health and becoming healthy, often moving between these states. I repeat this mapping exercise with two further cases that illustrate the production of both ill-health and becoming healthy assemblages.

I started my analysis by reading and re-reading interview transcripts, reviewing photographs and correspondence with participants, my field notes and reflective diary, attending specifically to narrative accounts and practices of what a painful body was doing. Each time I identified an instance of participants embodied action in relation to doing with pain, I started a connected list of words depicting what was constituting each assemblage. I noted words depicting common ideas within pain management, human bodies, non-human objects, and discourses as well as ways in which they related. In keeping with the metaphor of the rhizome, I traced these ideas through the data interpreting relationships that may not have been related chronologically. As such, the illustrations I present include territorialisation, deterritorialization and re-territorialisation towards what I consider to be normative ways of living with pain.

As is usual when using these analytic concepts, I illustrate these assemblages by combining the constituents components (words) into a line separated by dashes as demonstrated by Fox (2011).

7.5.1 John: The 'Pain relief seeking' assemblages

John and I met five times (over six months), spending time talking about how he was living with chronic pain and the practical regimes he engaged with to do so. As well as an initial biographical narrative interview, John also shared photos of objects that he identified as important for self-management and took me on virtual home tours (as we met during pandemic restrictions). Plugging in John's data to my reading on assemblage theory, I deduced that John's prevalent motivating desire was one oriented towards pain relief, producing a **'pain relief seeking'** assemblage. However, his accounts of living with chronic pain indicated that in his encounters with healthcare professionals, pain relief was not always a stated aim of their interactions. This led to multiple and heterogenous attempts at forming assemblages that would produce the desired pain relief. John's motivating desire at the point of his initial symptomatic tooth pain was to seek pain relief, then search for an explanatory diagnosis, then back to pain relief for his newly diagnosed 'neuropathic pain', better sleep, flexible work, reduced medication, more contact with his family, engagement with his musical hobbies and so on. His desire was not static and as such, produced different assemblages comprising at least:

John - facial pain clinic - pregabalin - pharmacy - Facebook™ - music- guitar - psychologist - book - partner - GP - employer - football - family- dentist - regulations - side effects - phone

John's biographical narrative highlighted episodes where he encountered the healthcare system in the Shire over time; each encounter drawing in varied elements and thus producing different assemblages that in turn produced different experiences of living with chronic pain. The two assemblages that I present below reflect the frequency with which John brought up these concerns in our encounters. He was particularly troubled by feeling

fatigued and often discussed with me what he thought was causing this. I deduced that for John, the 'fatigue producing' assemblage included the effort of experiencing troubling facial pain, compounded with trouble sleeping, social isolation, worries about work and the wider impact of seeking pain relief during a pandemic. John's '**fatigue'** assemblage comprised at least:

Neuropathic pain - pregabalin - sleeplessness - work - avoidance - social isolation - alcohol

During one of our meetings, he described the impact of a recent bad pain flare-up that illustrated how he experienced the fatigue inducing pain and the additional elements that produced it:

> *"Well it used to be incredibly scary, you know, I just... I just thought well, because it stops you sleeping, it stops you doing everything and you think, 'Well, you know, I've got a professional job, I've got responsibility, it's money coming in for me and my partner,' and, you know, all those things."*

John had made may efforts to deterritorialise away from his painful and fatigued body. He had tried to avoid succumbing to what he saw as a more *"helpless"* way of being with chronic pain. At our first meeting, he explained how he had started to use mindful meditation to address pain, stress and fatigue saying:

> *"I guess the general purpose is to relax myself after working. So, sometimes I am in pain when I'm doing them obviously because I get days when I'm in pain, and generally, it improves the situation, but I can tell you that if I am in the advanced stages of pain, if I'm in a proper flare up, it's all very difficult to do. So, I think the idea is really that it prevents a flare-up as much as possible, so it is directly therapeutic in that sense. It's therapeutic in the sense it would be for anyone who*

needed a winding down routine after work and... I mean to my mind why would you not, but it depends what you're doing I suppose and what kind of person you are. But yeh, I find... I find I get a little high just from finishing the working day, so whether that means I am highly strung or whether it means I enjoy my work or, you know... so, there's a positive and negative analysis of that, but I have always naturally done a kind of winding down after work, but with the pain, as I say, it's much more structured, the idea I think, the recommendations were that, you know, if I feel less stressed then it's less likely to aggravate my pain."

In the extract above, John presented several explanations as to why he had started mindful meditation for pain and fatigue and struggled to settle on any single one. The motivating desire of seeking pain relief and the practical regimes related to seeking respite, paradoxically and recursively produced an additional undesirable assemblage which John did not appear to have considered. The broader 'pain relief seeking' assemblage in turn contributed to the formation of a 'fatigue' assemblage. Both these assemblages served to continually reterritorialize John back into a limited and docile painful body.

Also emerging from the motivating desire for pain relief, I identified an 'addiction assemblage' comprising at least:

Pregabalin - pharmacy - prescriptions-surveillance-regulations-shame-stigma

Produced by a changing regulatory landscape, the medico-pharma industrial complex, the health system in the Shire, health care policy, cultural norms and beliefs about addiction, this assemblage constituted a particularly limiting painful self that was beyond John's gift to manage. John had been facing regular challenges when trying to fill and collect his prescription of Pregabalin since it had been reclassed as a controlled drug in April 2019. This

change in frequency of prescriptions to twice weekly compounded with drug supply shortages precipitated by the UK's exit from the European Union in December 2020, and John's previously stated fears of addiction, led to increasing feelings of shame. He described one particularly bad encounter which I include here in full:

> *"I went down to collect it. I was told again from X pharmacy that they didn't have any; they couldn't source any of the fifty milligram tablets for Pregabalin. So, OK. Well, in that case I will accept Amitriptyline and codeine. What I do know is I had to collect on three separate occasions; twice on the same day. So, the next day I was collecting Pregabalin from a different pharmacy, but they didn't have enough, so I had to go back for those. So, that's what it was. So, I got my Amitriptyline and codeine with my repeat prescription from X pharmacy on the day. On the day, I was meant to collect the controlled drug; this is why it's a farce. You know, so I did collect some of the controlled drug. Hang on, I had to go back on Saturday twice. That's right, I don't think... I really can't remember. What I do remember is I had to go three times to get everything. So, they've got three items that I'm meant to be able to collect on one day. And I'm meant to collect it on the one day because it's a controlled drug. Now I haven't chosen to... to be a control... and in fact, it seems a bit unfair because when I started on these, Gabalin... sorry, Gabapentin, they didn't seem to be used recreationally because there wasn't all that... or at least they were and there was no concern. But it's only a couple of years, I think, that's it been controlled."*

These *ill*-health assemblages were produced and situated within the normative and biomedical body that kept John entangled with the health system in the Shire, even when doing so limited the *"conditions of possibility for the body"* (Fox, 2011, 362). In trying to disentangle himself from Pregabalin, by seeking help to come off the drug, John was continually territorialised back into the painful organic body. This limited John's ability to reconstitute a different way of *doing* with pain. The healthcare system, with its embedded

ideas about biomedicine and the role of medication in managing neuropathic pain was preventing him becoming-other and doing more despite the pain. There were limited options for John to do self-management outside the biomedical parameters.

7.5.2 Jessica: from ill-health to becoming-healthy and back again

Jessica is a 61-year-old woman who lives with her husband just outside the city in the Shire. They own their home, a Victorian terraced house with a small garden close to local amenities. Jessica used to commute to work and had a busy job in accounting before she retired. She raised two children whilst also working full time, they are now adults. Jessica experiences widespread pain in different areas of her body and has done so for 18 years. She was initially diagnosed with rheumatoid arthritis, an autoimmune disorder that leads to swollen, painful, and stiff joints. She has also had stomach problems diagnosed as ulcerative colitis by a specialist rheumatologist at Foundation NHS Trust. She used to have steroid injections into her painful joints every 2 or 3 years, which helped her get through bad patches and *"keep going"*. She recalls taking one medication Methotrexate early on following her initial diagnosis, which to her was *"the medicine of the devil"*. In those early days, Jessica's overarching and motivating desire was centred around managing her symptoms (pain, swelling and stiffness) enough to allow her to continue her busy life in a number of roles. I refer to this as a '**medical treatment**' assemblage comprising at least:

Joints-rheumatologist-methotrexate-steroid injections-rheumatoid arthritis

Jessica has since been told that she doesn't have rheumatoid arthritis, commenting *"it's certainly not rheumatoid anymore"*. The **'medical treatment'** assemblage changed as the motivating desire shifted to one of being well, potentially without medication. The

decoupling of the rheumatoid arthritis diagnosis from the practical routines that constituted this assemblage appeared to lead to a change in purpose for Jessica. In this passage, we can map the shifting desire:

> *"I've never been told, 'Well, you know, you're having too many painkillers; we're going to restrict them,' apart from the consultant at the neuro... the neurologist last year said that I had to wean myself off them because that was what was triggering the migraines. You know, yeh, I feel very, very well looked after, but just can't get on top of this pain. I don't want to take massive amounts of painkillers just to live my life because then they do bother my stomach. And then... and they always cause constipation and that's not something that's just sorted out overnight. So, yeh, it's a bit of a... it's a bit of a... it's a dilemma really."*

Jessica deterritorialises from the biomedical imperative and clinical gaze that had guided her reality of doing pain *with* medicines. Following the change in her diagnosis, she takes steps to extricate herself from dependence on medications and is supported by health care professionals in this choice. She provides an alternative explanation for her pain that is not singular, but multiple; a **'running on empty'** assemblage comprising at least:

Stressful job- not eating right- teenagers at home - stress levels high - heavy cold 2 months before

This assemblage suggests an alternative causal explanation for her symptoms and therefore enabled a different direction towards the possibility of doing more despite the pain:

> *"I think now on reflection, it was a combination of different things like I was probably hitting peri-menopause, I was in a stressful job, I was probably not eating right. I had teenagers in the household, so the stress level was always quite high. And I think it was just a combination of probably a few months. I'd had like a cold, a really heavy*

cold, about two months beforehand, and I'd probably not built myself back up. You know, and I was probably running on empty for too long, but not recognising it because I was holding down a job, was functioning, but in hindsight, I probably wasn't caring for myself."

This different assemblage allows Jessica a reterritorialization to a different way of thinking and new possibilities. The possibilities thus produced started with unsuccessful attempts to deterritorialise from the biomedical doctrine. She reflects on her experience of falling in the past (when the rheumatoid diagnosis was less clear) and more recently:

"…if I fall down now, I can get up, whereas I've known periods where, you know, I've fallen in shops, for instance, and embarrassingly, had to help... ask for help."

The embarrassment of falling in public mobilised a different desire to have a reliable body she could trust to do things even if there was no medical cure for her pain. Faced with ongoing uncertainty about what her body could do, but differently motivated to explore alternatives Jessica *"mixed chillies with oil and pasted that on swollen bits"* because she liked the *"stinging nettle feeling on [her] joints"*. She *"just googled something on one of the sort of batshit crazy websites"* to explore what else outside medicine offered her possibilities of becoming-other.

Jessica also turned to physical activity and what she calls *"fitness training"* as a way of living with pain and stiffness. She expressed a desire to keep moving and not be constrained by her symptoms. She adapted her lifestyle to include *"walking fourteen thousand steps a day, every day, religiously"*, *"lifting weights… and just doing more strength training and that*

seems to keep everything fairly stable so far". Jessica's **'fitness assemblage'** includes material objects, human relationships, and the fitness community:

Yoga-stretching-personal trainer-gym-weightlifting-eating protein-bike with fat wheels-stairs-rheumatologist-Facebook-Zoom-smartwatch-allotment

Her rheumatologist is also a member of her gym and encourages her to continue with her training, whereas other healthcare professionals have discouraged her in the past. Jessica acknowledges that her confidence and ability to venture into fitness was supported and encouraged by key healthcare professionals. In contrast to John's experience, she has *"always been treated with a lot of respect... and seriousness and that somebody's always believed [her]"*. This assemblage allows Jessica to move away from the biomedical territory and it's dependent, poorly functioning body and towards the creative possibilities of becoming something else despite pain.



***Figure 9**: A picture Jessica sent to me just after she achieved a personal best in the deadlift. She also posted it on social media*

Jessica was becoming a healthy Body without Organs by experimenting and moving away from more restrictive ideas of what was possible with a painful body. But as Deleuze and Guattari intimated, the Body without Organs is not a position of stasis - it requires continual deterritorialisation away from settled ideas (e.g., in biomedicine) of what a painful body can do and reterritorialization into different possibilities (Buchanan, 2020). The Body without Organs is like a template of a human upon which different possibilities can be mapped to, each producing different selves.

At our last meeting, Jessica reported that she had finally had an appointment with a new rheumatologist following a 2-year hiatus (due to the Covid- 19 pandemic restrictions). She was given a diagnosis of fibromyalgia and a prescription for amitriptyline (an antidepressant used for chronic pain). The rheumatologist explained that fibromyalgia accounted for all her

symptoms including widespread pain, fatigue, and bowel disturbances. Jessica was shocked as this was the first time that fibromyalgia had been mentioned, and she did not want yet another diagnosis. This new diagnosis had thrown her off course and she was back to thinking of new ways to manage this unknown. The rheumatologist had *"recommended looking at a pro-inflammatory diet"* which Jessica was unsure about. She had already changed her diet to incorporate much more protein to support her weightlifting and suspected that pro-inflammatory *"means going vegetarian and stuff"* thus disrupting her attempts at becoming healthy/other.

This encounter with a different health care professional in the Shire seemed to have disrupted Jessica's movement in becoming a healthy Body without Organs. The new medication was producing a different possibility of doing with pain. Jessica reported being very fatigued and unable to keep up her fitness activities. She was despondent but determined to explore other solutions to help her return to health. The system was working to territorialise her back into biomedical doctrines which so far had contributed to a more limited way of being and doing with pain. Despite this, Jessica had plans to *"carry on, carry on, carry on"* and make concerted efforts to resist being territorialised into a docile, less able body. She reported that despite feeling despondent about the new diagnosis, she had started to consider and try out another different way of living and doing with it. I would say that she was following a new 'line of flight', starting to form different assemblages and enable her to again become-other. This new **'exploratory'** assemblage comprised of:

Weather-pollen-immune system-reduce caffeine-raised flower beds-movement planning

She was investigating different ways of being with a new (and limiting) diagnosis. For Jessica, living with (and self-management of) chronic pain was not a static enterprise, but rather comprised multiple motivating desires and assemblages, that allowed the formation of different 'lines of flight'. This allowed her to explore possibilities of becoming a healthy Body without Organs despite living with chronic pain.

7.5.3 Clare: Wanderlust, pain and the ageing body

Clare lives alone in a modest house adjacent to parkland in the Shire. She is 72 and prides herself on not matching people's expectations of an older person. She has had a busy and varied professional life and has always been an avid walker regularly covering "*between twelve and eighteen miles a day*". She has been *"travelling through the world on [her] feet"*, visiting different countries, camping in her *"tiny tent"* and communing with nature. Clare had lived without chronic pain almost all her life though she was familiar with short episodes of pain often explained by having sustained an injury in the course of her active life. Four years ago, she developed pain in her back and nerve pain that goes down both legs which has become increasingly debilitating over the years. At one point, she recalls:

> *"And I couldn't sit; I had to stand or lie down for four or five months. I was worried about my parathyroid, I was worried about my height, I was worried about my back, I was worried about my hips, I was worried that I would never get back in the wilderness again. And it was terrible."*

Clare finds that the **'wanderlust'** assemblages that have suited her desire to see the world and be in the world, are being disrupted. She and they are being territorialised to normative notions of what an ageing body can do; moving from good health to becoming an *ill*-health assemblage comprising at least:

sister-pain-inflammation-sacro-iliac joints-loss of height-co-codamol-ibuprofen

In this instance, her sister, also a doctor, plays a part in the territorialisation, into biomedical illness, though this is driven by fear for Clare. She reflects:

> *"My sister, as many doctors are, is an awfuliser, you know, everything is... becomes really awful, and she looked at my back and…, you know, she really had a go at me, and I felt that she'd taken me from being a healthy person to being a person with significant problems."*

Clare, initially territorialised into a painful biomedical body, succumbs to the narrative that things are indeed awful and reduces her physical activity, general movement, and social interaction. She further becomes ill through this withdrawing behaviour. Despite the *"awful state of affairs"*, Clare found a way to becoming-other with pain by unapologetic use of pain medication. In the previous two cases, John and Jessica, medication forming assemblages produced ill-health. Conversely, Clare's interaction with her private consultant, albeit one who waived their fees, led her to proclaim that *"I just felt loved and respected"*. She had similar, though more painful encounters with a private physiotherapist who *"just went at [her]"*. She concluded that *"it was really, really painful and it was so effective and honestly, I felt […] that once or twice I could fly, you know, it was just being lightened from all that and I could feel that I could move"*. This assemblage constituted by biomedical people, objects and spaces enabled Clare to complete a month or so of backpacking. She did not experience this euphoria for long, but long enough to undertake a much-desired pilgrimage. It temporarily produced a body that ran counter to normative notions of what a painful and ageing body can do. Clare had the social and monetary capital to affect these assemblages.

