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“Movement to help us move forwards in life”: An exploration of meaningful movement and chronic pain through zine-making

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Submitted by Emily Louise Martin-Ball

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Abstract

Chronic Pain (CP) is one of the most widespread long-term health conditions globally, and its prevalence is expected to rise in coming years. Physical activity is widely promoted as a best-practice intervention for people experiencing CP, yet engaging in movement is often challenging, with pain itself acting as a barrier. Existing research narratives of what constitutes *meaningful movement* are largely shaped by biomedical perspectives, leaving limited space for community-led understandings. CP is also frequently misunderstood and difficult to communicate, contributing to its status as an invisible and sometimes dismissed experience. This study worked collaboratively with members of a CP peer-support group to explore how they understand, express, and use meaningful movement to live well with persistent and fluctuating pain. Using arts-based methodology informed by participatory-action tenets, the research centred lived experience and the co-production of a collaborative zine. This approach aligned with participatory action researchers commitment to democratising knowledge and enable co-researchers to articulate embodied, emotional, and relational dimensions of moving with CP which are often overlooked in clinical framings. The findings highlight how meaningful movement is constructed through everyday movement, reciprocity, identity, and connection, offering rich and nuanced understandings of movement within the context of living with persistent and fluctuating pain.

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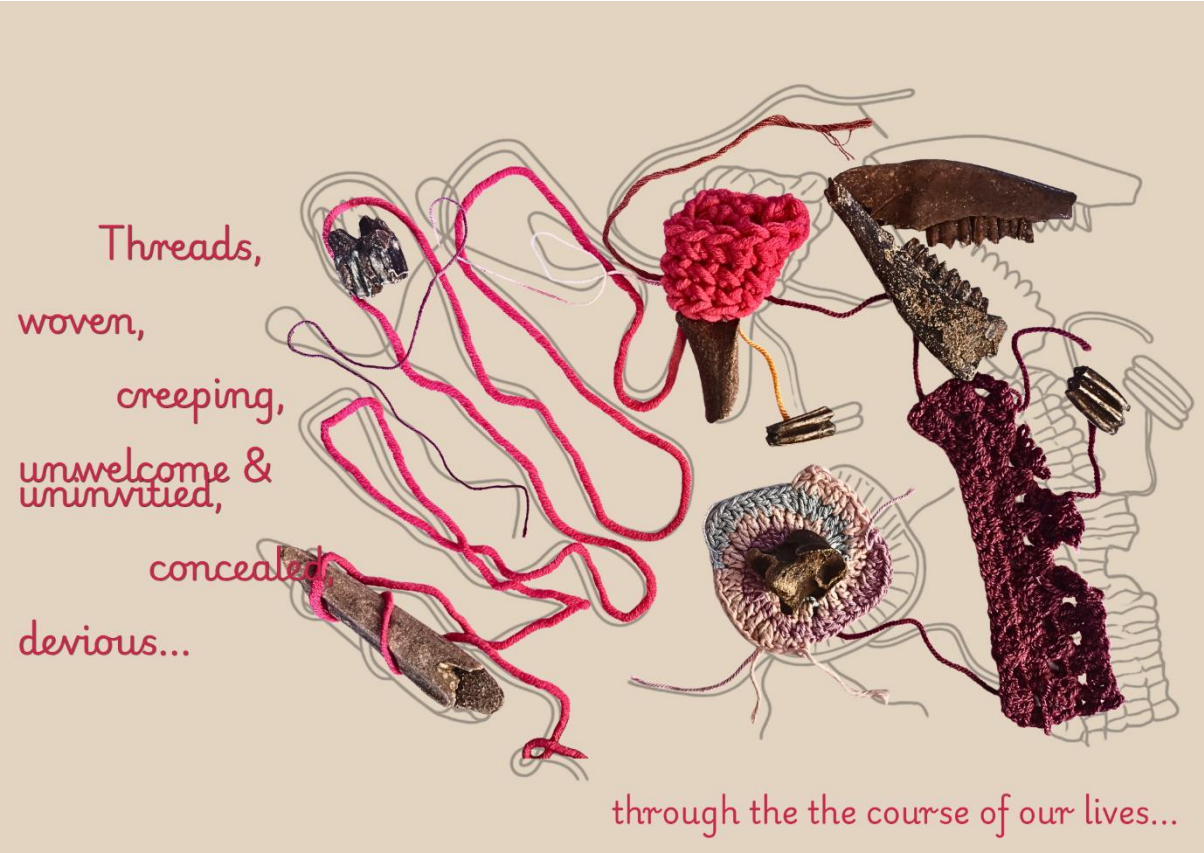
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Introduction

Figure 1:

Threads and bone: A reflective opening



Note. This image has been created by the lead researcher, Emily Martin-Ball. Materials used include semi-fossilised animal bones and teeth found while mudlarking on the Thames (South Bank, London), crochet scraps, woollen threads, and Canva editing software.

All people will experience pain throughout their lives, yet despite this commonality the subjective nature of pain and difficulty in articulating the embodied experience – particularly when chronic -- means people's testimonies are often dismissed. Pain is both objective and subjective, fluctuating from acute experiences of obvious tissue damage through to living with often unexplainable chronic persistent pain. Chronic, long-term and persistent pain (CP) is often referred to as an invisible condition, and remains misunderstood and obscured, in part because symptoms do not present visibly for objective observation (Toye et al., 2013a; Westergården et al., 2021). Pain is an embodied experience as it is felt and negotiated physically, while being shaped by less-observable histories, identities, and social conditions (Malpus, 2019; Tabor et al., 2017). The course of pain also does not

run in a linear fashion, and it twists and turns. These characteristics often lead to those experiencing CP not being believed, or the extent and impact being underappreciated by healthcare professionals, family, friends, and colleagues (Tosas, 2021; Werner & Malterud, 2003). This has serious implications: when a person's reality is devalued they can be left feeling isolated and unseen, with a diminished sense of control over their condition and how they navigate it. There is a recognition that at times academic research and clinical settings do not have the time, resources, or communication tools to allow for a language of pain to be authentically foregrounded (Houston et al., 2025; Munday et al., 2023; Toye et al., 2013b). Within health psychology, there is growing recognition that understanding chronic conditions requires attending to the behavioural and cognitive processes, and the lived experiences and embedded textures of everyday life as well (van Rysewyk et al., 2023). This present study aims to enable a group of people living with CP to share their knowledge and experiences through language and expression that exceeds what is traditionally available within clinical or academic settings.

This line of enquiry was inspired in part by findings from a report titled *Bridging The Gap,* which revealed that pain was the top perceived barrier to people living with long-term conditions to be physically active (Insight Angels Ltd., 2024). However, in the same report it was also highlighted that health and social care professionals, charity professionals, sport and physical activity sector professionals and those who work within national and local government believe the biggest barrier to people being active is cost and motivation. While movement and physical activity have consistently been shown to be beneficial in managing and living with CP, activity levels amongst those living with the condition are low (Leese et al., 2024). This gap in understanding and recognition of the real lives and experiences of those living their daily lives with CP led me to reflect on how we communicate our experiences and how we can build empathy and understanding across different types of knowledge – the professional and the personal. It also led the questioning of "*so what is seen as 'movement' anyway, and how is it meaningful rather than being measured through arbitrary physical activity metrics which don't fully represent movement in everyday life?".* As I wholeheartedly believe in the power of storytelling and creativity to build bridges between people and help people to understand others by stepping outside of boxes and pre-determined narratives, I wanted to use my own creativity to approach this study differently. It was also really important to me that this research contributed to something tangible, and was helpful in some way to the people I would be working with. This connects to a strong sense of social justice and a desire to help tip the scales of power in a way which enables those traditionally excluded from research-leadership to take the reins, and teach me (and others) something new with the added bonus of making research *fun!*

Thus, this will not be a typical Master of Science thesis, as in order to help bring the *invisible* front and centre, I have utilised a methodology which lends itself as much to the process of *doing* research as it does to articulating and showing phenomena which often remain unseen. As the reader, you will be asked to engage with the knowledge produced by the co-researchers. You are invited, through eight prompts (invitations) woven throughout the thesis like the one below, to actively take part in understanding co-researchers' perspectives and the process of knowledge creation and articulation of embodied experiences.

Invitation One: Welcome

In keeping with the participatory and arts-based orientation of this thesis, you are invited to keep a blank sheet of paper and a tool of your choice (pencil, pen, felt-tip) beside you as you read.

Use it to make marks on the page: doodle, sketch, map, trace shapes or jot down any thoughts, sensations, or reflections as they arise.

There is no wrong or right way to do this and this practice is intended to simply create space for your own responses to surface alongside the material.

We will return to these in the following chapters.

Chapter One: Chronic Pain - An Invisible Condition

Chapter One will set the scene for this research, which is based in the United Kingdom (UK). I unpack Chronic Pain (CP) theories and explore how CP is communicated and navigated by individuals, helping to situate this thesis within the wider field of CP research.

Prevalence and Theories

Some studies suggest over 30% of the global population lives with chronic pain (CP) and the condition remains one of the leading reasons for seeking healthcare – particularly among older adults (Kang et al., 2023; Reid et al., 2015; Zimmer et al., 2022). Prevalence is expected to increase further worldwide, with disproportionate growth amongst more deprived and marginalised communities (Macchia, 2022). Those from black and minority ethnic backgrounds in the UK are more likely to have a greater burden of CP experiences, as are those living in areas of greater deprivation or who had adverse experiences in childhood (Anderson et al., 2009; Davies et al., 2009; Jones et al., 2009). The cost-of-illness estimates for CP climb into the billions across countries and a recent study in Norway showed a societal cost (including productivity) of 4% of GDP connected to CP (Stubhaug et al., 2024). Living with CP is a burden on the lives of individuals, health and care systems, societies, economies and global health as a whole (Breivik et al., 2013; Stubhaug et al., 2024). This trajectory, alongside global patterns showing who is most affected by CP, highlights both the scale of the condition and its deep entanglement with broader social and structural inequalities (Macgregor et al., 2023). However, without a universal approach to measuring this impact it is difficult to determine what the true economic and ultimately human cost is (Phillips, 2006).

While CP is a widespread condition, there is limited understanding as to the causes, approaches to (successful) management, and treatment (Breivik et al., 2013; van der Linden et al., 2022). Despite the substantial burden illustrated, and high societal and personal cost, CP continues to receive disproportionately little investment in both treatment provision and research (Stubhaug et al., 2024). This underscores the need for approaches to researching and managing pain that attend to the embedded and intersectional inequalities shaped through lived experiences and evident across social and systemic contexts.

Pain is characteristically complex and heavily subjective. While it is a common universal experience, when pain is persistent it can be distressing, isolating, exhausting and life-limiting (Malpus, 2019; Miller & Kaiser, 2018; Munday et al., 2021). How we define pain influences how it is understood,

managed, and experienced, which in turn affects how it is able to be researched (Bourke, 2013; Mailis et al., 2020; Raffaeli et al., 2021). It is therefore essential we lay the foundations of this current thesis for the reader, grounding it in a shared and clear understanding of what constitutes as 'chronic pain' and the broader landscape of CP research. The following section examines how CP is defined and understood within health psychology and related fields, including through lived experiences, and how it is approached and managed within the socio-political context of the UK in 2025-2026 where this research takes place.

Throughout current research literature CP is most commonly categorised by the International Classification of Diseases' definition as "pain that persists or recurs for longer than 3 months" (World Health Organization, 2026, January). The International Association for the Study of Pain (IASP) describes pain as "an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage" (Raja et al., 2020). This definition is significant in recognising that pain is both sensory and emotional, bringing the definition in alignment with the biopsychosocial model and acknowledging pain as a multidimensional experience. Critique of the IASP definition of CP, however, suggests it remains grounded in biomedical assumptions and maintains a limited ability to acknowledge lived experience (Cohen et al., 2018).

Chronic pain is often categorised into nociceptive, neuropathic, and nociplastic pain, reflecting different underlying mechanisms (Kosek et al., 2016). Until 2022 CP was recognised as a symptom only and not as a condition itself, which affects the way in which we are able to recognise and support management. It is now classified with its own entry within the ICD-11, indicating its status as a primary condition (van der Linden et al., 2022). The ICD-11 definition of CP provides a useful boundary for diagnosis and further research, however it offers limited insight into the complexity of how CP is lived, negotiated, and ultimately managed in everyday life (Cohen et al., 2018). Further, due to the relatively new addition as a diagnosis, there is limited research available directly focused on primary CP (Barke et al., 2022; van der Linden et al., 2022). While a definitive cause of CP is yet to be identified and universally accepted, it is known to be connected to and may arise from acute injury, degenerative conditions, primary health conditions, or surgical and medical interventions (Linton et al., 2018; Mills et al., 2019). Many people's experiences of CP also do not fit neatly into these diagnostic criteria and biomedical descriptors and dominant definitions tend to privilege clinical measurability over subjective meaning-making.