Clare mobilised her assemblage to rally against societal norms of the possibilities available to an ageing body. Nevertheless, she appeared set for another becoming, territorialised into the very landscape she desperately wished to avoid:

> *"Is, you know, is being seventy-two…about what is legitimate to expect and what comes with this, you know, and what ought to be managed or, you know, sorted out in some way. I'm really interested in how, as you get older, this idea of managing and sorting out, fixing, resolving, removing. It's just not there anymore and some of that is wonderful, it's like, you know, all those times when you're working and you have to go to your annual performance review and you have to say what you're going to do to improve your personality and how you're going to deal with it. And I don't have to fucking do that anymore, you know, and that is wonderful. You know, I am what I am and I don't need to fix those."*

In this passage, Clare is clear about her identity, her 'self' grounded in a powerful sense of agency that she continually mobilises to achieve what was best for her at the time. She was able to draw on multiple and heterogenous ways of becoming, supported by (and in) the health system of the Shire. Clare closely embodied what it could mean to successfully self-manage her chronic pain.

7.6 Conclusion

The idea of self-management of chronic pain as presented in the academic literature and in practice is suggestive of a fixed, hierarchical process by which people achieve a known end point in their living independently with pain. The cases and assemblages I have presented above (informed from my longitudinal involvement with seven people living with or in pain)

suggest otherwise. My analysis has shown that living with pain involves multiple, ongoing efforts at forming and reforming assemblages. As Clare's experience showed us when coming to terms with the idea of an ageing body and Jessica's changing relationship to different diagnoses, production of these assemblages is not a static, linear, or hierarchical process. Instead the production of assemblages is influenced by wider social relations and wider entanglements reflecting the *"fluctuating nature of embodied health"* (Fox, 2011, 366). Resistance, refusal and rebellion sit alongside acceptance, and engagement of the biomedical landscape of thought and ideas as related to chronic pain. Dominant discourses of living with chronic pain - couched in either biomedical or behavioural terms - offer a limited view of what the painful body can do. These narrow possibilities are supported by associated hegemonic ontologies situated in biomedicine and behavioural psychology. Thinking with Deleuze and Guattari allows for divergent ways of thinking about and understanding how people live with chronic pain than more common dualistic mind- body (only) ontologies do. Their theories of embodied subjectivity allowed me to consider perpetual change and uncertainty in the presence of multiple pain ontologies when presenting accounts of how people lived with chronic pain. Contrary to the singular notions of the self in how self-management is construed in academic literature and in clinical practice in the Shire, I have demonstrated that the 'self' living with pain is continually constituted through assemblages with consideration for both social relations and practices.

Pain care needs to explore individuals' pain assemblages. As set out above, in the cases of John, Jessica and Clare, these assemblages produce different selves that may or may not include conventional ideas about self-management. Attending to the myriad of elements contributing to each assemblage as experienced by those living with or in pain may be more

amenable to change than having the express motive to directly change pain. Healthcare practitioners can work with their patients to identify assemblages and together 'change pain' and the experience of living with chronic pain. Acknowledging the contribution of multiplicity (in the form of multiple pain ontologies) and resisting the pull for ontological certainty that privileges either the body, the mind or the society potentially enables different ways of thinking about and living with chronic pain.

I have shown how wider societal discourses can be imbedded into the formation of both ill-health and health-making assemblages in the socially entangled practices of individuals living with chronic pain. In the next chapter, I adopt an interpretive policy as discourse approach to understand how macro level policy framings have contributed to the conceptualisation and practice of self-management in the context of pain care.

Chapter 8: How policy shapes self-management of chronic pain

8.1 Introduction

In earlier chapters I outlined the dominant ways of knowing pain (and chronic pain) and self-management. I detailed the presence of multiple ontologies of pain through an analysis of the practical regimes in the Shire in Chapter 6 and set out how the construction of assemblages constituted the subjective and embodied practices of living with pain in Chapter 7. In this chapter, I cast an interpretive lens on how macro level issues of policy converge with these concepts to shape how self-management is conceptualised and practiced. I draw on analysis of policy documents and in-depth interviews with policy actors to generate insights into how chronic pain is (or isn't) represented in health policy.

In the following sections I set out how the different meaning(s) of self-management of chronic pain are discursively constructed in policy (Yanow, 2000). Guided by an interpretive approach to policy analysis (Shaw, 2010; Wagenaar, 2014; Yanow, 2000), I argue that the absence of clear, state-sponsored public policy on chronic pain has led to the emergence of a range of different political framings and allied discourses that are often in tension with one another. Drawing on a range of policy documents and symbolic artefacts (e.g., websites, reports and public information) and interviews with policy actors, I highlight relevant interpretive communities involved in shaping chronic pain policy, the kind of knowledge they prioritise, how power circulates within and between them and, the meanings they

ascribe to self-management of chronic pain. An interpretive community refers to "groups of people who might share understandings of policy ideas and language that would be different from other groups' understandings" (Yanow, 2000, 27).

I show how 'received wisdom' about self-management of chronic pain in policy has been influenced by and has adopted the language of neoliberal political ideology, which typically fails to account for the meanings that are held by other interpretive communities such as member-led advocacy collaboratives. I show how chronic pain policy reflects the dominant ways of doing self-management of chronic pain previously discussed (Chapter 3). I align the most visible (in my data) interpretive communities of 1) uni-professional pain consultants and 2) multi-professional clinicians, with the dominant biochemical and cognitive behavioural ontologies (Chapter 6), underpinned by positivist epistemological paradigms (Chapter 2). I demonstrate how more collaborative grass roots interpretive communities are working to influence how pain care is practiced despite the dominance of historic powerful health care-led communities.

8.2 Chronic pain and self-management policy in England

From an interpretive policy analysis perspective, policy is *"…a set of shifting, diverse, and contradictory responses to a spectrum of political interests."* (Edelman, 1988, 16). Following my analysis of relevant health policy documents (see Table 9), I found that chronic pain is notably absent in formal, state centred policy in England, and as it relates to self-management, extremely limited. Policy documents from around 2000 - 2005 centred self-management as a service objective for the NHS. Initially embedded as part of a comprehensive plan that included initiatives such as the NHS direct telephone service

(Department of Health, 2000), the expert patient programme (Department of Health, 2001) and the entry-level intervention for the NHS and social care model (Department of Health, 2005b), self-management was linked specifically to managing chronic pain particularly as part of living with chronic illness and multimorbidity. As presented in Chapter 3, self-management in UK health policy was situated explicitly in the realm of chronic illness management and with historical roots in the Chronic Disease Self-Management Programme (CDSMP) at Stanford, USA (Lorig & Holman, 2003). Published in the same year as the NHS and social care model programme, the Department of Health's (2005a) paper on self-care (including for pain reduction) did not reference self-management as aligned with the CDSMP as prior documents had.

Chronic pain in England has not been a central state centred policy concern beyond early associations with self-management related policies. By 2012, self-management was used interchangeably with self-care and associated with shared decision making and choice centred rhetoric along with the use of personal health budgets to pay for these activities for people with long term conditions such as diabetes (Department of Health, 2012). NHS England's Five Year forward view (2014) made no reference to pain, chronic pain or self-management.

In contrast, MSK conditions are well represented in current health policy in England. MSK conditions are "a broad range of health conditions affecting bones, joints and muscles, pain syndromes and rarer conditions of the immune system" (Public Health England, 2019, 6). However, not all chronic pain is MSK pain, though many MSK conditions can lead to chronic pain. People experiencing chronic cancer pain, chronic neuropathic pain, chronic abdominal

pain, facial pain, headaches, amongst others are rendered invisible through this dominant view of MSK as being inclusive of chronic pain (Versus Arthritis, 2021; Zinboonyahgoon et al., 2021). MSK conditions have benefitted from an organised alliance of multiple state and non-state actors including various Royal Colleges representing powerful medical interests. These actors have successfully lobbied for recognition and are now represented at all levels of state level health policy with, for example, MSK conditions identified as a national priority initiative for NHS England; a national clinical director; and various national programmes dedicated to improvement of care, workforce development (Health Education England, 2018) and preventative care (Public Health England, 2019).

Though complex chronic pain conditions are included in the case for funding MSK care, the resources for a suitably trained workforce, service provision and specialist care do not always reflect this allocation. MSK services often do not have adequate provision, clinical expertise, or service configuration to support people with more complex, or non-MSK chronic pain. The lack of visibility of chronic pain conditions within state centred health policy, is replicated in the variability in availability, adequate staffing and quality standards within specialist pain services in England (Price et al., 2019).

More recently there have been efforts to highlight the challenge of chronic pain for decision makers in health and social care at a population level. The 2017 health survey for England (Public Health England, 2020) included chronic pain conditions for the first time thus increasing their visibility to policymakers. The survey data has subsequently been used to support other calls to policymakers to attend to chronic pain issues at a level on par with more measurable, and better understood conditions (Versus Arthritis, 2021).

Despite multiple and ongoing attempts, actors representing chronic pain, have not been as successful as their MSK counterparts in securing a place on the national policy landscape in England. Active between 2008 – 2019[18], the Chronic Pain Policy Coalition of stakeholders including health care professionals, professional bodies, parliamentarians, and industry had the aim of improving policy in the area. They had some success in gaining an audience with parliamentarians to argue the case for increased attention for chronic pain in 2008 (NHS England, 2019b) and again in 2019 but do not appear to have met their goal. The NHS Long Term Plan (NHS England, 2019a) and its subsequent implementation framework (NHS England, 2019b) did not specifically reference chronic pain or pain management services (but does include MSK services). In 2021, the minister of state for health in England published the Integration White Paper which set out proposals to accelerate and support better integration across primary care, community health, adult social care, acute, mental health, public health and housing (Department of Health and Social Care, 2022). It did not reference pain at all despite pain being a key troubling symptom for many chronic illnesses as well as a disease in its own right. The development of new pathways for MSK was included. To date, chronic pain continues to be absent from state centred policy attention in England.

[18] The Chronic Pain Policy Coalition was hosted by Policy Connect, a not-for-profit social enterprise and think tank, led by Former Government Minister, Jonathan Shaw. At the time of writing this thesis, it was no longer listed on their website and had not produced any further guidance since 2019.

8.3 Governing chronic pain

While there may not be a document(s) setting out policy vision or direction for chronic pain, this may well be a deliberate choice by the state, consistent with a neoliberal approach to policymaking. Neoliberal politics advocates for free-markets to provide services (including public goods), deregulation and reduced involvement of government and institutions in citizens lives (Harvey, 2007). Self-management fits with this ideal in that it suggests that institutions and the state have a role in providing guidance and steer (as outlined in section 8.2 above) but allow others to take up the mantle of delivering the detail of service delivery and support.

Health care professionals, represented by a range of professional interest groups have taken on trying to organise, deliver and sustain pain care for their communities. These organisations have been publishing and promoting documents and guidance that ostensibly fill the gap left by the absence of state centred chronic pain policy. These documents frequently provide guidance on service provision (British Pain Society, 2013), commissioning (Faculty of Pain Medicine, 2020b) and, evaluation (Faculty of Pain Medicine, 2019) with each document often referencing the prior one, thus discursively recreating a seemingly singular chronic pain community with shared meanings. However, there are examples of this not being the case and of there being different interpretive communities with conflicting meanings.

Practice in NHS provided services has been largely influenced by so-called 'evidence-based' clinical practice guidance produced by different professional bodies. The most influential being clinical guidelines issued by the National Institute for Health and Care Excellence

(NICE), an executive non-departmental public body of the Department of Health and Social Care in England. Early guidance tended to follow single condition issues that had relevance to chronic pain e.g., low back pain and sciatica (NICE 2016), neuropathic pain (NICE 2013). Despite an apparently rigorous, transparent, and unbiased policy development process in keeping with exemplar practice within this paradigm, these guidelines (as related to chronic pain conditions) have been plagued by dissent, claims of conflict of interest unduly influencing the findings and as a result, considerable difficulties with implementation in some sections of the pain management community (Wilson et al., 2014).

Guidance for the management of chronic low back pain first produced in 2009 resulted in a notable backlash particularly from doctors, specifically anaesthetists who had completed speciality training to become consultants in pain medicine (Wilson et al., 2014). 2009 marked the first time that NICE methodology had been applied to a specific chronic pain condition to produce clinical guidelines. Prior to that, there was little shared guidance for both medics and non-medical health care professionals. This guidance was issued with the stated aim of improving care and reducing variation of service provision and the cost of delivering care in the NHS. This guidance (National Collaborating Centre for Primary Care, 2009) and more extensive guidance covering all chronic pain in adults in 2021 (National Institute for Health and Care Excellence, 2021) were developed in partnership with the Royal College of Physicians and included varied stakeholder development groups. Many traditionally biomedical activities were *not* recommended in each successive guideline including imaging such as routine X-ray and Magnetic Resonance Imaging (MRI), spinal injections, and different medications.

There was again, extensive criticism of the 2021 guidelines and a range of public statements against the veracity of its processes, perceived harm and, claims of undue bias. It is under this background of ongoing tension and social drama, that I now look in detail at *what* and *how* the symbolic artifacts associated with several different interpretive communities have shaped the meaning of chronic pain and self-management.

Table 9: *Depiction of self-management and chronic pain in policy documents*

Policy document	Depiction of self-management and chronic pain
Department of Health. (2000). *The NHS Plan: a plan for investment, a plan for reform*	Increasing access to e.g. pain consultants, economic costs of back pain and related sickness absence) *Self-care* as part of comprehensive care: professional training to support self-care, NHS direct to contact self-help groups
Department of Health. (2001). *The Expert Patient: A New Approach to Chronic Disease Management for the 21st Century*	Unecessary pain as part of chronic disease, pain management via CDSMP, reduction in pain from self-management programmes (SMP), EPP to manage pain, challenge of increasing cost of back pain, reduction in hospital visits after completing SMP, expansion of user-led Self-Management (SM), use of complimentary therapies, commissioning SMPs, incoporate into policy frameworks, take personal responsibility, linked to self-efficacy, cost savings, SM central to long term illness
Department of Health. (2005a). *Self care – A real choice: Self care support – A practical option*	Leads to a reduction in pain, increased independence, maintenance of good health, prevention of ill-health, acknowledge risk: capacity to self-care No reference to self-management
Department of Health. (2005b). *Supporting People with Long Term Conditions: An NHS and Social Care Model to support local innovation and integration*	Acute and palliative care, back pain, EPP now self-care programme, NHS & social care long term conditions model, level one. Both self-care & SM – unclear distinctions
Department of Health. (2012). *Long Term Conditions Compendium of Information: Third Edition*	Long term conditions linked with having chronic pain, SM, shared decision making and choice linked rhetoric, self-care as support groups, personal health budgets to support self-management, self-management, self- care and self-help interchangeable
NHS England. (2014). *NHS Five Year Forward View*	No ref to pain, chronic pain or self- management
Health Education England. (2018). *Musculoskeletal core capabilities framework for first point of contact practitioners*.	SM referenced througout: “the knowledge, skills, confidence and support they need to manage their condition(s) effectively in the context of their everyday life” p36 (from Health Foundation) Chronic pain – limited to MSK conditions
NHS England. (2019a). *The NHS Long Term Plan*.	Pain – limited to neck and back pain, economic challenge SM and self-care in relation to diabetes, COPD and arthritis (ESCAPE Pain programme)
NHS England. (2019b). *NHS Long Term Plan Implementation Framework*	Refers to First Contact Practitioners in MSK to support more people to SM, shorter waits, SM support as part of digital offer
NHS England. (2019c). *Adult Specialised Pain Service Specification*.	Self care and rehabilitation as part of service spec No reference to self-management
Public Health England. (2019). *Musculoskeletal Health: A 5 year strategic framework for prevention across the lifecourse*.	MSK pain conditions SM support related to funded projects to SM support, SM techniques, SM education, activated patients, reduce inappropriate referrals to secondary care, scale up tested interventions
Public Health England. (2020). *Chronic Pain in Adults 2017: Health Survey for England*	SM advice to reduce burden of chronic pain
Department of Health and Social Care. (2022). *Joining up care for people, places and populations*.	Single reference to self-care for mental health

8.4 Interpretive policy analysis

My analysis was guided by interpretive policy analysis which acknowledges that language, texts, symbols (symbolic artefacts), and social interactions of different groups (interpretive communities) all potentially shape, enable and constrain policy (Shaw, 2010; Wagenaar, 2014; Yanow, 2000). This approach additionally allowed me to capture how relationships amongst these ideas, policies and groups may have influenced policy and changed over time.

I used a snowballing sampling strategy to identify policy actors with insight into both chronic pain and policy. I conducted in-depth narrative interviews with seven participants with some responsibility, oversight, or awareness of chronic pain relevant policy in the UK, to better understand the role of governance institutions in this field. I particularly sought out views that may explain the apparent disinterest of state and state-adjacent actors in chronic pain. I attended to areas of trouble and tension to unearth hidden or suppressed discourses not apparent in other parts of my case study.