Theories of Pain

Explanations for pain have shifted significantly over time. Early accounts from Hippocrates (ca. 460-370 BCE) framed pain as an imbalance of bodily humors, while Aristotle (384-322 BCE) conceptualised it from a more philosophical lens as an embodied expression of emotional distress (Vincenot et al., 2025). These understandings later gave way to the medicalisation of pain, shaped in part through the works of Charles Bell and Francois Magendie, whose demonstrations of sensory-motor pathways in the late 1800s helped establish *specificity theory,* which identifies pain as a physiological process (Bourke, 2013). Although these models provided important insights into biological mechanisms, they struggled to explain persistent pain in the absence of observable injury. The emergence of the *Gate Control Theory* marked a significant shift, proposing that pain perception is modulated by both peripheral and central processes, while also being influenced by psychological factors (Campbell et al., 2020; Melzack & Wall, 1965). This theory helped build on explanations of why pain is perceived and experienced differently by people in different states of mind. It challenged purely biomedical explanations and supported a shift towards the *biopsychosocial* model that continues to influence contemporary understandings of pain (Melzack & Wall, 1965).

It must be acknowledged that historical theories were focused on understanding *acute* pain experiences, and that robust theories specifically for *chronic* pain are varied. Applying the biopsychosocial model to experiences of CP recognises the experience as a dynamic interaction between biological (e.g., nociception, co-morbidities), psychological (e.g., stress, anxiety, depression), and social and environmental (e.g., cultural beliefs, social support, economic) factors (Gatchel et al., 2007; Hulla et al., 2019). This theory was established in response to the perceived inadequacy of a purely biomedical and disease/injury approach to understanding CP (Turk & Monarch, 2002). This distinction of CP as an experience beyond a disease to be treated shifts our focus away from purely biological processes and towards recognising the condition with an *illness* lens. From this perspective we can acknowledge and respond to how individuals and those around them respond to symptoms of CP and pain-related disability (Gatchel et al., 2007). It is a model that offers a holistic framework and foregrounds the intersections of emotion and psychological processes, alongside social environments, and biological measures (Lumley et al., 2011).

Psychological models of CP have focused on cognitive and emotional processes that shape the pain experience and offer explanations for why pain may persist beyond biological tissue healing or in the absence of observable biological indicators (Lethem et al., 1983). The *Fear-avoidance Model* (FAM) suggests that when pain is interpreted by individuals as threatening, a fear of pain and movement

may develop, which in turn can lead to avoidance behaviours (Vlaeyen & Linton, 2000). These behaviours can gradually lower confidence levels, lead to physical deconditioning, and ultimately impact negatively on quality of life (Boselie & Vlaeyen, 2017). Within this model, fear is positioned as a pivotal mechanism linking pain perception to pain-related disability (Meulders, 2019). Movement is associated with risk and the body approached with caution and hypervigilance (Vlaeyen & Linton, 2000). The FAM explanation of CP processes resonates with the everyday experiences of constant appraisal whereby individuals determine whether actions are safe and make movement choices dependant on whether pain is seen as a signal that movement might make things worse (Bunzli, Smith, Schütze, et al., 2015; Bunzli, Smith, Watkins, et al., 2015).

Many contemporary approaches to understanding CP still struggle to capture the relational and embodied dimensions that people describe as central to their experiences beyond sensory observations and psychological processes. Kiverstein et al. (2022) argue for an *Embodied Predictive Processing (EPP) Theory*, which looks at CP not as solely neural signals, but as an embodied process distributed across multiple physiological systems. EPP helps to separate acute and chronic pain by explaining the difference between the mechanisms and functions (Hudspith, 2025). Pain is widely understood as a protective response of the body to perceived threat of tissue damage (Kang et al., 2023). It is suggested that the immune, endocrine and automatic systems work together throughout the body to anticipate threats and maintain homeostasis (Kiverstein et al., 2022). EPP suggests that CP is a result of erroneous predictions of threat by the brain, not in response to tangible threats but derived from strong emotional and fearful reactions to pain (Kiverstein et al., 2022; Tabor et al., 2017). Several parts of the brain, including those involved in learning, memory, mood, sleep, movement, and sensation, work together to try to accurately predict danger signals, and this is why other factors, such as stress, can trigger worsening of symptoms (Yang & Chang, 2019). Through this model, the traditional boundaries between biological and psychological mechanisms are removed, allowing for the recognition of the contribution of beliefs, emotions and memories in shaping CP experiences. EPP moves towards an explanation for why CP can persist long after an injury has healed, arise from seemingly ‘nothing’, why emotional pain can be felt physically, and why the experience of all these is entirely embodied.

Cross-cultural and relational understandings of CP extend embodied views by emphasising that CP is not only generated within an individual’s body, but that it is continually shaped through relationships, sociocultural contexts, and structural realities. Pain is expressed, interpreted, and responded to in interpersonal contexts including through family dynamics, clinical encounters,

workplace expectations, and broader social narratives about legitimacy and personal value (Goubert & Bernardes, 2025; Meints & Edwards, 2018; Nicolardi et al., 2020). Experiences of safety, compassion, exclusion, or discrimination can reinforce or disrupt the predictions that underpin chronic pain (Kapos et al., 2024). This in turn influences how the body anticipates threat and how a person moves, participates, and relates to others. From this perspective chronic pain becomes a socially situated pattern of the embodiment of physiological mechanisms. Further, different cultural understandings of pain can also help extend understanding beyond the biomedical and Western-dominated narratives (Okolo et al., 2024; Singh et al., 2018). Indigenous models of health and CP, such as Te Whare Tapa Whā through a Māori worldview, consider pain a multidimensional holistic experience (Durie, 1985; Lewis et al., 2024). Thoughts and emotions held in the body, whānau relationships, and environmental factors were noted to influence pain, but so too were spiritual factors and historic events. In a study by Antunovich et al. (2024) these facets were not observed in silos but were seen to be intertwined. Pain was also found to be intergenerational where impacts of colonisation are felt through generations. Additionally, the impacts of pain were not just felt in one area of life but many. Notably, treatments were ideally seen as multidimensional, culturally appropriate and a blend of traditional and modern (Devan et al., 2021).

Communicating Chronic Pain: Stigma and Intersectionality

Communicating chronic pain (CP) is a common challenge for many people living with the persistent condition (Bourke, 2014; Clarke et al., 2012). The invisibility of CP creates a fundamental communication gap, leading to experiences of stigma, and invalidation within healthcare and social relationships (Werner & Malterud, 2003). Pain is notoriously difficult to articulate, and clinical and research language that classifies the experience of CP as *pain catastrophising* or *kinesiophobia* does not resonate with those who live with the condition and at worst can further stigmatise (Connoy & Webster, 2024). The limitations of language in expressing pain have been well documented, with those living with the condition often using metaphor, imagery, or silence to convey what they feel (Munday et al., 2021; Munday et al., 2020). These studies illustrate how individuals living with chronic pain draw on these language and communication techniques to convey the intensity, unpredictability, and emotional weight of their symptoms. Commonly used metaphors such as *stabbing, burning and sharp* serve as linguistic bridges between the private sensations of pain and shared understanding (Johnson et al., 2023; Semino, 2010). These metaphors can help translate embodied experiences into forms that others can grasp, engaging empathy and making the invisible visible. There is growing argument that metaphors and creative communication should be more

intentionally integrated into clinical communication to support mutual understanding between patients and clinicians (Munday et al., 2023).

Communication plays an essential role in access to and relationships with healthcare professionals. Clinical encounters are structured around biomedical norms that privilege objective measures, diagnostic criteria, and linear narratives (Kenny, 2004; Munday et al., 2023). Due to the nature of CP patients may struggle to present their experiences in ways that align with these clinical frameworks, leading to different explanatory models being used: that of social consequences of pain and another of pathology and objective observations (Kenny, 2004)**.** This ultimately leads to clinicians often underestimating the severity of patients' CP, contributing to the undertreatment of pain (Seers et al., 2018). This communication gap can lead to epistemic injustice, whereby a person's testimony is undervalued because it does not conform to dominant medical ways of knowing (Tosas, 2021). For individuals from marginalised groups and underserved communities, whose voices are often not heard, these communication barriers are often intensified by racialised, gendered, and class-based assumptions about credibility, how one displays emotion, or compliance (Diniz et al., 2020; Hoffman et al., 2016; Samulowitz et al., 2018; Werner & Malterud, 2003). For example, women are routinely dismissed and their pain underestimated by medical professionals leading to a particular health and communication burden for women living with CP (Samulowitz et al., 2018; Zhang et al., 2021). This communication gap and feelings of being misunderstood and, at times, gas-lit by medical professionals mirrors broader issues connected to gender inequalities in healthcare (Khan et al., 2024; Thompson et al., 2023). In this way, communication plays a role in how broader social and health inequalities are enacted and reproduced.

Beyond verbal language, turning to alternative or embodied forms of communication to convey aspects of their CP that resist verbal articulation can be helpful for those living with the condition. Tools and techniques such as drawing, body-mapping, photography, or other creative expression can enable CP narratives to be foregrounded in ways that traditional conversations struggle (Main, 2014; Padfield et al., 2015). These methods help people to externalise sensations that are shifting or difficult to locate, and to represent the emotional and relational dimensions of pain that language cannot easily communicate. Visual and embodied forms of communication have been shown to support richer, more nuanced accounts of pain, enabling individuals to articulate intensity, texture, and temporality in ways that verbal metaphors alone cannot capture (Broadbent et al., 2009; Meehan & Carter, 2021; Tarr et al., 2018; Walsh et al., 2014). Importantly, these approaches challenge dominant biomedical communication tools and the assumptions that come with these, as

they foreground lived experience as a legitimate source of knowledge and valid language. In this sense, creative and embodied communication practices not only expand the expressive possibilities of pain, but also function as tools of agency within contexts where individuals often struggle to be heard.

As pain is not only experienced within clinical settings, the experience of CP in every-day life also requires interpretative and communication work (Aldrich & Eccleston, 2000). Individuals draw on personal history, cultural norms, and social expectations to make sense of and communicate pain. Aldrich and Eccleston's (2000) findings reinforce that pain is not a purely sensory event, but that it is always mediated by meaning, identity and context. Communication gaps in everyday life has significant relational consequences. When family members believe those with CP and provide supportive communication there can be a positive impact on the individual's ability to manage their condition while feeling acknowledged (Rosland et al., 2012)**.** When pain cannot easily be expressed, however, individuals report that their attempts are met with scepticism, minimisation, or dismissal (Werner & Malterud, 2003). These experiences are described in qualitative research with participants highlighting the emotional toll of repeatedly having to justify or prove their pain to others (Fenelon et al., 2025). The absence of visible causes of pain, and difficulty in gaining a diagnosis, can lead to doubts of credibility, reinforcing stigma and contributing to social withdrawal (Werner & Malterud, 2003). The communicative burden for individuals can add another layer to the persistency of CP and there remains a challenge of not only living with the condition, but continually translating it into terms that others will accept.

A growing body of research shows that experiences of CP are profoundly influenced by prejudice, discrimination, and structural violence (Craig et al., 2020; Wallace et al., 2021). Black patients, for example, report higher levels of disbelief, undertreatment, and racialised assumptions about pain tolerance or credibility (Green et al., 2003; Hood et al., 2023). These patterns are not accidental but reflect the enduring influence of colonial legacies, racialised medical histories, and neoliberal welfare policies that shape how bodies are valued and whose *pain* is recognised.

Context: The United Kingdom

This research is situated with the broader sociopolitical context of the United Kingdom (UK) in 2025-2026. Understanding CP in the UK requires recognising not only the contextual CP landscape – including prevalence and how it is approached in a research and clinical setting – but also that the experience is deeply shaped by contextual social structures, cultural narratives, and historical

inequalities (Agénor, 2020; Bambra, 2022). The social dimensions of chronic pain do not exist in a vacuum, but are embedded within broader systems of power that determine whose pain is believed, whose suffering is legitimised, and ultimately whose needs are prioritised within healthcare systems (Potthoff et al., 2025; Rice et al., 2026; Webster et al., 2023). Chronic pain is a major public health issue in the UK, affecting an estimated one-third of the British adult population, with up to 14% reporting moderately to severely disabling CP (Fayaz et al., 2016; Shetty et al., 2025). In the UK, much like globally, CP disproportionally affects women, older adults, and those living in areas of greater deprivation, highlighting existing health inequalities (Lynch et al., 2023; Versus Arthritis, n.d.). The Faculty of Pain Medicine emphasise that chronic pain is both widespread and unevenly distributed, with significant implications for quality of life, employment, and social participation (Faculty of Pain Medicine of the Royal College of Anaesthetists, n.d.).