I purposively selected eight strategy documents and objects (e.g., websites, reports) produced by a selection of interpretive communities and combined with narratives drawn from the policy interviews, interrogated these data further asking, “in the absence of a comprehensive state driven policy direction, who or what is shaping the construction of self-management policy in context of chronic pain in England?” And additionally, “how is the policy issue being framed by the various parties to the debate?” (Yanow, 2000, 11). I treated these documents as symbolic artifacts that accommodate different meanings (see Figure 10) and embodying discourses that act on the world and social relationships differently.

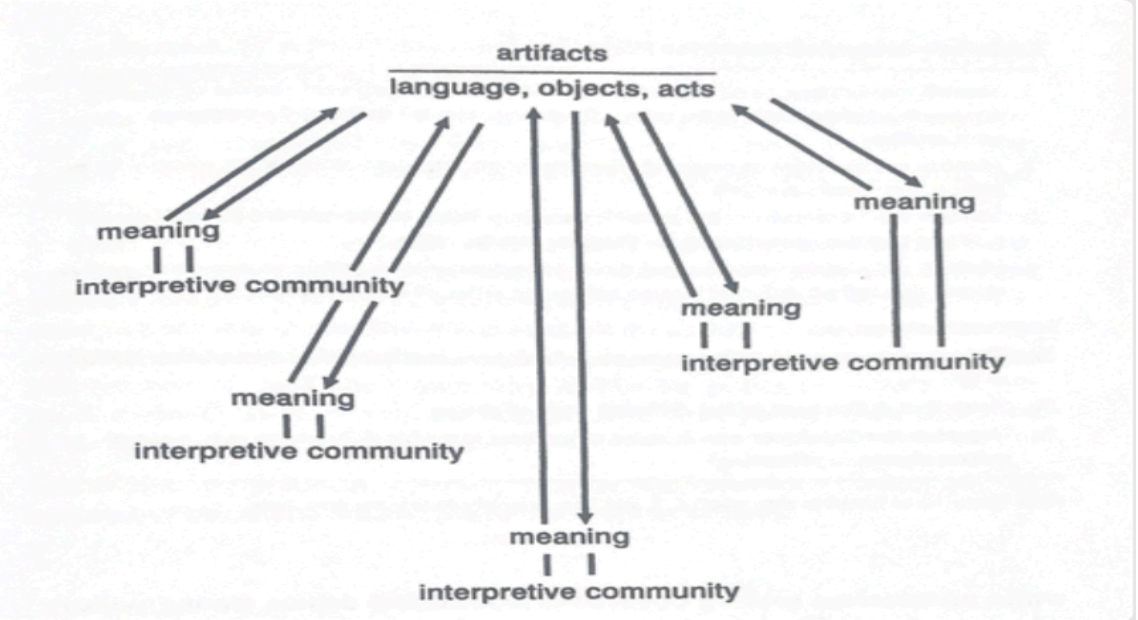

***Figure 10**: Symbolic artifacts accommodate different meanings (Yanow, 2000, 21)*

I additionally identified possible ontologies expressed in these symbolic artifacts and discourses. I present a summary of my interpretation in Table 10 and in narrative form below.

8.5 Interpretive communities and their symbolic artefacts

My analysis showed that the different groups influencing the policy direction, their artefacts, discourses and meanings were multiple, varied and unclear on the meanings of self-management of chronic pain. The policy response to a complex and messy, non-linear phenomenon was equally as complex, messy and non-linear. There were no distinct disciplinary groups (for example) advocating for one specific meaning or discourse. Instead, groupings appeared fluid and changing over time with overlapping membership in many instances. These groups worked as interpretive communities arising from *"a shared point of*

view relative to a policy issue" (Yanow, 2000, 37). These communities broadly fell into four groupings; 1) formal policy actors as creators of state sponsored policy 2) expert multi-professional collectives with an emphasis on interdisciplinary and collaborative working, 3) expert uni-professional groups focussed on i) a more traditional, medically driven rhetorical discourse and ii) providing competence frameworks for delivering care and 4) community collaboratives with an emphasis on mutual aid. This has implications for the contemporary practice of self-management in chronic pain, which reproduces certain ways of doing self-management of chronic pain at the expense of others. I now discuss each community in turn supported by illustrative quotes from the relevant data sources and their contributions to discursive meanings of self-management of chronic pain.

8.5.1 Formal policy actors as creators of state sponsored policy

This interpretive community was represented through interview texts with policy actors as well as some of the policies they were involved in steering, producing, or implementing. In section 8.2, I showed that self-management of chronic pain was largely absent from formal state-sponsored policy documents. Following analysis of interviews conducted with formal policy actors with some oversight of wider policy as it might relate to chronic pain along with insight from reading the policy agendas that they represented, I concluded that the process of excluding chronic pain from formal policy and not having a clear set of guidance was a deliberate policy decision.

Policy actors were aware of the messy pot of politics and ideas as related to self-management of chronic pain, some of which stemmed from a history of having delivered pain (and pain related) services in prior roles. Policy actors thought about and sought to

influence chronic pain care indirectly by considering chronic pain provision when setting out fragments of policy elsewhere (e.g., under the umbrella of MSK conditions or other long-term conditions). Take the following example from a participant interview:

> *In terms of general policy with pain…largely that is... I would say it's thought of as a component of MSK or, as I said, it can... it's got broader elements in that.* ***(Regional Professional Lead 19)***

He goes on to acknowledge that the organisation of MSK services excludes more complex cases, including chronic pain, by design, saying that; *"there's a degree of…selectability"* and that *"MSK has the largest exclusion criteria of any of the clinical specialties"*. He speculates on reasons for the coupling of MSK with chronic pain continuing:

> *"Now, to be fair, much of that is based on the commissioning history of MSK services and so, what we have seen back to the world class commissioning days into any qualified provider was MSK being seen as a discrete thing; it was easy to commission, was all relatively easy to commission and define, therefore relatively easy to open up to the market, and we saw the progression through any qualified provider models which didn't really work for anyone; it didn't work for the private practitioners who wanted to provide; it didn't work for the patients; it didn't work for the incumbent NHS services. But what that's done over a number of years is to make that exclusion criteria even greater."* ***(Regional Professional Lead 19)***

Whilst acknowledging that chronic pain was (and continues to be) a complex problem for health policy, state policy actors interviewed did not feel that this complexity was *special*, or different to other complex conditions. Another participant outlined their thoughts, saying:

> *"I think the whole paradigm is wrong and I think really when I talk to general practitioners about managing or supporting people with chronic pain to manage better, or to feel better or to be able to cope better is... we've made it a mystery like pain management is this really difficult thing, and it's not, and its basic primary care; it's basically what practice... good old fashioned practice nurses, good old fashioned GPs getting away from, you know, this world of QOF, which I think has driven prescribing in pain, which is almost all harmful because none of it works."* ***(National/Cross sector Policy Advisor 21)***

Rather, they speculated that perhaps the existing power dynamics within the field had supported more biomedical modes of intervention at the expense of different approaches advocated by e.g. evidence-based national guidance (National Institute for Health and Care Excellence, 2021). A number of participants spoke at length about what they considered the disruptive elements within the pain community (pushing biomedical views of pain) and offered reflections on how those with vested interests had derailed progress towards embedding chronic pain into formal NHS policy in England. This participant expressed his frustration at the missed opportunity to follow on from recommendations made by the then chief medical officer, Sir Liam Donaldson, naming chronic pain as a national pain priority in the 2008 annual report (Department of Health, 2009):

> *"We've just given you the best policy opportunity that you're likely to get in twenty to thirty years, and you're literally destroying it."*

And concludes by explaining that:

> *"I think when you've got very powerful people and institutions defending a certain way of working, and that's what it is, it's closed shop. It's, you know, it's Thatcher smashing the trade unions…"* ***(National/Cross sector Policy Advisor 21)***

Some participants expressed regret at their prior involvement in what they considered failed initiatives (e.g., the pain as the 5th vital sign campaign) either as practitioners, managers, commissioners or policymakers. They considered that these had overly focused on medically and behaviourally dominant specialised pain care at the expense of more distributed initiatives that were embedded in communities and offered more sustainable alternatives given the increasing prevalence and morbidity of chronic pain. All the participants interviewed were either sceptical or overtly critical of the emphasis on the biochemical ontology. This participant saying bluntly:

> *"But I think the critical thing for people with long term pain is that the health system, frankly on the whole does them no good at all […] And people with pain, a biomedical model, frankly they're a product of the misuse of the biomedical model. So, the biomedical model is of no use. So, it is about them managing in the community with their peers, with their carers, with their friends and doing so as effectively and efficiently as possible, and I think we have a minimal role other than helping them move into that space and their lives".*
>
> ***(National Policy Programme lead/ Clinical Director 23)***

The perspectives above were in stark contrast to the clinically focussed, specialist pain management services I discussed in Chapter 5. There, the narrative was more focussed on expanding the capacity for specialist services to improve access. The problem with pain care was framed as one of scarcity or lack of capacity that could be resolved by improved commissioning and resourcing of existing pain services. General practitioners in the case study, were more sceptical of this view as they framed specialist pain services, overall, as unhelpful.

The push for continued or increased investment in existing pain management services was not an imperative shared with the participants involved in policymaking or decision-making roles. For them, this was unaffordable and unlikely to resolve the problem of providing good pain care. When considered from a macro-economic perspective, pain care in its current form, did not have enough *"valuable productivity"*, which a participant described as:

> *"The component attributes of value and of productivity… value being the relationship between cost and quality".* ***(Regional Professional Lead 19)***

This *"valuable productivity"* may have influenced the conception of self-management of chronic pain as a cost containment measure and a counter to more expensive, unaffordable, difficult to access and, arguably ineffective specialist models of pain care. Policy actors in this study argued that other, far reaching policy initiatives would implicitly include coverage for people living with chronic pain without needing a separate policy or programme. It was thought that this approach would lead to better pain care *by default* rather than by intention, what one participant (National Policy Programme lead/ Clinical Director 23) referred to as the *"default care model"*. Another participant describes what a default care model looked like enacted in practice:

> *"So, what do you do? You say, 'Right, we've got this deprescribing agenda. We've got this personalisation of care. We've got new roles in primary care. We've got primary care networks; it's a real opportunity. We've got integrated care systems. Let's just ignore... let's just not let pain be driven by that special interest, let's just do other stuff. And you just make the other stuff better, more interesting, more compelling. You create the evidence and you just do it on the ground."* ***(National/Cross Sector Professional Advisor 21)***

This go-around approach circumvents historical barriers to changing the delivery of pain services and is evidence that the apparent invisibility of chronic pain in state directed policy initiatives and programmes is driven by what I call an 'exclusion by design' approach. It is suggested that more can be achieved by building a broad scaffolding of services and initiatives for other chronic illnesses instead of focussing directly on pain care. This strategy could lead to potential problems in delivering the *"default care model"* specifically for people living with chronic pain, as the wider workforce, (e.g., in MSK or in newer roles like the first contact practitioner) has been reported as feeling unskilled and under supported to work with the complexity (see e.g., Chapter 5). The current workforce structure is built around conditions or speciality groupings and tends to have associated knowledge practices. As pain crosses these speciality divides, more complex cases involving multi-site or multi symptomatic profiles are likely to continue to be excluded by this policy decision. Proponents of the 'exclusion by design' principle recognised this issue, with this participant musing about how services could work together when currently, they do not:

> *"OK, this is what your problem... you're not going to be operated on, you're not going to get an injection,' but they've still got their issue and there's that massive gap between actually, 'There's not much more we can do here apart from say self-manage,' versus actually, 'We can send you to hospital but it is going to bounce you back.' And then those... the things that are actually needed aren't available in the community. So, I think it's recognised, I'm not sure there's a coherent plan to resolve that issue if I'm honest. I think... and this is just me speaking, I think part of the way to resolve that is going to be around really transforming and really imagining how we think about healthcare."* ***(Policy Implementation Manager 11)***

As well as suggestion incorporating pain care into primary and community care, there was an appetite amongst decision makers to deconstruct the dominant models that privileged existing specialist care for models aligned with other non-disease specific initiatives including personalised care, social prescribing, and rehabilitation. This participant reiterates that embracing multimorbidity is key:

> *"So, actually, you know, multi morbidity that's the agenda. So, people need pain management services; let them be run as part of rehabilitation and they can have physiotherapy and pharmacology and psychology as part of rehabilitation; let's stop saying pain is special. I think that would be helpful."* ***(Policy Advisor 21)***

From a policy-makers perspective, self-management of chronic pain was seen mostly as a form of rhetoric and not really present in historical and current iterations of pain management service delivery. This participant expresses his scepticism:

> *"There's all the rhetoric about people spending between three and ten hours a year with health and care professionals and the rest of the time they're on their own; well yeh, they are…So, there's that element to it; it's the default care model. The other piece is that forty to fifty percent of the population don't have the knowledge, skills and confidence to self-manage anyway****." (Policy Programme Lead/Clinical Director 23)***

Instead, they framed pain care as dominated by outdated and immovable biomedical and behavioural psychology perspectives that were inaccessible for much of the population and unaffordable for the state. There was an expressed desire to explicitly get involved in setting direct pain policy but a stated weariness at the prospect of facing up to the traditional medical hegemony. This participant said:

> *"This has... this whole thing has to be professionally led, so if... if we do dip our toes into pain policy then it will include... it will need to include lots of conversations with professional leads because frankly, clinicians can just stymie it."* ***(Policy Programme Lead/Clinical Director 23)***

Backed by another participant:

> *"But I think it's going to take some real leadership, some real... you know, individual leadership, personal leadership, local leadership, organisational leadership to really grapple this. And as [name redacted] found out if that comes from within the pain world, the pain world will reject. And as NICE are finding out, even if it comes from outside, the pain world will do their best to derail and to destroy."* ***(Policy Advisor 21)***

Given these stated difficulties engaging meaningfully with some parts of the pain community, the decision to enact an 'exclusion by design' approach seems defendable. I argue that this absence of engagement has influenced the prominence of self-management approaches of chronic pain. Self-management is a core component of managing many chronic illnesses and would make intuitive sense to be part of chronic pain care. Lack of engagement and collaboration between actors will have contributed to the many meanings of self-management when it comes to chronic pain.

8.5.2 Multi-professional clinicians delivering pain services

I drew on data from the Shire (see Chapter 5), my reflexive diary (from attending national meetings in England where chronic pain policy was discussed) and textual data from policy artefacts (see Table 10) to demonstrate the influence of a *multi-professional* interpretive community (including physiotherapists, nurses, psychologists, consultants in pain medicine,

general practitioners, occupational therapists, and patients) on how formal policies were enacted in the delivery of pain services in England. As charted in Chapter 6, this community subscribed to multiple pain ontologies, most commonly, a cognitive-behavioural ontology situated in the neuron doctrine.

Self-management, though used throughout their symbolic artefacts, was not described and its meaning seemed to be inferred as literal and again 'self-evident' (in terms of linguistics). Self-management was seen as a small part of a bigger, more complex intervention that included cognitive behavioural therapy, skill acquisition and activity management delivered by expert multi-disciplinary clinicians. For example, this statement referencing self-management as part of pain management programmes:

> *"PMPs consist of methods to promote behaviour change and promote well-being. They include education on pain physiology, pain psychology, general health and pain self-management."* (British Pain Society, 2013, 8)

Inclusion of self-management (for example as a component of pain management programmes) was also seen as a good use of limited resources and an important way of supporting patients with chronic pain to return to the workplace as productive individuals. Self-management as cost-containment was also linked with ableist notions of being in the world, suggesting that there is a right way of doing so.

> *"The principal aims of PMPs are to enable people with chronic pain to achieve as normal a life as possible by reducing physical disability and emotional distress, and improving the individual's ability to self-manage pain-associated disability and reduce reliance on healthcare resources."*(British Pain Society, 2013, 10)

Training and support for self-management was understood as important to allow patients to become experts in managing their pain condition after a period of education by more professional experts. Self-management here was specifically *not* that associated with the lay-led Expert Patient Programme. Despite the ableist perspective linked with this way of doing self-management, self-management for this interpretive community was aligned with social justice principles and the inclusion of self-management was considered to be part of minimising discrimination in access to pain services. The guidance stipulated that:

> *"Selection is important but great care must be taken to maximise access of people with chronic pain to PMPs. There are no grounds for discrimination on the basis of age, literacy, litigation or judgement of motivation."* (British Pain Society, 2013, 22)

More formally, the multi-professional community was represented in guidance issued from NICE on assessment and management of chronic pain in adults (National Institute for Health and Care Excellence, 2021). This guidance was explicitly positioned within an evidence-based narrative and assumed an empirical-discursive ontology of pain, making recommendations based on a review of research evidence and the hierarchy of evidence. They recommended patient-centred approaches including self-management but as with previous artefacts, no definition or description of self-management was offered. Despite stating that *"evidence showed that discussions about self-management often happen late in the care pathway, or not at all."* (25), the evidence for this case is not presented or referenced. The self-evident assumptions of what self-management is or does is reproduced in guidance for this community.

Interventions classed as non-pharmacological including supervised exercise, physical activity, cognitive behavioural therapy, and acupuncture were recommended suggesting their acceptability for inclusion in self-management. Many pharmacological and minimally invasive interventions considered the domain of consultants in pain medicine (e.g., gabapentinoids, steroid injections, local anaesthetics, and opioids) were not recommended based on the conclusions of the guideline development process. This reflects the views of pain specialist clinicians in the Shire who also framed self-management as excluding biomedical practices but contrast with other framings presented in Chapter 3.

8.5.3 Uni-professional interpretive communities

The symbolic artefacts produced by more uni-professional interpretive communities appeared to embody and reiterate previously stated discourses on self-management of chronic pain. The artefacts for these communities reproduced personal responsibility and cost-containment discourses but without guidance on what their practical regimes could look like. I use consultants in pain medicine (due to the prolific nature of their document provision) and the physiotherapists in pain management (as a comparator with frequently cited and accessible artefacts) to illustrate this interpretive community.

The uni-professional interpretive community of *consultants in pain medicine* were represented by a series of documents and guidance produced by the Faculty of Pain Medicine of the Royal College of Anaesthetists that were highly rhetorical. As well as ascribing to semiotic and biochemical pain ontologies, this community produced a discourse that explicitly argued *against* the empirical-discursive pain ontology and the use of statistical, population level evidence to guide practice. Specifically arguing against the

recommendations from the NICE guidelines for chronic primary pain (2021) and the *"general limitations of conventional evidential approaches in Pain Medicine"* (Faculty of Pain Medicine, 2022, 2). The NICE guideline had made recommendations against some of the most frequently used treatments provided by and in pain medicine and this response could be interpreted as backlash against the resultant threat to their position as pain experts. This community's view of self-management deliberately positioned the pain consultant as the expert supporting patients (along with a wider multidisciplinary team) to gain the skills deemed necessary to live with pain (Faculty of Pain Medicine, 2020c).

Self-management in these set of artefacts was linked to *"promoting individualised care for people with complex pain"* (Faculty of Pain Medicine, 2022, 1). They argue that the multimodal package of care was sufficiently complex, *"mutually and critically interdependent"* (1) that it could not be researched using common population and statistical models of research. This discourse appears to be counter that promoted in earlier documents where pain consultants were committed to leading the delivery of so-called evidence-based pain care in line with the traditional evidence based hierarchy in the form of randomised controlled trials (Faculty of Pain Medicine, 2021). This earlier document, endorsed by different professional groups has multiple references to self-management and evidence for self-management as part of several named initiatives e.g., *"Expert Patient Programme, Back in Action programme, Pain Management Programme, Mindfulness based pain and stress management and Acceptance and Commitment therapy"* (Faculty of Pain Medicine, 2021, 16). There was no specific description of their meaning of self-management other than it being separate from self-care. In keeping with the multi-professional

interpretive community, self-management was depicted as an important form of cost-containment.

Uni-professional guidance aimed at physiotherapists, repeatedly referenced the use of a self-management approach as an essential core competency for working in pain management stating for example that physiotherapists are required to:

> *"demonstrate an awareness of the psychological, social and cultural factors that will influence a patient to engage with and continue a pain self- management approach"* (Physiotherapy Pain Association, 2014, 23)

Despite the document being a guide to practical competencies that practitioners were expected to demonstrate as part of an assessment, there was no indication as to what this might look like in practice. As with the other documents, the meaning of self-management was not explicitly described. Rather the term appeared to be functioning as a rhetorical artefact, promoting something that has no fixed or agreed meaning, but which is taken for granted (Yanow, 2000). This competency document included discourses aligned with multiple pain ontologies including the semiotic, biochemical, empirical-discursive, non-modern practical and non-modern discursive as well the embodied-intersubjective ontology.

These uni-professional interpretive communities reproduced self-management as an object and sustained the cost-containment discourse and desirability of self-management as an approach and outcome for people living with chronic pain. Rhetorical ideas about healthcare being unsustainable previously identified in relation to chronic illness (Rogers et

al., 2009) were repurposed here by different uni-professional groups suggesting that the personal responsibility discourse was common across groups.

8.5.4 Member-led advocacy collectives

The fourth interpretive community was not as well defined along professional boundaries but instead consisted of a broad collective that specifically included people living with chronic pain, their advocates and families as well as health and social care professionals. The first example of artefacts from this interpretive community, the Flippin Pain initiative (funded by a private healthcare provider) promoted public health messages embedded within the biochemical ontology (specifically the neurone doctrine), arguing for an alternative to existing myths about pain originating in some of the other ontologies (Flippin' Pain, No date). Messaging urged caution about adopting the semiotic and more pharmacological spectrum of the biochemical ontology of pain. One of their key messages stated that:

> *"Medicines and surgeries are often NOT the answer"(4) [emphasis in original]*

Though the general narrative supported a person-centred, personal responsibility perspective, self-management was not referenced. Instead, descriptions of different forms of knowledge (in the form of myth busting) were offered along with the suggestion that adopting counter-narratives derived from the neuron doctrine and described using the language of neuroscience meant that *"recovery is possible"*(6).

The second artefact from the co-operative interpretive community was a website hosting a year-long festival for those living with pain and their communities (Footsteps Festival, 2021).

The online festival events were co-produced, delivered and curated by people living with pain and invited community members including authors, researchers, and health care professionals. Events did not have a pure health focus but covered a broader interest such as singing, nutrition, crafts and reading groups. The conception of pain here was truly multiple and most closely aligned with an embodied-intersubjective pain ontology that allowed for less certain claims about the nature of pain. Community members shared interests and activities related to a range of ideas that have previously not been formally associated with the idea of self-management in chronic pain. No single type of knowledge was presented as 'truth' and creative, relational, community focussed action was positioned alongside more traditional health messaging.

Membership of these interpretive communities was not mutually exclusive, in that actors often contributed to multiple communities through a shared discourse and practice. In this case, self-management represented different discourses mobilised in the service of various pain ontologies, especially those that presupposed that pain was indeed *manageable*, suggesting some form of suppression or control. Self-management within the interpretive communities I have presented was often not described, but accepted as self-evident, received wisdom and, something that should be aspired to. As within the case study in the Shire, the changeable function of the notion of self-management served each interpretive community differently, often with its manifestation shaped by different forms of power at play.

Table 10: *Interpretive communities, their related pain ontologies, type of power and their meanings of self-management of chronic pain*

Interpretive community	**Discourses: Self-management of chronic pain is?**	**Pain ontologies**	**Illustrative policy artefacts**	**Basis of power**
Formal policy actors as creators of state sponsored policy	Not special to pain Cost containment: Way into complexity Subversive to biomedical hegemony	*Anti*-biomedical (semiotic and biochemical)	Interview transcripts Reflexive diary (researcher)	Countervailing to hegemony Distributive
Multi-professional (including physiotherapists, nurses, psychologists, consultants in pain medicine, occupational therapists, and patients)	Not described or defined: linguistic meaning Small part of a complex intervention delivered by multiple professionals **Cost containment:** a good use of resources, return to work **Skills:** to practice at home after education to "become expert"; "training and support offered to participants" by specialist and non-specialist staff Social justice: "no grounds for discrimination" **NOT** expert patient programme	Empirical-discursive Cognitive behavioural Non-modern practical Biochemical	Guidelines for Pain Management Programmes for adults (British Pain Society, 2013) Authors cited Extensively referenced	Countervailing to hegemony Mutual amongst professions Disciplinary to 'participants'
Multi-professional- expert	Not described or defined: linguistic meaning "Expert Patient Programme, Back in Action programme, Pain Management Programme, Mindfulness based pain and stress management and Acceptance and Commitment therapy." Separate from self-care Cost containment **Skills:** to manage setbacks and flare-ups	Cognitive behavioural Non modern practical Empirical-discursive Biochemical Psychological Semiotic Embodied - intersubjective	Core Standards for Pain Management Services in the UK (Faculty of Pain Medicine, 2021) Endorsed by different professional groups. Authors cited Extensively referenced	Rhetorical or mutual Disciplinary
Multi-professional - expert	Not described or defined: linguistic meaning Rhetorical artefact Management strategy Naïve rationalism – statements at face-value	Empirical-discursive Semiotic	Chronic pain (primary and secondary) in over 16s: assessment of all chronic pain and management of chronic primary pain (National Institute for Health and Care Excellence, 2021) Multi stakeholder; produced with Royal College of Physicians; evidence-based medicine (EBM) Extensively referenced	Disciplinary

Consultants in Pain Medicine; medically trained; anaesthetists with additional training in pain medicine.	*"Promoting individualised care for people with complex pain"* **Paternalistic:** care options decided by practitioner **Treatment:** "self-management strategies" and "self-help" as part of multimodal package, not possible to research. "mutually and critically interdependent" in complex package of care.	Semiotic Biochemical *Anti*-(empirical-discursive)	Practical Pain Management in Specialist Care: How to help people with chronic pain when population based national guidance fails to help (Faculty of Pain Medicine, 2022) No authors cited Minimal referencing	Rhetorical Disciplinary Attempts to *restore* traditional hegemony
Consultants in Pain Medicine; medically trained; anaesthetists with additional training in pain medicine	No reference to self-management Expertise provided by pain medicine specialist	Semiotic Biochemical Non-modern discursive Counter to empirical-discursive	The Role of the Pain Medicine Specialist (Faculty of Pain Medicine, 2020c) No authors cited (5 of 7 references FPM publications)	Hierarchical Professional expertise
Pain specialist physiotherapists	Not described or defined: linguistic meaning Rhetorical artefact "Engage with and continue a pain self-management approach"	Cognitive behavioural Biochemical Non-modern practical Non-modern discursive Anti-biomechanical Embodied - intersubjective	PPA Physiotherapy Framework - Entry Level Graduate to Expert: Describing the values, behaviours, knowledge & skills of physiotherapists working with people in pain (Physiotherapy Pain Association, 2014) Authors cited	Disciplinary Professional expertise
Multi-professional; multi stakeholder; co-produced; co-designed	"Everything matters when it comes to pain" Public health messaging No reference to self-management "Recovery is possible"	Biochemical (excl pharmacological) Embodied - intersubjective Anti-semiotic Anti-biomechanical Non-modern discursive	Flippin' Pain: Key messages (Flippin' Pain, No date)	Disciplinary Mutual Countervailing
Community led; coproduced by people living with pain and invited community members. Events list available	Something 'other' lived experience, varied innovative, intersubjective, complex	Embodied - intersubjective Non-modern discursive	Footsteps Pain Festival: an online celebration of living well with pain (Footsteps Festival, 2021)	Rebelling and resistance Mutual Personal empowerment Reciprocity

8.6 Conclusion

Self-management of chronic pain is a ubiquitous and often used term. I have argued that a singular interpretation of its meaning is unhelpful. Just as I have demonstrated that pain is multiple, so too are experiences and perspectives of self-management of chronic pain. I have shown that self-management of chronic pain is discursively constituted as part of a socially constructed storyline in pain care. Dominant discourses of self-management of chronic pain – personal responsibility, self-evident received wisdom, cost-containment, skills imparted by experts - have been driven by strong realist assumptions and sustained by traditional and hierarchical power dynamics. Though there are different ways of conceptualising and enacting pain care, only a small range have been mobilised, evaluated, and promoted in the Shire, and seemingly at the expense of less visible ones. The existing apparatuses and structures of pain services favour both biomedical and behavioural psychological approaches, which continue to shape normative practice including self-management.

I have discussed tensions between the formulation of policy - what and who is contributing to that, who and why - and the translation of that in different communities in the Shire. More generally, interpretive communities formed of people living with chronic pain and those providing care for them who have been dissatisfied with the normative version of pain care, have worked around the problem leveraging indirect and mutual forms of power to begin creating alternative versions of pain care. These versions do not centre on protocolised state sponsored forms of self-management, but instead acknowledge the complexity of living with chronic pain within society and embrace uncertainty about which

approaches may or may not be helpful. These new collectives appear to have more legitimacy amongst people who have experienced pain care as patients or practitioners and found it wanting. Their non-attendance and non-participation with existing services represents a productive form of power, rebelling against normative, hierarchical offerings of pain management.

In my concluding chapter, I discuss my findings with reference to the existing literature. I make recommendations for policy, practice and research that might attend to the issue of designing services and interventions for pain care that align more broadly with the multiple understandings of pain and ways of living with pain.

Chapter 9: Discussion and conclusion

9.1 Introduction

I started my doctoral research by situating myself as a curious clinician seeking to understand the experiences of my patients as well the system in which I offered care. I honed in on how those not supported by specialist services practiced and understood self-management asking:

1) How is 'self-management' accomplished by people living with chronic pain who have been excluded from (or have dropped out of) existing pain management services?
2) How can people who have been excluded from, or dropped out of pain management services be better supported in practice and through policy?

In this final chapter of my thesis, I conclude by offering insights into how I think clinical pain care might be improved. I summarise my findings and make recommendations for policy and practice, and potential directions for future research. I relate potential challenges that decision makers, practitioners, researchers, patients, and publics will need to consider when using insights from this work into existing health systems. I reflect on my interpretive and interdisciplinary approach to applied health research and how this has extended and added to existing research.

Flyvbjerg (2001) stated *"that a discipline without a large number of thoroughly executed case studies is a discipline without systematic production of exemplars, and that a discipline*

without exemplars is an ineffective one" (87). I agree. I conducted an in depth, case study of self-management of chronic pain, which has contributed to the limited number of exemplars of how people live with pain, how services understand self-management and how they support (or do not) those living with pain, and how policy is constructed and influences services available. I have drawn on different theories - largely concerned with complexity and social practice - to better understand how assumptions about 'self-management' are enacted in relation to chronic pain, a contested and multi-faceted condition. Below I summarise my interpretive approach, and set out how it has enabled what Tsoukas (2017) refers to as a conjunctive approach to theorising that "seeks to make connections between diverse elements of human experience through making those analytical distinctions that will enable the joining up of concepts normally used in a compartmentalized manner" (Tsoukas, 2017, 216). This has contrasted with the positivist framings of chronic pain – and chronic pain research – that have tended to dominate this field. I conclude by arguing that the field of pain management and clinical pain care (including self-management) needs more of these contrasts to ensure future progress.

9.2 Summary of methods and findings

I examined how the much-used concept of 'self-management' of chronic pain is understood and enacted. I began by setting out my motivations for researching self-management of chronic pain (Chapter 1), before chronicling recent understandings of both pain (Chapter 2) and self-management (Chapter 3) and presenting the particular historical and geographical context in which my research was located. I provided a detailed account of my methodological approach (grounded in interpretive philosophy) and the way I conducted my

research in Chapter 4. This involved an empirical (intrinsic) case study examining how people living with chronic pain did, or do, 'self-management' without the support of specialist services. My analysis and findings were presented in Chapters 5-8.

9.2.1 Meanings of self-management of chronic pain are varied and contested

On reflection, the assumptions I initially held about self-management of chronic pain were challenged by my research process and subsequent analysis and interpretation. I started my research seeking to understand how a single and self-evident 'self-management' was done by people living with pain. The approaches that I have used and theoretical lenses I have brought to the work have led me to, not only unpack the many varied meanings of concepts related to self-management, but also surface intersubjective complexities related to how people live with chronic pain and how they seek support from formal and informal services in order to live with (and in) pain. Rather than a single unified meaning, I found that self-management was a term variably embedded in (and understood in relation to) the wider context of NHS organisations, politics and policy, and lived experience.

My inquiry of chronic pain in Chapter 2 highlighted that, in the academic literature, different epistemological accounts are used to frame and know chronic pain. Chronic pain was most commonly understood in biomedical terms with common definitions related to the nature of an injury and the duration of healing, repair, and recovery. Disease specific explanations broadly aligned with the clinical and disciplinary perspectives within medicine and their preferred mode of treating pain. Treatment practices involved the use of pharmacological agents, imaging to aid diagnoses and surgical procedures to address anatomical faults.

There were alternative epistemological accounts such as the biopsychosocial model of pain (Engel, 1977), which featured as a dominant discourse amongst more multidisciplinary clinical practitioners. However, critics of the BPS model have argued that though present in discourse, in practice practitioners continued to focus on biomedical explanations to understand psychological contributors to pain, and that the social was rarely considered (Mescouto et al., 2020; Stilwell & Harman, 2019). Studies from clinical psychology adopting quantitative, experimental studies of complex interventions were also prevalent and framed pain as a result of neuronal signals modifiable by behavioural techniques. There was a small number of critical studies drawing on social sciences that included patient narratives to understand the subjective experience. There was a small, but growing, literature that aligned with my own research and attended to the social conditions within which people lived with pain and how more socio-cultural insights might impact on how pain could be known.

Just as there were varied epistemological accounts of chronic pain, my hermeneutic literature review in Chapter 3 found that 'self-management' of chronic pain had many discursively constructed meanings leading to three main storylines aligned with particular assumptions, theories, and methods of argument. The three storylines presented self-management of chronic pain as:

- An intervention
- A set of behaviours
- Cost-containment

I found little acknowledgement of the multiple ways that different authors conceptualised self-management of chronic pain. This has implications for how the knowledge created by research is translated into practice. The wider research on self-management engaged critically with socio cultural interpretations e.g., the role of neoliberal politics in the implementations and scale of so-called self-management interventions for chronic illness (Rogers et al., 2009; Rogers et al., 2008). Adopting critical perspectives when thinking about chronic pain, how this knowledge is produced, and how it is practiced within healthcare could support the inclusion of more diverse perspectives thus potentially transforming the pain management landscape and the range of available interventions.