Within the UK, CP is predominantly managed through the National Health Services' (NHS) pain services, which typically adopt a multidisciplinary approach involving medication, physiotherapy, and psychological interventions (Copley et al., 2025). The main route into a pain management pathway for individuals is through a General Practitioner (GP), who provides diagnosis, initial treatment, and onward referral where deemed appropriate (National Health Service, n.d.). Specialist pain clinics offer more comprehensive assessment and may provide access to pain management programmes (PMPs) which focus on improving quality of life, rather than reducing pain levels. These services are grounded in the biopsychosocial model, emphasising the interplay of physical, psychological, and social factors (Cole et al., 2021). However, the organisation of care remains largely medicalised, with most pathways situated within clinical settings and shaped by medical or therapy-led approaches to pain management (The British Pain Society, 2026). This limits opportunity for community-based approaches that may better reflect the lived realities of living with CP.

Pharmacological approaches to managing CP, particularly opioid-based treatments, have come under scrutiny due to limited long-term effectiveness and higher risks of harm (Alenezi et al., 2021a). Consequently, more holistic approaches have emerged, including a focus on physical activity and psychological therapies, alongside self-management education. Despite these shifts in approach to pain management across the UK, there remains inconsistent access to well-rounded PMPs, with long waiting times and regional variation of access (Connelly, 2020; Copley et al., 2025). These gaps in provision particularly impact those individuals who are already facing socioeconomic disadvantage, who may have fewer resources to navigate fragmented services or seek private alternatives.

In 2024, the UK Labour party entered government for the first time in 14 years, promising *change* (*Change: Labour Party Manifesto 2024*). Part of this pledge focused heavily on building a NHS 'fit for the future'. Decades of sweeping austerity measures under consecutive governments have played a role in the systematic decline, privatisation and depersonalisation of care in the UK, reframing patients as consumers and care as a commodity (Stuckler et al., 2017). Communities across the UK have experienced growing and intersecting health inequalities. Public consultations in 2025 highlighted widespread dissatisfaction with transactional models of care and called for a system that prioritises personalised, relational, and patient-centred approaches (UK Government, 2025). The Government's 10-Year Health Plan published 3 July 2025 laid out three 'shifts' proposed to help secure the NHS' future and support a more efficient, effective, and equitable health system.

Chronic pain, and those living with the condition, sits at a complex intersection within the UK's sociopolitical context. Policy discourse surrounding long-term conditions often emphasises economic inactivity and the perceived burden of chronic illness on the labour market (Gregg, 2024; Office for Health Improvement & Disparities, 2026). A 2016 governmental green paper highlighted that an estimated 30.8 million working days were 'lost' to musculoskeletal conditions in the UK (Department for Work & Pensions, 2016). This framing positions CP not only as a health issue but as an economic and moral concern, shaping how services are designed and how individuals are assessed for support (Crawshaw et al., 2024). Such narratives risk obscuring the lived experience of pain and reinforcing stigma, particularly for those whose symptoms are invisible, persistent, and fluctuating (Rice et al., 2026).

These dynamics are further compounded by the hierarchy of evidence that underpins UK health policy (Parkhurst & Abeysinghe, 2016). Clinical studies and positivist research is often privileged in decision-making, while qualitative accounts and lived experience are afforded less legitimacy (Greenhalgh & Russell, 2009). This reflects broader neoliberal and capitalist values of economic activity reflecting one's worth in a society, and as a measure for quality of life (Madden & Speed, 2017). Recognising the value and reliability of personal accounts and perspectives is an important activity to inform practice and implementation of policies and services if change is to happen. This current research aims to support by validating knowledge which is seldom 'validated' through academic activity and thus is not taken into account in a systematic way within healthcare and policy practices. It therefore aligns with growing advocacy for patient-led, holistic approaches to CP management (Jamil et al., 2025). By foregrounding the voices of people living with CP, this study

contributes to ongoing efforts to reshape pain services in ways that are more inclusive, relational, and responsive to the realities of those most affected.

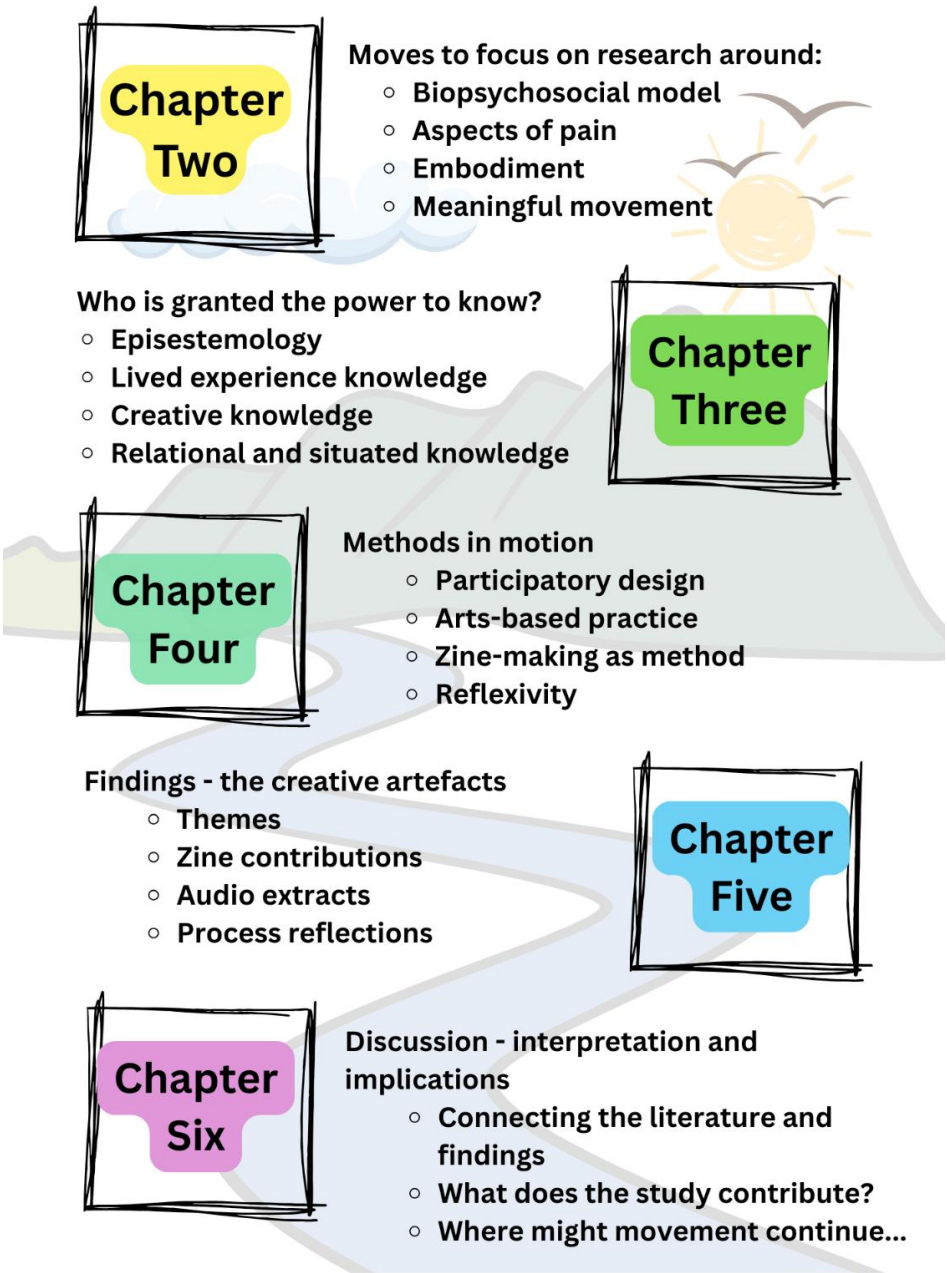
Research aims

The purpose of this current study is to explore how people living with CP define and experience 'meaningful movement'. Central to this aim is a commitment to positioning individuals with lived experience as knowledge-holders and co-constructors of their own narratives. The study is therefore grounded in a community participatory ethos that aligns with principles of social justice, empowerment, and the democratisation of knowledge (Cargo & Mercer, 2008; Phillips et al., 2022; Wallerstein & Duran, 2006).

Thesis overview

Figure 2:

Thesis Overview: What comes next



Chapter Two: The Dance Partner – Living and Moving with Pain

Chronic pain (CP) is like an unpredictable dance partner: single-minded, unreliable, and with a disputatious nature. It can be challenging for individuals to get the necessary support to cope with their offbeat and invisible partner (CP) due to its character. In the UK, CP management is predominantly delivered within healthcare settings and is orientated towards adaptation and sustaining quality of life rather than finding a cure – adapting partner dancing techniques to the changing rhythms, rather than expecting to learn a solo dance routine (Büssing et al., 2010; Esteve et al., 2007; McGhie & Grady, 2016; Peres & Lucchetti, 2010). The focus, where possible, for this chapter is on the UK setting; this is where the present research was based, and care and management plans reflect contextual geographic variations.

There are a range of different strategies through which individuals may approach managing their physical pain sensations, regulate emotional responses, and negotiate social expectations (Peres & Lucchetti, 2010; Wang et al., 2025). In practice, individuals with CP often describe this as a continual process of trial-and-error, paying for and coordinating care largely on their own, with little joined-up or formal support (Hadi et al., 2017; Hartley & Penlington, 2023; F. Toye et al., 2013b). There is a broad recognition of the need for multidisciplinary approaches to CP management due to intersecting biopsychosocial factors. Best practice management, therefore, includes a mixture of pharmacological, psychological, and social interventions (Cole et al., 2021; Gauntlett-Gilbert & Brook, 2018). While multidisciplinary approaches are held up as the gold-standard of CP management, lived experience narratives frequently highlight inequitable access to these PMPs and long waiting times, which has been corroborated through repeated critical analysis of pain management services in the UK (Copley et al., 2025; Hartley & Penlington, 2023; Price et al., 2019). There is also the feeling that individuals are expected to assemble their own care from disparate sources, often without guidance and emphasising ongoing personal labour of navigating pain (Slade et al., 2009; F. Toye et al., 2013b; van Rysewyk et al., 2023). Research supports the effectiveness of multidisciplinary treatment plans, yet these approaches remain contested and inconsistently available, highlighting the gap between recommended practice and the realities of navigating health systems and day-to-day life with CP (Flor et al., 1992; Scascighini et al., 2008).

The introduced metaphor of the unpredictable dance partner is difficult to capture through much of traditional CP research and emphasis tends to be on treatment and support. What a lot of research

misses is the number of different types of dances this partner can pull us into. Some days the dance is slow and methodical, other days erratic and jagged, and sometimes there is no music and thus no dance at all. This metaphor of CP as a dance partner helps to illustrate how CP can shape, constrain, or redirect movement but also risks implying that a dance has a fixed choreography or genre. In reality, the dance that is performed with CP as a partner varies across bodies, contexts, histories, and social worlds. The next part of the thesis discusses the wider biopsychosocial factors that shape how people move with pain. This section will focus on the voices of those with lived experience, to help us (the audience members) understand these dances from their perspectives – allowing us to recognise the emotional, relational and social conditions which influence the choreography.

Physical

A defining characteristic of CP, which makes it difficult to recognise and manage for individuals, is the invisibility of the condition (Tarr et al., 2018; Toye et al., 2013a; Westergården et al., 2021). Unlike *acute* pain, where biological indicators clearly signal threat and trigger observable physiological responses similar to anxiety symptoms, CP is associated with more subdued and less objectively observed patterns. These often resemble symptoms seen in depression, including low energy, reduced activity, and bodily fatigue (Eldabe et al., 2022; Igwesi-Chidobe et al., 2017; Keen et al., 2021). This shift in physiological expression contributes to the difficulty clinicians face in identifying CP through biomedical markers alone, and complicates individuals' efforts to articulate their physical symptoms in ways that can be externally recognised and validated.

Overall, the experience of CP is inconsistent, which makes it difficult to integrate into a universal concept (Keen et al., 2021). Throughout the reviewed literature, CP is commonly described as unpredictable, intrusive, and persistent, disrupting everyday bodily rhythms and routines (Igwesi-Chidobe et al., 2017; Toye et al., 2013a; van Rysewyk et al., 2023). Individuals often characterise CP as something that takes over, flares, is stealthy, and has a tangible effect on how one is able to interact physically with the world (Christidis et al., 2025; Keen et al., 2021; van Rysewyk et al., 2023; Voorhees, 2023). CP is therefore not a discrete event but a pervasive bodily state that demands attention and continuous adjustment (Keen et al., 2021; Kugelmann, 1999; Westergården et al., 2021).