9.2.2 Pain care is distributed across multiple boundaries

My in-depth intrinsic case study of self-management of chronic pain in the Shire reflected how the different epistemologies and disciplinary perspectives identified in earlier chapters played out when providing care for those living with pain. I found that pain care was widely distributed across primary, secondary, community and non-health services; with tensions between the linear, top-down operational models that guided formal services and the more complex, relational ways of working that characterised the everyday practice of professionals working in pain management and the experiences of patients. Practitioners within formally commissioned specialist pain services most commonly used the term self-management in accounts of their practice. It was embedded in organisational documents, websites, protocols, and psychometric measures. Self-management also worked as a boundary concept (Allen, 2009), serving as a placeholder for different meanings (including epistemologies, paradigms, and professional perspectives), variably employed by different

professional disciplines as shorthand to communicate and work with each other in their multidisciplinary work. The assumption by healthcare professionals that self-management held the same meanings sometimes led to difficulties for patients trying to access ontologically aligned care. Patients also held their own, different meanings about self-management that included socio-material practices broadly considered by researchers and health care professionals as being poor (e.g., seeking out and accessing alternative medicine or so-called passive treatments). In contrast to those in formal pain services, many practitioners in primary care did not see self-management as a valid way of managing complex pain issues as they felt that patients required support to negotiate the complex and messy system.

9.2.3 Pain is multiple

Alongside multiple epistemological accounts of self-management and chronic pain, I found multiple ontologies of pain enacted by (and in the practices of) healthcare professionals in the Shire. This contrasted with the normative definitions and descriptions of 'what pain is' that often fail to fully account for complexity (e.g., Treede et al., 2019). Theories of multiple ontologies applied to atherosclerosis (Mol, 2002) and pain medicine (Graham, 2015) emphasise that reality is constructed through practices and is therefore multiple. Drawing on these theories, I presented eight ontologies of chronic pain, as done by practitioners in the Shire, and argue that as well as using self-management as a boundary object to negotiate epistemic differences and disciplinary perspectives, health care practitioners also work through ontological calibration practices to provide disciplinary care. They negotiate multiple intersecting layers of messiness and complexity in order to provide care, adding

extra meanings to what it means to support people to self-manage chronic pain. I propose that adopting an embodied inter-subjective ontology of pain offers another way to think about complex chronic pain that does not require healthcare professionals to act biomedically, behaviourally or biomechanically. The option of 'doing nothing' opens up the possibility of doing something different when faced with messiness and uncertainty.

9.2.4 There is no single way of living with (and in) pain

In my research, people living with pain frequently engaged with the option of doing something other than the standardised normative (biomedical, behavioural, and biomechanical) ways of doing self-management of chronic pain. They continually formed assemblages which included relations with people, discourses, places, and objects. These varying assemblages allowed for different ways of living with chronic pain. Here I drew on Deleuze and Guattari's theoretical concepts of the assemblage (2013) that enabled me to (a) consider the different ways that people could live with pain beyond the normal conventions, and (b) broaden my analysis within an interpretive framework that factored in the layered and entangled meanings, realities and practices evident in self-management of chronic pain. Rarely used in the current academic literature on self-management of chronic pain, Deleuze and Guattari's thinking on connectivity has been applied to health more broadly to facilitate thinking differently for innovation and contemporary models of practice (Fox, 2002; Nicholls et al., 2016). Their work on assemblages has also been applied within rehabilitation, to examine how people living with health conditions use objects and human relations in achieving their goals and leading to critique of mainstream concepts such as 'patient centred care' (Gibson et al., 2021). Their work guided me to include the multiple things (and

relations) that people living with pain mobilise in the face of minimal engagement with socio-material relations in the pain field.

9.2.5 Chronic pain policy is shaped by different interpretive communities

Shifting to policy, I adopted an interpretive approach (Shaw, 2010; Wagenaar, 2014; Yanow, 2000) to understand how macro level policy framings have contributed to conceptualisations and practices of self-management in the context of pain care. Despite high epidemiological estimates of the prevalence of chronic pain in the UK (Fayaz et al., 2016), I found that there was no formal document setting out policy vision for chronic pain. Instead, policy was formed by different interpretive communities formed of fluid and interdisciplinary groupings holding shared points of view. I argue that the way chronic pain policy unfolds is shaped by power and knowledge, but that this is also shaping what is understood and done in practice.

9.3 Knowledge and shifting power shape the self-management of chronic pain

Power is a helpful lens from which to consider how, and why certain knowledges and practices are valued and promoted over others. I argue that power works to continually reproduce a version of self-management of chronic pain that is routed in behavioural psychology and aligns with personal responsibility ideals of neoliberal politics. I found different ways of living with chronic pain and doing (and sometimes not doing) self-management of chronic pain that reflects a rejection of and rebelling against normative and existing practices.

Power can be thought of as multidimensional: consisting of direct power, indirect power, and subconscious power, all of which impact on decision-making, agenda setting, and preference formation (Lukes, 2005). From this perspective, power is not always wielded in a negative way, for example by a sovereign power onto a subjugated population (Downing, 2008). Rather, power has different facets that come into play dependent on socio-cultural contexts. In the context of self-management of chronic pain, different forms of power were associated with certain interpretive communities.

My analysis showed that different interpretive communities promoted varied and sometimes conflicting discursive meanings of self-management of chronic pain. In the absence of agreed definitions or descriptions of self-management, I found that actors used rhetoric to persuade audiences of the strength of particular discursive meanings of self-management. Rhetoric here was a form of indirect power, liberally used to persuade the reader (e.g., of public facing materials) of the strength of a preferred perspective. This included documents highlighting the suffering of those living with pain (Faculty of Pain Medicine, 2021), the increasingly complex care required for them (Faculty of Pain Medicine, 2020c; Physiotherapy Pain Association, 2014) and, the scarcity of resources available to provide this care (British Pain Society, 2013; Faculty of Pain Medicine, 2022). Pain consultants additionally leveraged the traditional hegemonic power of medicine (a form of direct power) to present self-management of chronic pain as part of a complex package of care, delivered by medical experts, though *"mutually and critically interdependent"* (Faculty of Pain Medicine, 2022, 1). They challenged the use of previously accepted positivist paradigms to examine pain care e.g., in most recent guidance (National Institute for Health

and Care Excellence, 2021) and instead promoted the role of individualised, tailored care albeit as determined by the medical experts. However, this was in direct opposition of the standardised, evidence-based approaches extolled in prior documents from the same interpretive community e.g. (Faculty of Pain Medicine, 2019). These alternative conceptions of self-management from within the same interpretive community indicate that in this case, ideological positions foregrounding the role of personal responsibility in pain care were at odds with longstanding ways of doing pain care, with professional expertise and traditional hierarchical power at the helm.

In addition to the role of rhetoric and hegemony surfaced in my analysis, I propose that disciplinary power and surveillance within pain care serve to maintain and propagate a single meaning of self-management in chronic pain. Disciplinary power manifests when subjects adopt the tools of self-surveillance that shape them into “docile bodies” and adopt these disciplining forces as their own (Downing, 2008). “Lukes' third dimension of power exists where people are subject to domination and acquiesce in that domination” (Dowding, 2006, 136). In my analysis, the use of surveillance was not an entirely deliberate or conscious choice, rather the systems and structures of pain care formed from multiple influences (e.g., the use of standardised self-report measures), reproduced themselves in how pain care was done. Overall, the overarching self-management discourse was maintained by the promotion of detailed and ongoing surveillance of (mostly) behavioural measures. Guidance documents e.g. (Faculty of Pain Medicine, 2019) extolled the collection of outcome measures to determine the efficacy of pain management interventions, which in turn provided evidence of efficacy encouraging their ongoing usage. Those working in pain

care may not question the origin of such embedded practices and ways of knowing self-management of chronic pain. This was reflected in my findings characterised by the acceptance of the literal meaning of self-management as well as the absence of descriptors of self-management. Though on paper the more multidisciplinary interpretive communities espoused a self-management that was different from the medical driven described above, both privileged the role of the expert clinician in providing skills to their patients. There was the potential for more mutual understandings of self-management of chronic pain evidenced through the emergence of collaboratives that included patient perspectives. Additional participatory approaches to research and service delivery would be helpful to explore this perspective.

Self-management practices depict how governmentality functions in common approaches to pain management. "*Governmentality depicts a style of governing in which all aspects of public life and individual conduct are in principle subject to regulation*" (Wagenaar, 2014, 125). Behaviour change approaches delivered in the form of pain management programmes (British Pain Society, 2013), offer up a specific (normative and desirable) way of managing pain throughout all aspects of a person's life with the goal of living well with pain. Cognitive behavioural approaches, explicitly encourage people to think differently about pain and re-attribute meanings of pain considered as maladaptive (Williams et al., 2020). All aspects of an individual living with chronic pain are subject to a form of regulation as laid out by the procedures of pain management services. Behaviour is surveilled by the ubiquitous use of empirical psychometric and pain questionnaires that quantify and coalesce complex and multiple meanings, thus producing *"a particular vision of the self-managing patient"* (Rogers

et al., 2009, 734). Here, both practitioners and users of pain services contribute to normalising, embedding, and promoting a particular and singular version of pain care, effectively *"transmitting the rhetoric"* (Rogers et al., 2009, 738).

The version of self-management of chronic pain produced from these standardised approaches is one aligned with care as defined by clinical experts. A good self-manager can absorb knowledge and skills and reproduce them in different contexts. They are literate and have experience of formal education and embrace the educational format of many pain services. They respond to aversive events (such as pain flare ups) with resilience using the prescribed knowledge and skills. They are good citizens, economically active and do not require repeat interactions with services as they become independent, successfully self-managing their chronic pain. They cannot reject this care as this is then seen as rejecting help from experts.

There were interpretive communities (and patients living with pain) that did not subscribe to this version of self-management of chronic pain and offered up resistance to these more professional modes of knowing and doing self-management. The inclusion of diverse perspectives, valuing lived experience, lay perspectives and multi-disciplinary health care professionals all contribute to an alternative self-management storyline in a demonstration of hidden mutual power. Self-management has been theorised as a form of mutual power where communities actualise reciprocal arrangements with health care providers, often rebelling against more dominant medical models (Fletcher et al., 2019; Kendall et al., 2011). Mutual power was evident in the constitution and practice of member-led advocacy

collectives suggesting a shift in the previous medical and behavioural modes of doing pain care.

Self-management was not assumed to possess a singular meaning. Instead, illustrative data from this group referred to self-management less often and instead, described opportunities for pain care that were embedded in socio-cultural and material practices. The Footsteps festival, for example offered opportunities for reciprocal transfer of knowledge of pain between health care professionals, researchers and people livening with chronic pain (Footsteps Festival, 2021). The events they hosted and promoted were not confined to more conventional ways of *doing* self-managing of chronic pain e.g., pain management programmes. Instead, they offered up alternative and plural ways to think of pain care such as with inclusion of nutrition, cooking, singing, and crafting sessions. Light (1991) framed such instances of rebellion and resistance as a form of countervailing power. Though initially discussed in reference to *increasing* medical professionalism as a counter to the growing power of institutions in American healthcare markets, countervailing power of mutual collectives here as a counter to dominant hegemonic pain care bears similarities.

In sum, there are challenges to medical (and to a lesser extent, behavioural psychology) dominance in the conceptualisation and enactment of self-management of chronic pain, both in policy and in practice. The declared prerogative of pain medicine consultants to unilaterally decide the best care for their patients (Faculty of Pain Medicine, 2022) was eroded by the direct power of evidence-based guidance challenging the validity of this position (National Institute for Health and Care Excellence, 2021). Additionally, in a

demonstration of indirect power, the mobilisation of a "default model of care" and "exclusion by design" within formal policy making spaces appears to be questioning the expertise of the pain community to deliver pain care, overtly challenging physicians' authority, and calling for demedicalisation of chronic pain. Finally, community-led co-operatives are subverting established models of pain care as well as explicitly rebelling against traditional hegemony. My findings across micro, meso and macro levels indicate that community led co-operative, advocacy groups and coalitions that centre and accommodate different ways of living with pain (and the lived experience of pain), have the potential to change pain care in England.

9.4 Original contributions of my research

I have brought critical perspectives, grounded in social science and philosophy, to bear on applied clinical pain care. In doing so I 1) surfaced multiple understandings and practices of self-management of chronic pain, 2) broadened the concept of self-management of chronic pain to include socio-material and embodied practices, 3) highlighted the dominance of behavioural psychology and biomedical paradigms in pain research and practice, 4) applied multiplicity theory to pain and 5) extended the theory to additional pain ontologies.

Whilst some of the critical perspectives I have presented are known in other clinical and disciplinary areas, they have not been applied to applied clinical pain care. I have problematised the concept of self-management of chronic pain as presented in the academic literature, clinical practice and policy arguing that rather than being a singular or unified concept, it is instead one with multiple meanings and practices. The dominant

models of self-management of chronic pain, couched in the language and routines of behavioural psychology promote a focus on cognitive perspectives over lived, embodied ones. Though frequently described as complex interventions, they only offer a partial view of how self-management of chronic pain can be understood, achieved, and supported. I have presented a multi-level case study that demonstrates a more nuanced, complex and multiple representation of self-management of chronic pain that includes individual, as well as socio-material contributions to how pain care is done. Self-management as linked to dominant personal responsibility narratives was not a prominent feature in my case study and its neat, bounded, linear, technocratic assumptions applied in real-life messy contexts can lead to exclusion, ontological conflict and epistemic injustice.

I have applied social theory to explain my research findings including that self-management is used as a boundary concept by multidisciplinary health care professionals to communicate and function in uncertain changing practice contexts; that there are multiple ontologies of pain done by healthcare professionals (with their patients); that living with (and in pain) is an embodied and inter subjective social practice supported by the making, breaking and re-making of assemblages; and that in the absence of more formal policy direction, interpretive communities are shaping what pain care looks like in England.

This thesis extends multiplicity theory by applying Mol's (2002) thinking on the body multiple to chronic pain through self-management practice(s) in a UK context of distributed organisational boundaries rather than a single organisation. I applied Graham's (2015) reading of multiple *pain* ontologies, identifying, and describing two additional ontologies

that were done in the Shire suggesting that adopting the embodied intersubjective ontology opens up the option for healthcare professionals to 'do nothing' from existing perspectives and try different ways of doing chronic pain care. Multiplicity and connectivity theories provide different ways of thinking about self-management of chronic pain. The insights I have provided may have relevance to other contested and invisible illness where biomedical paradigms lack explanatory power.

My hermeneutic approach to the qualitative synthesis of literature on self-management highlighted the dominance of positivist biomedical and behavioural psychology research paradigms and suggested alternative scholarship, grounded in critical social science, that could be applied to self-management of chronic pain.

9.5 Strengths and limitations of my research

I have highlighted some of the strengths of my research above as I set out my original contributions. Additionally, my perspective as a practitioner and researcher looking into my field, allowed me to consider clinical problems through rigorous and analytical study. The insights from this work have already started to influence my own clinical practice as well as others within my influence. My focus on the lived experience of pain and the patient perspective generated data that enabled me to consider a different analytic frame to that commonly used in pain research.

Both Graham and Mol used ethnography as their primary mode of inquiry observing their research sites in person arguing that this methodology added to rich and in-depth insights.

My research was conducted under pandemic restrictions due to Covid-19 and relied on accounts of practice rather than observations. Though not the ideal conditions for this type of research, I had the opportunity to explore, adopt and refine alternative methods that of data collection that generated rich data for analysis.

9.6 Recommendations for practice, policy, research, and publics

I first summarise the overarching implications of my main findings for a broad audience interested in self-management, chronic pain or both. I then turn to set out recommendations, and potential actions, for key groups.

There is a preference for protocolised, linear standardised models in current pain management research and practice. The unintended consequence of this is to discount and edit away aspects of pain (e.g., trauma histories) that do not fit. The complex and messy reality of chronic pain as experienced by those living with chronic pain threatens to disrupt such order. I have shown that political and social meanings are also important and shape origins, trajectories, and provenance of ideas about self-management of chronic pain. The default, unchallenged view of self-management of chronic pain as an expert sanctioned, predominantly behavioural intervention, could prevent other approaches (including non-health approaches) from being explored, discussed, and practiced. The focus on personal responsibility and individual behaviour in preferred biomedical and behavioural psychology models for self-management of chronic pain might disenfranchise people who choose to 'self-manage' in different ways including engaging with alternative or non-health practitioners. Poorly considered interventions from health care professionals often drawing

on protocolised procedures and not taking the individuals particularities into account "*may disrupt the gestalt flow in which patients have learned to self-manage the whole and thus may in practice introduce instability or deterioration*" (Pickard & Rogers, 2012, 108). The routine use of standardised questionnaires in self-management of chronic pain risks continually encoding and reifying contested and unchallenged concepts into service provision e.g., into digital technologies potentially masking issues around choice and epistemic injustice. Interventions are tested using the same standardised measures, which are then included in research protocols, publication, and national guidance.