Across studies, repeated accounts emphasise the tension between a 'healthy' outward appearance and the contradicting internal experience of CP (Campbell & Cramb, 2008; Kenny, 2004; Kugelmann, 1999; Westergården et al., 2021). These embodied realities have significant implications. The lack of

visible signs can lead to feelings of invalidation or disbelief from others, while the internal, persistent nature of CP shapes how people move, and engage with their bodies (Igwesi-Chidobe et al., 2017; Kugelmann, 1999; Tarr et al., 2018; Toye et al., 2013a). While nociceptive processes are an important and well researched aspect of the biological experiences of CP, qualitative accounts highlight that the negotiation of energy, mobility, and unpredictability are equally central physical experiences that people must navigate (Keen et al., 2021; Kugelmann, 1999; Voorhees, 2023; Westergården et al., 2021). These embodied realities intersect closely with psychological and social dimensions, shaping how CP is understood and managed.

Finally, the reliance on pharmaceuticals expressed in Igwesi-Chidobe et al. (2017) and Campbell and Cramb's (2008) studies highlight how CP is often framed as an illness or disease requiring medical treatment. There was, however, a dissatisfaction for the level of alleviation and ongoing management that medication could provide (Campbell & Cramb, 2008). Individuals also cited physical activity and lifestyle changes to be beneficial preventative measures and management techniques, as they recognised that medication would not 'cure' their pain and was accompanied with other unwanted side-effects (Campbell & Cramb, 2008; Igwesi-Chidobe et al., 2017). This helps to illustrate the different physical strategies people adopt and the varied meanings they attach to their bodily experiences.

Physical Treatments: Pharmaceuticals & Physiotherapy

Pharmacological treatment continues to play a central role in UK healthcare services' approach to CP management, reflecting the long-standing dominance of biomedical models of care (Ferreira et al., 2023; National Institute for Health and Care Excellence, 2021, April 7; Zambelli et al., 2022). Clinically grounded approaches have traditionally centred medication as the primary means of reducing pain intensity and improving function, and this remains prevalent in contemporary clinical practice (Dai et al., 2026). Commonly prescribed medicines for persistent pain include non-steroidal anti-inflammatory drugs (NSAIDs), antidepressants, anticonvulsants, and opioid analgesics (Bonezzi et al., 2020; Dai et al., 2026; Faculty of Pain Medicine of the Royal College of Anaesthetists, n.d.)**.** While these medications can offer short-term relief and support the management of comorbid symptoms, there is growing appreciation that a clinical-first, pharmaceutical-heavy approach is insufficient for the long-term multidimensional nature of CP (Alenezi et al., 2021b). Evidence suggests that pharmacological interventions alone rarely produce sustained improvements in quality of life and may inadvertently reinforce expectations that pain should be eliminated rather than managed (Gill et al., 2022).

The limitations of a medication-led model is illustrated by the rise in opioid prescribing in the UK. Despite limited evidence supporting the long-term effectiveness of opioids for CP, rates of prescription more than doubled between 1998 and 2018 in England (Curtis et al., 2019; Shipton et al., 2018). There are over 20 different types of opioids that are currently authorised for use in the treatment of pain in the UK and in 2017-2018 approximately 13% of the population were dispensed an opioid prescription (Medicines and Healthcare Products Regulatory Agency, 2020; Public Health England, 2020). This escalation has contributed to what is now widely described as the UK's opioid epidemic, characterised by rising opioid-related harms and deaths (Alenezi et al., 2021a; Jani et al., 2020). Qualitative studies further highlight the real-life consequences of opioid prescriptions, with individuals reporting sedation, cognitive impairment, emotional blunting, self-neglect, and dependency concerns (Frank et al., 2016; Quinlan et al., 2021). Many also describe feeling under-informed about the risks and addictive potential of prescribed medications, expressing a desire for clearer guidance from clinicians to support informed decision-making about their own healthcare (Kinnaird et al., 2019). Lived experience perspectives expressed through the reviewed literature favoured a holistic approach to pain management, with many individuals highlighting meaningfully improved wellbeing after tapering opioids, with pain severity remaining unchanged, suggesting that medication and pain severity may not be the primary determinants of quality of life (Frank et al., 2016; McPherson et al., 2018).

Within a biopsychosocial model of care, biomedical and pharmacological interventions do retain an important but proportionate role, however, and should not be completely ruled out (National Institute for Health and Care Excellence, 2021; Shaheed et al., 2020). Medication can support individuals to stabilise symptoms, engage in rehabilitation, or manage acute exacerbations, but it is most effective when embedded within a coordinated multidisciplinary approach rather than positioned as the primary or default response to CP (National Institute for Health and Care Excellence, 2021; Turk et al., 2011). A considered use of medication helps prevent the dominance of a biomedical model and reduces the risk of long-term dependence on prescriptions or unnecessary continuation of medication (Bonezzi et al., 2020). Framed in this way, pharmacological treatment becomes one component of a broader therapeutic approach and supports psychological, social, and behavioural interventions.

As CP is experienced within the physical body, biologically-focused therapies also encompass movement as treatment. Physiotherapy is predominantly used within clinical settings and forms a core part of multidisciplinary CP care and management (Geneen et al., 2017). This approach helps

individuals to rebuild confidence in movement and restore functional capacity that might have been impacted by the pain. Physiotherapy and physical therapy interventions focus on gradual steps towards exploring movement safely, and expanding tolerance and capabilities. Movement interventions align with a biopsychosocial approach to pain management, and also with lived experience accounts that emphasise the importance of reclaiming agency and recultivating meaningful and sustainable forms of movement (André & Lundberg, 2022). Whilst physiotherapists are trained to approach their work through the biopsychosocial model, it is worth noting that qualitative accounts from these professionals show current gaps in skills and confidence when it comes to the psychological side of multidisciplinary interventions (Synnott et al., 2015). Therefore, it is important to upskill and either approach physiotherapy with a psychological lens, or work within a multidisciplinary team with specific specialities in order to provide truly well-rounded and impactful physical interventions that fit into the biopsychosocial model (Poolman et al., 2024; Wilson et al., 2017).