Reconsidering the role of multiplicity, connectivity and plurality has the potential to expand how pain care is provided, moving beyond linear to multiplicity of particularities. This expansion could happen at the macro, meso and micro levels influencing policy, research, practice and the lived experience of those living with pain. Simplicity is attractive when compared to complex, participatory, embodied ideas that my research has shown is the reality of how people live with chronic pain.

For practitioners, I suggest acknowledging that pain is multiple and there is no one way of supporting people living with pain. Concurrently, attending to different types of evidence and knowledge has value, not just that generated within empirical-discursive ontological practices. To acknowledge that, for people to live with pain, they form assemblages which often involve socio-cultural discourses and material objects and that a singular focus on the individual body leading to missed opportunities to support people in living well with pain

differently. Consider that non-attendance and dropping out of specific services could reflect an active and engaged choice not to participate in ontologically incompatible care.

For commissioners of pain services, I caution against frequent and technocratically driven reorganisations of services unduly influenced by tenders and service design specifications that reproduce ineffective care or disrupt historic and contingent, complex, relational care. Additionally, consider providing care in and with the communities that people live in to consider their lived environments.

For formal policymakers and those with influence in shaping national service recommendations through their interpretive communities, I encourage a broader consideration of the nature of evidence and the form that evaluation takes to include less heard perspectives. Widening what counts as policymaking and involving wider and diverse communities has the potential to generate different perspectives (Levac et al., 2022).

For researchers, I recommend a divergence in the choice of methodologies for exploring issues in chronic pain and other complex conditions to include corporeal as well as cognitive dimensions, engage with participatory methods and observation, engage alternative sites of research, and conduct evaluation that does not rely on pre-determined psychometric measures. Naturalistic and functional ways of knowing that value theory and interpretation could offer useful insights practicable in real-life contexts (Greenhalgh & Engebretsen, 2022).

For patients and people living with chronic pain, I revisit to Jovita's case from Chapter 1 to consider what services (and self-management) might look like if my recommendations were taken up.

9.7 Jovita's pain care re-imagined

Jovita has been out of hospital for six months now following her most recent operation under gynaecology. She attended her follow-up appointment with a nurse practitioner where she relayed her progress. Jovita had been offered a pre-assessment appointment with the inpatient pain team 1 month before her surgery. She had the opportunity to raise her concerns and worry that her pain would not be well controlled given she was already taking many different medications. She was also concerned about how she would manage childcare if the pain was not tolerable. The duty anaesthetist (also a pain doctor) completed a medication review with her at the pre-assessment appointment and together, they determined that the opioids she was prescribed were not providing much relief and she was having trouble making the weekly appointments at her community pharmacist to pick them up. They agreed that the best plan involved gradually tapering her medications according to an agreed plan with her community pharmacist. They agreed a safety net should she need to speak to someone about pain flares and was given a telephone number advice line to the specialist nurses.

Jovita had been attending a parent's group at her local library that was supported by the local authority. The group had a children's play session followed by a 1-hour creche. During this time, Jovita had met a group of other parents who she had become friends with. One of the other parent's had suggested she go along to a crafting session run in of the rooms

downstairs. Jovita now regularly attended the crafting session which she says helps her direct her attention to other things other than pain.

Jovita attended a brief weekly session with her community pharmacist where she gradually was able to reduce her dose of opioids. She continued to take medication as required but did not feel as reliant on them and did not feel she needed to see her GP as regularly. She was walking more to and from her visits to the library and to the pharmacy and felt better for being outside during the winter months.

Though her pain had not been completely resolved by the surgery, Jovita was not as worried about having something wrong with her insides anymore. She had an appointment in six months at her local pain service to consider attending a patient led- recovery session where she hoped to hear from others with experience of living with pain. She had expressed an interest in their advertised sessions on singing for health and wellbeing. Her prescription was stable, she was happy to keep tapering her medications with the pharmacist's support. Jovita had a multi-agency plan in place embedded in the local hospital and local authority electronic records that summarised her difficult experiences in the past. This had suggestions for health and care workers to consider should they encounter Jovita when she was feeling overwhelmed and/or distressed.

9.8 Conclusion

Just as there are different pains and ways of knowing pain, so too are there many selves tasked with living with (and in) pain. Variously constructed identities (selves) are reified

through the objects and ideas that are inscribed upon them. These inscribed selves are not fixed or predetermined. They are continuously in flux. The assemblages from which each self is constructed adapt and change, remaking, and reimagining different possibilities for living with pain.

The notion then, of self-management of chronic pain is nullified as a single unified concept. Each meaning constructed is a complex relational assemblage that evolves and changes at every iteration. It's rhizomatic capabilities can be optimised therapeutically to open up possibilities or stifled (go unacknowledged or unexplored) and limited in misguided attempts to 'manage' both the self and the pain experienced by the self. Existing models of what I now deliberately call pain *care* (not pain management), serve a limited proportion of particularly inscribed selves. However, both ontological blindness and epistemological alliances currently limit the possibilities of broadening pain care that are more supportive of plurality. The result is that practitioners may experience ontological conflict when trying to deliver modernised, technocratic, protocolised services which privilege hegemonic biomedical and empirical logics, often removed from the broader goal of improved pain care. People living with pain sometimes choose to bypass these services in favour of more workable ontologically aligned care. Therefore, in thinking of differently located, articulated and practiced ways of providing pain care, there is an imperative to draw on different knowledges to reconstitute pain care. The sociological imagination allows for different ways of thinking about pain care beyond hegemonic biomedical and behavioural ways

In conclusion, existing definitions of self-management of chronic pain, drawn from limited disciplinary perspectives, influence the provision of a version of pain care which prioritises individual behaviour change and is often delivered in technocratic and protocolised forms. There is not much room for practical regimes that account for multiplicity, uncertainty, or divergence from these embedded forms of self-management of chronic pain. Interpretive communities that detract from this particular type of self-management and allow for 'doing differently' and in relation with others are emerging and offer an alternative to current dominant ways of doing pain care.

Completing this thesis has been an exercise in epistemic humility for me, allowing me to critically engage with difference and uncertainty in how self-management and chronic pain is known and done. This has enabled me to begin re-imagining pain care in my own sphere of influence as a clinician, advocate, researcher, and policy stakeholder. Alongside the original contributions from my research that I set out above, I take away from this thesis an on-going accommodation of ambiguity in the complex landscape of chronic pain practice, policy, advocacy, and research.

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Appendices

Appendix 1: Table illustrating clinical and disciplinary perspectives on pain

Clinical field	Main underpinning academic disciplines	Assumptions about the nature of reality (ontology)	Pain broadly conceptualised as	Main research methods	Patient viewed as
Clinical medicine	Anatomy, physiology, pharmacology, cognitive neuroscience, neuro-imaging	There is an objective reality which can be measured and on which doctors can intervene ('positivism')	Abnormal nerve signals, due to a pathological process e.g. inflammation, tissue damage, disrupted homeostasis	Basic (laboratory) science and imaging to understand processes and develop candidate drugs; testing drugs and behavioural interventions in clinical trials	Person with disease or disability; recipient of medication
Clinical nursing	Biomedical disciplines as above but also professional models of good nursing practice plus interdisciplinary (biopsychosocial) models	Pain reflects an objective reality but also has a subjective component in how the patient interprets and comes to terms with pain signals	Suffering that can be partially alleviated by medical therapies; empathetic nursing care; and support to 'self-manage'	Health services research (and audit/evaluation) to optimise services and ensure no-one misses out on the care they need; qualitative studies (patient narratives)	Person who is suffering; recipient of care; someone who, with support, may become more independent and learn 'self-management' skills

Clinical psychology	Cognitive psychology (especially cognitive-behaviourist traditions and psychometrics)	Mostly takes an objectivist (positivist) approach, using psychological models to explore, explain and try to change behaviour	Signals occurring in the human nervous system which can be modified through behavioural techniques	Quantitative, experimental studies of complex interventions, mainly using questionnaire-based outcomes	A body and a linked mind; a 'self' that can learn to manage
Clinical occupational therapy	Clinical practice literature along with cognitive psychology, biopsychosocial or psychotherapy (acceptance and commitment therapy, ACT)	Focuses predominantly on the subjective component of pain. Dealing successfully with pain requires the person to mentally come to terms with it	Affecting a person in their lived situation and requiring holistic management with attention to activities of daily living, life goals and use of tools/aids	Clinical case studies; qualitative studies (patient narratives); performative studies (e.g. ethnographic case studies)	Active participant in recovery. Can be enacted in passive way e.g., by offering equipment, modifying homes
Clinical physiotherapy	Clinical (practice-based) literature; some but not all influenced by the biopsychosocial model	Pain has both an objective and a subjective component; it plays out differently in different family, social	Arising from imbalances in nerve signals, muscle responses and how the patient positions themself, moves and responds	Mostly quantitative (e.g. surveys, trials of interventions) in positivist tradition; less commonly, qualitative studies in interpretivist tradition	Recipient of instruction, education, manual therapy; person who may apply self-management skills; person who may rethink their pain, re-engage and recover

		and cultural contexts			
Clinical rehabilitation	Clinical practice literature on multi-disciplinary management of complex conditions; biopsychosocial model; embodied cognition	The 'objective'/ 'subjective' dualism is unhelpful for pain. Rather, pain can be thought of as 'embodied cognition'	An embodied experience in which sense data are interpreted through social and cultural frames	Qualitative and mixed-method studies, including patient narratives and ethnographies. Health services research to optimise services.	Person whose life goals have been thwarted by pain and who needs support to adjust and strive for these goals despite pain and impairment
'Critical' studies undertaken by nursing and allied professions	May draw on all the above but also critical social sciences (e.g. feminism) and phenomenological philosophy	Various ontological approaches embraced under the banner of 'post-positivism' (most are beyond the scope of this thesis). See chapter 6 for further discussion on ontologies.	Pain is something the individual experiences (phenomenology) based on sense data, interpreted in particular cultural frames and reflecting power imbalances in society	Patient narratives to understand the subjective experience of pain taking account of wider structural causes such as various kinds of oppression and disempowerment.	Person whose experience of pain may be inexorably bound up with multiple and interacting structural inequities (e.g., gender, class, race)

Appendix 2: Recruitment poster for patients

Recruitment poster for patients, 17th February 2021, v2.0

Can you help us with our research on:

Self-management for people living with chronic pain

How is 'self-management' achieved by people living with chronic pain?

Who are we?

We are a research team based at the University of Oxford studying how people living with chronic pain (pain lasting longer than three months) and not attending specialist services for pain are living with their condition.

This research aims to improve support for people living with chronic pain and to make recommendations for how specialist services are run. It is part of a four-year research programme, funded by the National Institute for Health Research.

What will taking part involve?

If you decide to take part, you will meet with the researcher to talk about how much or how little you would like to be involved. You will be interviewed about your experiences of living with chronic pain. You will be interviewed again after at least four weeks. There will be the opportunity to continue to meet with the researcher as you go about your daily life. They will be interested in seeing how you manage without the help of specialist services.

Where and when?

Due to the pandemic, we are happy to 'meet' with you via videoconferencing (Zoom) or via telephone.

Who can I contact?

If you would like to take part or have any questions about the research, please contact the research team [Jackie Walumbe – Jacqueline.walumbe@phc.ox.ac.uk] or take one of the slips below and use the details provided to contact the research team.

Jackie Walumbe
Jacqueline.walumbe@phc.ox.ac.uk

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Appendix 3: Interview topic guides

DRAFT Topic guide for patients: initial interview

8th April 2019, version 1.0

Introduction: *Researcher to introduce self, check consent has been given, ask the participant if its ok to record the interview, remind about confidentiality. Also to remind the participant that they can stop any time they wish.*

Researcher will use the questions below to guide the interview, but will also respond to the participant, following their lead on the areas they wish to discuss, e.g. asking questions in a different order to allow the participant to tell their story in the way they choose.

1. I am doing research about support for people living with chronic pain. I'm interested in your experience. I'd like you to tell me about your pain – can you tell me when it first started and what happened from there? I won't interrupt you; I'll just make some notes. Feel free to begin.

Prompts for Q1, enabling the researcher to pick and explore key elements of the interviewees story as it unfolds:

   a. Can you tell me a bit more about what was happening in your life at the time?
   b. Can you say a bit more about what happened since [cue phrase]?
   c. Have you had any support from health or social care to help with your pain? If so, what has that involved, and how have you found it?

2. What kind of help and support do you have in managing your chronic pain? How has this changed over time
3. How does your pain currently affect you day-to-day? Does this vary at all, if so how?
4. What kind of things do you do to help you manage the chronic pain? How has that changed over time?
5. Is there something else you'd like to talk about that we haven't discussed?

Conclusion: Finish with thanks, arrange preferred way of keeping in contact and explain that will arrange follow-up interview in 2-3 months, and opportunity for participant to ask any questions.

DRAFT Topic guide for patients: follow-up interview

8th April 2019, version 1.0

Introduction: Researcher to confirm consent still in place, ask participant if its ok to record the interview and remind them that they can stop or pause any time they like.

Researcher will use the questions below to guide the interview, but will also respond to the participant, following their lead on the areas they wish to discuss, e.g. asking questions in a different order to allow the participant to tell their story in the way they choose.

1. Can you tell me how you been since our last interview? I'm interested in how you have been managing your chronic pain since we last met. I won't interrupt you; I'll just make some notes. Feel free to begin.

Prompts for Q1, enabling the researcher to pick and explore key elements of the interviewees story as it unfolds:

   a. We can go through the journal you have been keeping and any pictures you have taken.
   b. Can you say a bit more about these pictures?
   c. Have you had any support from health or social care to help with your pain? If so, what has that involved, and how have you found it?

2. What kind of help and support have you had in managing your chronic pain since we last met? How has this changed over time?
3. How does your pain currently affect you day-to-day? Does this vary at all, if so how?
4. What kind of things are you doing to help you manage the chronic pain? How has that changed over time?
5. Is there something else you'd like to talk about that we haven't discussed?

Conclusion: Finish with thanks. If participant has consented to continue with additional visits and 'go-along' interviews, arrange preferred way of keeping in contact and explain that will arrange follow-up visits, and opportunity for participant to ask any questions. If this is the final visit, thank participant for taking part and confirm that this is the last interview.

'Go-along' interviews will follow similar format to above, checking in on self-management activities between visits.

Topic guide for staff interview

3rd February 2020, version 1.1

Introduction: *Researcher to introduce self, check consent has been given, check with the participant that it is ok to-record the interview and remind about confidentiality. Also to remind the participant that they can stop any time.*

1. So [name], you know that I'm doing this research on the self-management of chronic pain. I'm interested in *your* experiences of pain management. I'd like you to tell me about how you came to be working in Oxford and your experience of pain management here in your own way, what's been important for you. I won't interrupt you, I'll just make some notes.

In the second part of the interview, I'll draw questions from what participants bring up, making notes in the order that they come up. The questions below are examples that may be relevant but I will be guided by the emerging narrative.

2. What are the challenges and opportunities currently facing pain management services? (eg, demand, funding).
3. What does self-management support for chronic pain mean to you?
4. Is there a role for specialist pain management service is in providing self-management support? If yes, what might this involve? If no, where might this support come from?
5. Can you talk through how you make decisions about which services/programmes to commission/refer patients with chronic pain to? [inclusion and exclusion criteria]

For service providers

6. How does the service support those who drop out or?
7. Why do you think patients drop out or choose not to engage with self-management support for chronic pain? What, if anything, do you think services might do differently to support them?
8. Is there anything else you'd like to tell me about self-management support for chronic pain that we haven't already discussed?

Conclusion: Thanks, request for any relevant documents related to self-management and opportunity for participant to ask any questions.

Appendix 4: Example MAXQDA data management and initial coding

Appendix 5: Study sponsorship



RESEARCH SERVICES
Clinical Trials and Research Governance
Joint Research Office
Boundary Brook House
Churchill Drive
Headington, Oxford
OXON
OX3 7GB

To whom it may concern

Date: 08/05/2019

Dear Sir/Madam,

Title: Supporting successful self-management strategies for people living with chronic pain: a mixed methods study focused on those who have been excluded from or dropped out of pain management services

PID: 14270

Protocol Date/Version: 15.04.2019 Version 1.0

The above study has been designed by Ms Jacqueline Walumbe and colleagues at the University of Oxford and funded by the National Institute for Health Research (NIHR). I confirm that the University will accept the role of Research Sponsor of this Study and will comply with the requirements of the UK Policy Framework for Health and Social Care Research October 2017.

Insurance-provided indemnity arrangements are in place for the project:
Newline Underwriting Management Ltd., at Lloyd's of London.

Sponsorship is confirmed subject to the condition that the following are sent to Clinical Trials and Research Governance for review prior to submission to the Research Ethics Committee. Failure to do so may compromise insurance cover for the project.

- Any minor or substantial amendments
- Any extension to the study end date
- Addition of any new research site or patient identification centre

In addition, annual progress reports, the end of study notification and final report must be copied to Clinical Trials and Research Governance.

Lastly, where they exist, University Core SOPs must be followed by default for all clinical research sponsored by the University. Further information can be found here: https://researchsupport.admin.ox.ac.uk/ctrg/resources

Any communications relating to Research Sponsorship should be directed to the undersigned, whose contact details are given in this letter.

Yours faithfully

N.a.wellman

Nigel Wellman
Clinical Trials and Research Governance

Tel: +44 (0)1865 616480 Web: https://researchsupport.admin.ox.ac.uk/ctrg
Email: Heather.house@admin.ox.ac.uk or Elaine.Chick@admin.ox.ac.uk

Appendix 6: IRAS ethical approval

Health Research Authority

London - Camberwell St Giles Research Ethics Committee
Level 3, Block B
Whitefriars
Lewins Mead
Bristol
BS1 2NT

Telephone: 02071048138

01 October 2019

Ms Jacqueline Walumbe
Clinical Doctoral Research Fellow/ DPhil student
University of Oxford
Nuffield Department of Primary Care Health Sciences
Radcliffe Observatory Quarter
Woodstock Road, Oxford
OX2 6GG

Dear Ms Walumbe

Study title:	**Supporting successful self-management strategies for people living with chronic pain: a mixed methods study focused on those who have been excluded from or dropped out of pain management services**
REC reference:	**19/LO/1278**
Protocol number:	**000000**
IRAS project ID:	**257463**

Thank you for your letter of 20 September 2019, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation, as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database. For this purpose, 'clinical trials' are defined as the first four project categories in IRAS project filter question 2. Registration is a legal requirement for clinical trials of investigational medicinal products (CTIMPs), except for phase I trials in healthy volunteers (these must still register as a condition of the REC favourable opinion).

Registration should take place as early as possible and within six weeks of recruiting the first research participant at the latest. Failure to register is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see here for more information on requesting a deferral:
https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registration-research-project-identifiers/

As set out in the UK Policy Framework, research sponsors are responsible for making information about research publicly available before it starts e.g. by registering the research project on a publicly accessible register. Further guidance on registration is available at:
https://www.hra.nhs.uk/planning-and-improving-research/research-planning/transparency-responsibilities/

You should notify the REC of the registration details. We will audit these as part of the annual progress reporting process.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report

The latest guidance on these topics can be found at https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/.

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites listed in the application subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Recruitment poster for patients]	1.0	09 January 2019
Covering letter on headed paper [NHS REC Cover letter response]	1.0	20 September 2019
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of sponsor Insurance]	1.0	08 May 2019
Interview schedules or topic guides for participants [Patient topic guide initial interview]	1.0	08 April 2019
Interview schedules or topic guides for participants [Patient topic guide follow up interview]	1.0	08 April 2019
Interview schedules or topic guides for participants [Topic guide for staff interview]	1.0	03 April 2019
IRAS Application Form [IRAS_Form_07062019]		07 June 2019
IRAS Checklist XML [Checklist_07062019]		07 June 2019
IRAS Checklist XML [Checklist_06082019]		06 August 2019

IRAS Checklist XML [Checklist_20092019]		20 September 2019
Letter from funder [Letter from funder - Email]		24 January 2018
Letter from sponsor [Letter from Sponsor]		08 May 2019
Letters of invitation to participant [Letter of invitation for patients]	1.0	09 January 2019
Letters of invitation to participant [Letter of invitation for staff]	1.0	09 January 2019
Other [NHS REC Further Information Required Response]	1.0	20 September 2019
Participant consent form [Consent form patients]	1.0	08 April 2019
Participant consent form [Consent form staff]	1.0	03 April 2019
Participant information sheet (PIS) [Participant Information Sheet Patient]	2.0	04 September 2019
Participant information sheet (PIS) [Participant Information Sheet Staff]	2.0	09 September 2019
Referee's report or other scientific critique report [Review Panel Assessment]	1.0	17 May 2017
Research protocol or project proposal [Research Protocol]	1.0	15 April 2019
Summary CV for Chief Investigator (CI) [Summary CV CI]		15 May 2019
Summary CV for student [Student CV]		15 May 2019
Summary CV for supervisor (student research) [Sara Shaw CV]		15 May 2019
Summary CV for supervisor (student research) [Deborah Swinglehurst CV]		21 May 2019
Summary CV for supervisor (student research) [Alan Silman CV]		28 May 2019
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Plain English summary]	1.0	15 April 2019

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

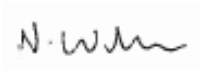
HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at:
https://www.hra.nhs.uk/planning-and-improving-research/learning/

19/LO/1278	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely



PP
Mr John Richardson
Chair

Email: nrescommittee.london-camberwellstgiles@nhs.net

Copy to: N/A N/A CTRG, sponsor contact

Appendix 7: HRA approval letter

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Ms Jacqueline Walumbe
Clinical Doctoral Research Fellow/ DPhil student
University of Oxford
Nuffield Department of Primary Care Health Sciences
Radcliffe Obsevatory Quarter
Woodstock Road, Oxford
OX2 6GG

Email: hra.approval@nhs.net
HCRW.approvals@wales.nhs.uk

01 October 2019

Dear Ms Walumbe

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Supporting successful self-management strategies for people living with chronic pain: a mixed methods study focused on those who have been excluded from or dropped out of pain management services**
IRAS project ID:	**257463**
Protocol number:	**000000**
REC reference:	**19/LO/1278**
Sponsor	**University of Oxford/Clinical Trials and Research Governance**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **257463**. Please quote this on all correspondence.

Yours sincerely,

Natalie Wilson
Approvals Specialist

Email: nrescommittee.london-camberwellstgiles@nhs.net

Copy to: *N/A N/A CTRG, Sponsor contact*

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Recruitment poster for patients]	1.0	09 January 2019
Covering letter on headed paper [NHS REC Cover letter response]	1.0	20 September 2019
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of sponsor Insurance]	1.0	08 May 2019
Interview schedules or topic guides for participants [Patient topic guide initial interview]	1.0	08 April 2019
Interview schedules or topic guides for participants [Patient topic guide follow up interview]	1.0	08 April 2019
Interview schedules or topic guides for participants [Topic guide for staff interview]	1.0	03 April 2019
IRAS Application Form [IRAS_Form_07062019]		07 June 2019
IRAS Checklist XML [Checklist_07062019]		07 June 2019
IRAS Checklist XML [Checklist_20092019]		20 September 2019
IRAS Checklist XML [Checklist_06082019]		06 August 2019
Letter from funder [Letter from funder - Email]		24 January 2018
Letter from sponsor [Letter from Sponsor]		08 May 2019
Letters of invitation to participant [Letter of invitation for patients]	1.0	09 January 2019
Letters of invitation to participant [Letter of invitation for staff]	1.0	09 January 2019
Organisation Information Document	1	06 August 2019
Other [NHS REC Further Information Required Response]	1.0	20 September 2019
Participant consent form [Consent form patients]	1.0	08 April 2019
Participant consent form [Consent form staff]	1.0	03 April 2019
Participant information sheet (PIS) [Participant Information Sheet Patient]	2.0	04 September 2019
Participant information sheet (PIS) [Participant Information Sheet Staff]	2.0	09 September 2019
Referee's report or other scientific critique report [Review Panel Assessment]	1.0	17 May 2017
Research protocol or project proposal [Research Protocol]	1.0	15 April 2019
Schedule of Events or SoECAT	1	06 August 2019
Summary CV for Chief Investigator (CI) [Summary CV CI]		15 May 2019
Summary CV for student [Student CV]		15 May 2019
Summary CV for supervisor (student research) [Sara Shaw CV]		15 May 2019
Summary CV for supervisor (student research) [Deborah Swinglehurst CV]		21 May 2019
Summary CV for supervisor (student research) [Alan Silman CV]		28 May 2019
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Plain English summary]	1.0	15 April 2019

IRAS project ID	257463

Information to support study set up

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	Expectations related to confirmation of capacity and capability	Agreement to be used	Funding arrangements	Oversight expectations	HR Good Practice Resource Pack expectations
Research activities and procedures.as per the protocol and other study documents will take place at participating NHS organisations.	Research activities should not commence at participating NHS organisations in England or Wales prior to their formal confirmation of capacity and capability to deliver the study.	An Organisation Information Document has been submitted and the sponsor is not requesting and does not expect any other site agreement to be used. The above can be adapted/localised as appropriate for the CRN and NHS sites.	Sponsor is not providing funding to participating NHS organisations	A Principal Investigator (PI) is expected at some participating NHS organisations (OUH). A Local Collaborator (LC) is expected at some participating NHS organisations (GPs in CRNs).	It is expected that the principles of the HR Good Practice Pack are followed for researchers working in primary care. Researchers are advised to follow the processes of the local primary care management function. Where arrangements are not already in place, research staff not employed by the NHS host organisation undertaking any of the research activities listed in the research application would be expected to obtain a Letter of Access based on standard DBS checks and occupational health clearance. External staff only undertaking interviews with staff participants in non-clinical areas/admin building do not require letters of access, DBS checks or occupational health clearance.

Other information to aid study set-up and delivery

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.
The applicant has indicated that they intend to apply for inclusion on the NIHR CRN Portfolio. Ownership of IP generated by employees of the University vests in the University. The protection and exploitation of any new IP is managed by the University's technology transfer office, Oxford University Innovations.

Appendix 8: Minor amendments 1 and 2

Dear Jackie,

RE: Minor amendment 1 COVID-19 (dated 17.03.2020) IRAS ID:257463, approved by study sponsor.

Thank you for sending in the minor amendment for review. I can confirm that the amendment has now been approved by the sponsor. Feel free to now submit the documentation to your site(s) directly, as per the HRAs guidance 3.1.2. https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/covid-19-guidance-sponsors-sites-and-researchers/

This amendment doesn't required HRA assessment/categorisation.

Please also include a copy of this email as proof it has been approved by the study sponsor. We do not have the capacity to wet-ink sign the sponsor declaration.

Kind regards
Karl
PID14270-A002-SP001-AC001

Amendment Tool

v1.2 11 Jun 2020

For office use

QC: No

Section 1: Project information

Short project title*:	Supporting self-management strategies for people with chronic pain
IRAS project ID* (or REC reference if no IRAS project ID is available):	257463
Sponsor amendment reference number*:	Minor Amendment 2
Sponsor amendment date* (enter as DD/MM/YY):	09 November 2020
Summary of amendment including justification*:	Change to procedures to limit travel and non essential contact with participants to minimise risk to participants and researchers during COVID-19 pandemic.

Project type:	◉ Specific study ○ Research tissue bank ○ Research database	
Has the study been reviewed by a UKECA-recognised Research Ethics Committee (REC) prior to this amendment?:	◉ Yes	○ No
What type of UKECA-recognised Research Ethics Committee (REC) review is applicable?:	◉ NHS/HSC REC ○ Ministry of Defence (MoDREC)	
Is all or part of this amendment being resubmitted to the Research Ethics Committee (REC) as a modified amendment?	○ Yes	◉ No
Was the study a clinical trial of an investigational medicinal product (CTIMP) OR does the amendment make it one?:	○ Yes	◉ No
Was the study a clinical investigation or other study of a medical device OR does the amendment make it one?:	○ Yes	◉ No
Did the study involve the administration of radioactive substances, therefore requiring ARSAC review, OR does the amendment introduce this?:	○ Yes	◉ No
Did the study involve the use of research exposures to ionising radiation (not involving the administration of radioactive substances) OR does the amendment introduce this?:	○ Yes	◉ No
Did the study involve adults lacking capacity OR does the amendment introduce this?:	○ Yes	◉ No
Did the study involve access to confidential patient information without consent OR does the amendment introduce this?:	○ Yes	◉ No
Did the study involve prisoners OR does the amendment introduce this?:	○ Yes	◉ No
Did the study involve NHS/HSC organisations prior to this amendment?:	◉ Yes	○ No
Did the study involve non-NHS/HSC organisations OR does the amendment introduce them?:	○ Yes	◉ No

	England	Wales	Scotland	Northern Ireland
Where is the NHS/HSC Research Ethics Committee (REC) that reviewed the study based?:	◉	○	○	○
Lead nation for the study:	◉	○	○	○
Which nations had participating NHS/HSC organisations prior to this amendment?	☑	☐	☐	☐
Which nations will have participating NHS/HSC organisations after this amendment?	☑	☐	☐	☐

Section 2: Summary of change(s)

Please note: Each change being made as part of the amendment must be entered separately. For example, if an amendment to a clinical trial of an investigational medicinal product (CTIMP) involves an update to the Investigator's Brochure (IB), affecting the Reference Safety Information (RSI) and so the information documents to be given to participants, these should be entered into the amendment tool as three separate changes. A list of all possible changes is available on the "Glossary of Changes" tab. To add another change, tick the "Add another change" box.

Change 1	
Area of change (select)*:	Participant Procedures
Specific change (select - only available when area of change is selected first)*:	Procedures - Change to the procedures undertaken by participants where there is no increased risk to the participant (e.g. changing site visits to phone calls or postal questionnaires)

Further information (free text):	During the pandemic, conducting interviews with patient participants by phone or video link instead of face-to-face in order to reduce burden on and physical contact with NHS and community sites and to reduce physical contact with research participants in their homes. We will take verbal rather than written consent and email the completed from to participants.

Applicability:	England	Wales	Scotland	Northern Ireland
Where are the participating NHS/HSC organisations located that will be affected by this change?*:	☑	☐	☐	☐
Will all participating NHS/HSC organisations be affected by this change, or only some?:	◉ All		○ Some	

Add another change: ☑

Change 2	
Area of change (select)*:	Participant Procedures
Specific change (select - only available when area of change is selected first)*:	Procedures - Change to the procedures undertaken by participants where there is no increased risk to the participant (e.g. changing site visits to phone calls or postal questionnaires)
Further information (free text):	During the pandemic, we will not leave participants with a pack of cultural probes (digital camera plus journal) to record their experiences of chronic pain and self-management. This will reduce unnecessary physical contact with research participants. Participants will instead have the option of conducting a video home tour whilst on the video call, highlighting e.g. objects or spaces that are important to them in living with chronic pain.

Applicability:	England	Wales	Scotland	Northern Ireland
Where are the participating NHS/HSC organisations located that will be affected by this change?*:	☑	☐	☐	☐
Will all participating NHS/HSC organisations be affected by this change, or only some?:	◉ All		○ Some	

Add another change: ☑

Change 3	
Area of change (select)*:	Study Documents
Specific change (select - only available when area of change is selected first)*:	Other minor document change that can be implemented within existing resource in place at participating organisations - Please specify in the free text below
Further information (free text):	New document - verbal consent form. Covid-19 section added to Protocol

Applicability:	England	Wales	Scotland	Northern Ireland
Where are the participating NHS/HSC organisations located that will be affected by this change?*:	☑	☐	☐	☐
Will all participating NHS/HSC organisations be affected by this change, or only some?:	◉ All		○ Some	

Add another change: ☐

Section 3: Declaration(s) and lock for submission

Declaration by the Sponsor or authorised delegate

- I confirm that the Sponsor takes responsibility for the completed amendment tool
- I confirm that I have been formally authorised by the Sponsor to complete the amendment tool on their behalf

Name [first name and surname]:*	Carol Cornelius
*Email address**:	carol.cornelius@admin.ox.ac.uk

Lock for submission

Please note: This button will only become available when all mandatory (*) fields have been completed. When the button is available, clicking it will generate a PDF copy of the completed amendment tool that can be included in the amendment submission. Please ensure that the amendment tool is completed correctly before locking it for submission.

Lock for submission

After locking the tool, refer to the "Submission Guidance" tab for further information about the next steps for the amendment.

Section 4: Review bodies for the amendment

Please note: This section is for **information only**. Details in this section will complete automatically based on the options selected in Sections 1 and 2.

	Review bodies																	
	UK wide:						England and Wales:				Scotland:				Northern Ireland:			
	REC	Competent Authority MHRA - Medicines	Competent Authority MHRA - Devices	ARSAC	Radiation Assurance	UKSW Governance	REC (MCA)	CAG	HMPPS	HRA and HCRW Approval	REC (AWIA)	PBPP	SPS (RAEC)	National coordinating function	HSC REC	HSC Data Guardians	Prisons	National coordinating function	Category:
Change 1:	(Y)					N				N									C
Change 2:	(Y)					N				N									C
Change 3:	N					(Y)				(Y)									C
Overall reviews for the amendment:																			
Full review:	N					N				N									
Notification only:	Y					Y				Y									
Overall amendment type:	Non-substantial																		
Overall Category:	C																		

Appendix 9: Patient and staff information sheets

FUNDED BY NIHR | National Institute for Health Research

UNIVERSITY OF OXFORD — NUFFIELD DEPARTMENT OF PRIMARY CARE HEALTH SCIENCES

PATIENT INFORMATION SHEET

Supporting successful self-management strategies for chronic pain

Version 2.0, 4th September 2019

We'd like to invite you to take part in our research study. Before you decide, it is important that you understand why the research is being done and what it would involve for you. Please take time to read this information, and discuss it with others if you wish. If there is anything that is not clear, or if you *would like more information, please ask us.*

What is the purpose of the study?

We are a research team based at the University of Oxford. We are studying how people living with chronic pain (pain lasting longer than three months) and not attending specialist services for pain are living with their condition.

This research aims to improve support for people living with chronic pain and to make recommendations for how specialist services are run. The focus is on finding out: (a) how patients are coping without specialist support and what they do (how and with whom) to help themselves; (b) how health professionals do (or perhaps don't) support patients who drop out of or who are not able to attend pain management services; and (c) what is currently happening to support self-management for people with chronic pain in policy.

It is part of a four-year PhD research project, funded by the National Institute of Health Research.

To achieve our research aims we are conducting a detailed study of the experiences of people living with chronic pain, the specialist services that offer support for chronic pain and the different policies that shape how these services are delivered. We will be conducting face to face interviews which will be audio and/or video recorded. We are looking to recruit people living with chronic pain in the community, patients and staff from specialist services to take part in this research.

Why have I been invited?

You have been invited because you have been living with chronic pain for at least 3 months, have expressed an interest to one of our researchers or your clinician has identified you as someone who may be suitable for our study and you are currently not attending specialist services for help with managing your chronic pain.

Do I have to take part?

No, taking part is entirely voluntary and you can withdraw at any time if you later change your mind, without giving a reason. Withdrawal will not affect your current or future clinical care in any way, as the research team is separate from your medical team.

What will happen to me if I decide to take part?

At this stage you have given consent for the research team to contact you. They will do so in the next 7 days. They will then tell you more about the study, ask if you have questions and if you are ready to make a decision about whether or not you would like to take part. If you decline to take part, then we will not contact you again. If you confirm that you would like to take part in the research, then the researcher will set a time to visit you at a time convenient to you for your first visit. We will ask you to sign a consent form agreeing to take part. If you would like anyone else present during your interview (e.g. carer or interpreter), we will also ask them to sign a consent form.

You will be given a choice on how much you would like to be involved:

a) Two face to face interviews between 2-6 months apart. We will leave you with a research pack which includes a journal and a digital camera to record things you feel relate to the self- management of your chronic pain.

And if you would like to continue to be involved:

b) Ongoing visits by the researcher who will accompany you as you complete activities to help self-manage your chronic pain. They will speak to you about these activities and how they do or don't help with self-management. This will involve between 6-10 visits over a 6-9 month period.

The researcher will interview you about your experiences of living with chronic pain. With your permission, the researcher would like to audio/video record the interview. If you agree, a small video camera will be positioned unobtrusively in the room to capture the interview. At the end of the interview the researcher will check that you are still willing for the audio/video material to be used in the research. If you are more comfortable with being audio-recorded, rather than video recorded, this is also possible. The interviews can be held at your home or at another preferred location. They will last no more than 1 hour each.

The video and audio recordings will be anonymised before anyone else sees it – your name will be "bleeped" and your face and other identifying features will be blurred – unless you give us permission not to.

What should I consider?

The main things to consider are whether you are comfortable with researchers asking you questions and accompanying you as you go about different activities (of your choosing). You also need to consider if you are comfortable with interviews being audio and/or video recorded and how you feel about your interview being including (in part) in a film about the study.

Are there any possible disadvantages or risks from taking part?

The main disadvantage of the interview is we are asking you to commit some time and we will ask questions about living with chronic pain that may be upsetting. If sections of your video recorded interview are included in a film about the study, these will be available online on a public facing website. The research team will check with you if you are happy to have selected clips from your interview included. They will offer to hide your identity using software that can mask your face and/or voice should you wish to do so.

What are the possible benefits of taking part?

The main benefit of taking part in the research is an opportunity for you to contribute to a programme of research that focuses on improving support for other people like yourself living with chronic pain.

Will my taking part in the study be kept confidential?

Yes. All data from the study (tape recordings, videos) will be made anonymous (unless you would prefer us not to blur your face). They will be kept on a secure part of the server at the University of Oxford and only accessible by the research team. In those stored data, you will be referred to only by a code name ('pseudonym'). We will keep a separate paper record in a locked cabinet of participants' real names and corresponding code names. All specific video and audio recordings will be destroyed at the end of the study. The final edited video which may include you will continue to be available online for others to view.

Responsible members of the University of Oxford and the relevant NHS Trust(s) may be given access to data for monitoring and/or audit of the study to ensure that the research is complying with applicable regulations.

Will I be reimbursed for taking part?

No, since the interview/recording will usually take place in your home. If you prefer to have the interview at the university or other location, we will reimburse any travel expenses.

What will happen to my data?

We will keep the data we collect during the research for up to six years after the end of the study. This will ensure that we have time to analyse it all, write papers and reports. Once these are completed, all video and audio data will be destroyed. Anonymised transcripts of interviews may be kept for up to 10 years.

You can stop at any time. Participation is voluntary and even if you originally said yes, you may change your mind at a later stage. If you withdraw from the study, unless you state otherwise, any interview or video material that has been collected whilst you have been in the study will be used for research as detailed in this participant information sheet. Data already recorded will be kept.

Withdrawal from the study will NOT affect the care you receive from the NHS now or in the future.

What will happen at the end of the study?

We will analyse the data and write some papers and reports, including a 'lay summary'. We will provide you with a summary of the findings if you would like us to.

We will produce a video that explains the experiences of people living with pain and may ask to use sections from your own video interviews. This will be available on the study website. If you are happy for this to happen, tick the relevant box on the consent form.

You will not be identified from any report or publication placed in the public domain.

The research being undertaken will contribute to the fulfilment of an educational requirement, a doctoral thesis.

What if you find something unexpected?

If anything you tell us in an interview has a direct bearing on your clinical care (for example if you disclose to us that you have a new symptom), we may inform your clinical team, as appropriate.

What if there is a problem?

The University of Oxford, as Sponsor, has appropriate insurance in place in the unlikely event that you suffer any harm as a direct consequence of your participation in this study.

If you wish to complain about any aspect of the way in which you have been approached or treated during the course of this study, you should contact Jackie Walumbe whose details are given below, or Professor Sara Shaw (Ms Walumbe's academic supervisor), same address). Alternatively, you may contact the University of Oxford Clinical Trials and Research Governance (CTRG) office on 01865 572224, or the head of CTRG, email ctrg@admin.ox.ac.uk.

How have patients and the public been involved in this study?

People like you with experience of living with chronic pain were involved in helping design this study and have also checked this information sheet and consent form.

Who is organising and funding the study?

The study is funded by National Institute of Health Research (NIHR). It is part of the *CHronic pain Self-Management* (CHASM) research project. The study is led by Jackie Walumbe, who is a PhD student at the University of Oxford; she is also custodian of the study information.

Who has reviewed the study?

This study has been reviewed and given favourable opinion by London - Camberwell St Giles Research Ethics Committee. The reference number is 19/LO/1278

Further information and contact details:

Please contact the following individual if you would like further information.

Jackie Walumbe (Chief Investigator)
Nuffield Department of Primary Care Health Sciences
University of Oxford
Radcliffe Observatory Quarter
Woodstock Road
Oxford OX2 6GG

T: 01865 617830
E: Jacqueline.walumbe@phc.ox.ac.uk

Thank you for considering taking part.

FUNDED BY NIHR | National Institute for Health Research

UNIVERSITY OF OXFORD — NUFFIELD DEPARTMENT OF PRIMARY CARE HEALTH SCIENCES

STAFF PARTICIPANT INFORMATION SHEET

Supporting successful self-management strategies for chronic pain

Version 2.0, 9th September 2019

We'd like to invite you to take part in our research study. Before you decide, it is important that you understand why the research is being done and what it would involve for you. Please take time to read this information, and discuss it with others if you wish. If there is anything that is not clear, or if you would like more information, please ask us.

What is the purpose of the study?

We are a research team based at the University of Oxford. We are studying how people living with chronic pain (pain lasting longer than three months) and not attending specialist services for pain are living with their condition.

This research aims to improve support for learning self-management skills for people living with chronic pain and to make recommendations for how specialist services are run. The focus is on finding out: (a) how patients are coping without specialist support and what they do (how and with whom) to help themselves; (b) how health professionals do (or perhaps don't) support patients who drop out of or who are not able to attend pain management services; and (c) what is currently happening to support self-management for people with chronic pain in policy.

It is part of a four-year PhD research project, funded by the National Institute of Health Research.

To achieve our research aims we are conducting a detailed study of the patient experience of self-management, the specialist services that offer support for chronic pain and the different policies that shape how these services are delivered. We are looking to recruit patients and staff from specialist services to take part in this research.

Why have I been invited?

You have been invited because you have expressed an interest to one of our researchers or you have been identified as someone who is involved in commissioning or providing specialist pain services for chronic pain.

Do I have to take part?

No, taking part is entirely voluntary and you can withdraw at any time if you later change your mind, without giving a reason. Withdrawal will not affect your professional or employment status in any way.

What will happen to me if I decide to take part?

If you agree to participate, we would like to interview you. This would be a one-off interview that will last between 45-60 minutes at a time and location of your choice (e.g. a

private room at your workplace, university meeting room). With your permission, the interview will be tape-recorded. Interviews are likely to include the following broad areas:

What should I consider?

The main things to consider are whether you are comfortable with researchers asking you questions and accompanying you as you go about different activities (of your choosing). You also need to consider if you are comfortable with interviews being audio and/or video recorded and how you feel about your interview being including (in part) in a film about the study.

Are there any possible disadvantages or risks from taking part?

The main disadvantage of the interview is we are asking you to commit some time.

What are the possible benefits of taking part?

The main benefit of taking part in the research is an opportunity for you to contribute to a programme of research that focuses on improving self-management support for people living with chronic pain.

Will my taking part in the study be kept confidential?

Yes. All data from the study (tape recordings, transcripts) will be made anonymous. They will be kept on a secure part of the server at the University of Oxford and only accessible by the research team. In those stored data, you will be referred to only by a code name ('pseudonym'). We will keep a separate paper record in a locked cabinet of participants' real names and corresponding code names. All specific audio recordings will be destroyed at the end of the study.

Responsible members of the University of Oxford and the relevant NHS Trust(s) may be given access to data for monitoring and/or audit of the study to ensure that the research is complying with applicable regulations.

Will I be reimbursed for taking part?

No, since the interview/recording will usually take place at your workplace.

What will happen to my data?

We will keep the data we collect during the research for up to six years after the end of the study. This will ensure that we have time to analyse it all, write papers and reports. Once these are completed, all video and audio data will be destroyed. Anonymised transcripts of interviews may be kept for up to 10 years.

You can stop at any time. Participation is voluntary and even if you originally said yes, you may change your mind at a later stage. If you withdraw from the study, unless you state otherwise, any interview material that has been collected whilst you have been in the study will be used for research as detailed in this participant information sheet. Data already recorded will be kept.

What will happen at the end of the study?

We will analyse the data and write some papers and reports, including a 'lay summary'. We will provide you with a summary of the findings if you would like us to. We will produce a video that explains the experiences of people living with pain. This will be available on the study website.

You will not be identified from any report or publication placed in the public domain.

The research being undertaken will contribute to the fulfilment of an educational requirement, a doctoral thesis.

What if there is a problem?

The University of Oxford, as Sponsor, has appropriate insurance in place in the unlikely event that you suffer any harm as a direct consequence of your participation in this study.

If you wish to complain about any aspect of the way in which you have been approached or treated during the course of this study, you should contact Jackie Walumbe whose details are given below, or Professor Sara Shaw (Ms Walumbe's academic supervisor), same address). Alternatively, you may contact the University of Oxford Clinical Trials and Research Governance (CTRG) office on 01865 572224, or the head of CTRG, email ctrg@admin.ox.ac.uk.

How have patients and the public been involved in this study?

People with experience of living with chronic pain were involved in helping design this study and have also checked information sheet and consent form.

Who is organising and funding the study?

The study is funded by National Institute of Health Research (NIHR). It is part of the *CHronic pain Self-Management* (CHASM) research project. The study is led by Jackie Walumbe, who is a PhD student at the University of Oxford; she is also custodian of the study information.

Who has reviewed the study?

This study has been reviewed and given favourable opinion by London - Camberwell St Giles Research Ethics Committee. The reference number is **19/LO/1278**.

Further information and contact details:

Please contact the following individual if you would like further information.

Jackie Walumbe (Chief Investigator)
Nuffield Department of Primary Care Health Sciences
University of Oxford
Radcliffe Observatory Quarter
Woodstock Road
Oxford OX2 6GG

T: 01865 617830
E: jacqueline.walumbe@phc.ox.ac.uk

Thank you for considering taking part.

Appendix 10: Consent forms

FUNDED BY NIHR | National Institute for Health Research

UNIVERSITY OF OXFORD — NUFFIELD DEPARTMENT OF PRIMARY CARE HEALTH SCIENCES

CONSENT FORM FOR PATIENT PARTICIPANTS

Supporting successful self-management strategies for chronic pain

v1.0, 8th April 2019

Name of Researcher: _____

Chief Investigator
Jackie Walumbe
+44 (0)1865 289300 • Jacqueline.walumbe@phc.ox.ac.uk

Study Code: *Site ID Code:* *Participant identification number:*

If you agree, please initial box

1. I confirm that I have read the information sheet dated..... (version.....) for this study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	
3. I understand that data collected during the study may be looked at by researchers and by individuals from University of Oxford, from regulatory authorities and from the NHS Trust(s), where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
4. I agree to audio recording of one or more interviews	
5. I agree to the use of anonymised quotes from audio recordings to be used in research reports, publications and presentations.	
6. I agree to take part in this study.	

Additional		
7. I agree to video recording of one or more interviews	Yes	No
8. I agree to a researcher observing me as I carry out my daily activities.	Yes	No
9. I agree to the use of stills (pictures) from video data to be used in research reports, publications and conference presentations	Yes	No
10. I agree to a short clip of the audio interview being used to develop a film	Yes	No
11. I agree to a short clip of the video interview being used to develop a film	Yes	No
12. I agree to a short clip of the video interview being used to illustrate talks about this research at conferences or for teaching purposes	Yes	No
13. I would like blurring to be used in the video to ensure that I am not recognisable.	Yes	No

_____	_____	_____
Name of Participant	*Date*	*Signature*

_____	_____	_____
Name of Person taking Consent	*Date*	*Signature*

**1 copy for participant; 1 copy for researcher file*

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UNIVERSITY OF OXFORD — NUFFIELD DEPARTMENT OF PRIMARY CARE HEALTH SCIENCES

VERBAL CONSENT FORM FOR PATIENT PARTICIPANTS

Supporting successful self-management strategies for chronic pain

v1.0, 11th November 2020

Name of Researcher: _____

Chief Investigator
Jackie Walumbe
Jacqueline.walumbe@phc.ox.ac.uk

Study Code: *Site ID Code:* *Participant identification number:*

Researcher to seek and record informed oral consent, after participant has had sufficient time to think about whether they want to take part.

Please check the boxes to record that the question has been asked by the researcher and that the participant has responded in the affirmative:

1. Do you confirm that you have read the information sheet dated..... (version.....) for this study? Have you had the opportunity to consider the information, ask questions and have these answered satisfactorily?	
2. Do you understand that your participation is voluntary and that you are free to withdraw at any time without giving any reason, without your medical care or legal rights being affected?	
3. Do you understand that data collected during the study may be looked at by researchers and by individuals from University of Oxford, from regulatory authorities and from the NHS Trust(s), where it is relevant to your taking part in this research. Do you give permission for these individuals to have access to my records?	
4. Do you agree to audio recording of one or more interviews?	
5. Do you agree to the use of anonymised quotes from audio recordings to be used in research reports, publications and presentations?	
6. Do you agree to take part in this study?	

Additional		
7. Do you agree to a researcher observing you via remote video as you carry out a home tour?	Yes	No
8. Do you agree to the use of stills (pictures) from video data to be used in research reports, publications and conference presentations	Yes	No
9. Do you agree to a short clip of the audio interview being used to develop a film	Yes	No
10. Do you agree to a short clip of the video interview being used to develop a film	Yes	No
11. Do you agree to a short clip of the video interview being used to illustrate talks about this research at conferences or for teaching purposes	Yes	No
12. Would you like blurring to be used in the video to ensure that you are not recognisable.	Yes	No

Name of Participant

_____

Name of Researcher taking consent Date Signature

_____ _____ _____

**1 copy for participant (e.g. emailed securely to participant); 1 copy for researcher site file.*

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UNIVERSITY OF OXFORD — NUFFIELD DEPARTMENT OF PRIMARY CARE HEALTH SCIENCES

CONSENT FORM FOR STAFF PARTICIPANTS

Supporting successful self-management strategies for chronic pain

v1.0, 3rd April 2019

Name of Researcher: _____

Chief Investigator
Jackie Walumbe
+44 (0)1865 289300 • Jacqueline.walumbe@phc.ox.ac.uk

Study Code: *Site ID Code:* *Participant identification number:*

If you agree, please initial box

1. I confirm that I have read the information sheet dated..... (version.....) for this study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my professional or employment status being affected.	
3. I understand that data collected during the study may be looked at by researchers and by individuals from University of Oxford, from regulatory authorities and from the NHS Trust(s), where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
4. I agree to audio recording of one interview	
5. I agree to the use of anonymised quotes from audio recordings to be used in research reports, publications and presentations.	
6. I agree to take part in this study.	

_____	_____	_____
Name of Participant	*Date*	*Signature*
_____	_____	_____
Name of Person taking Consent	*Date*	*Signature*

**1 copy for participant; 1 copy for researcher file*