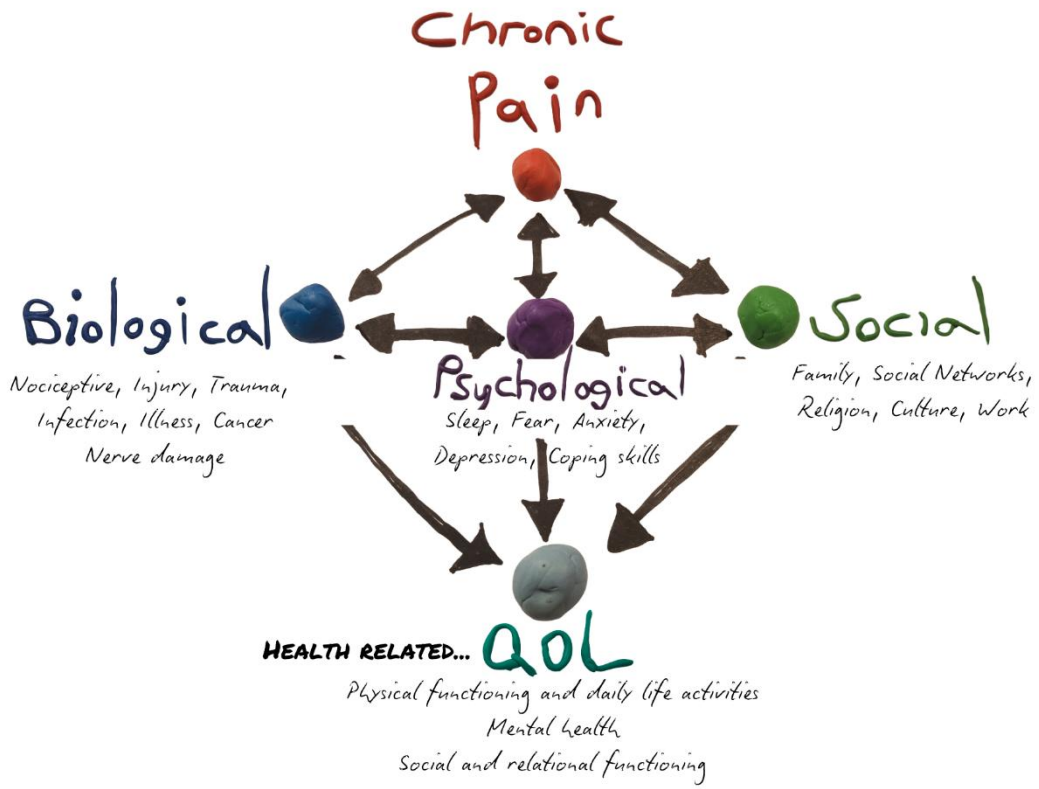
Living with Chronic Pain: Biopsychosocial Considerations

Clinical definitions and theories of CP, alongside prevalence data, outline the scale of the condition and provide a shared diagnostic language (Barke et al., 2022; Zimmer et al., 2022). These definitions are constructed predominantly through biomedical, scientific, and academic lenses, and while they may describe the mechanisms and processes of pain which can be objectively observed, they offer limited insight into the realities of how CP is negotiated and experienced in everyday life by a person (Aldrich & Eccleston, 2000). To understand CP as a lived phenomenon, it is essential to consider how people with CP themselves describe what it is, what it feels like, and how it shapes their sense of self, relationships, and daily routines. Qualitative studies consistently show that people with CP define it not as a collection of symptoms which can be categorised, but as an ongoing and disruptive presence that reshapes daily life and identity (Harasymchuk et al., 2024). These experiential accounts highlight dimensions of *living with* CP that are largely absent from dominant biomedical definitions and frameworks, revealing the complexities of living with the condition. Crucially for this present study, these personal accounts help to foreground the embodied nature of CP – how it is felt and moved with. People often describe pain as altering their bodily capabilities and how they are able to engage with their environments (Engman, 2019). Movement becomes something that is no longer taken for granted but is negotiated, paced, sometimes feared and carefully cultivated (Lundberg & Bullington, 2007). This embodied dimension is central to living with CP and managing its effects on one's daily life, including agency and the confidence of what one's body can or cannot do.

Understanding CP through a biopsychosocial lens requires attending to the intertwining embodied, psychological and social dimensions which shape people's experiences. Figure 3 visualises a biopsychosocial model of CP, highlighting interacting elements that demonstrate the intersections of a person's day-to-day life while managing and coping with persistent pain. The following section uses the studies conducted by Keen et al. (2021), Westergården et al. (2021), Kugelmann (1999), Igwesi-Chidobe et al. (2017), Campbell & Cramb (2008) and Voorhees (2023), alongside other relevant literature, to invite a closer look at these dimensions. They are used to highlight CP as not only a physical health condition but as an ongoing, relational, and embodied experience shaped by meaning, context, and the body and mind's interactions with the world.

Figure 3:

Biopsychosocial model of pain and consequences on the quality of life



Note. Reproduced by lead researcher, Emily Martin-Ball, from (Dueñas et al., 2016). Materials used include modelling clay and marker pen and the image has been edited using Adobe Express and Canva.

Psychological

Psychological processes play a central role in how CP is perceived, interpreted, experienced, and therefore managed. Research demonstrates that the experience of living with persistent pain is closely intertwined with catastrophising, fear-avoidance, depression, anxiety, and low self-efficacy (Miller & Kaiser, 2018). This is reiterated through qualitative studies where individuals reinforce that experiencing CP is overwhelming, depressing, burdensome, isolating, and despairing (Campbell & Cramb, 2008; Igwesi-Chidobe et al., 2017; Keen et al., 2021; Kugelmann, 1999; Voorhees, 2023; Westergården et al., 2021). These processes often cut across diagnostic categories and frequently co-occur, forming mutually reinforcing cycles that intensify pain and disability (Linton et al., 2018). Rather than being symptomatic to a biological condition, these psychological patterns actively shape the *meaning* of pain, the attention drawn toward it, and the behavioural responses that follow (Bunzli, Smith, Schütze, et al., 2015; Eccleston & Crombez, 2007). They influence how individuals interpret bodily sensations, anticipate future pain, and navigate daily activities.

The emotional experience of communicating CP is particularly significant. Qualitative studies consistently highlight how people living with CP frequently encounter disbelief, minimisation, or dismissal from clinicians, employers, and even family members (Igwesi-Chidobe et al., 2017; Werner & Malterud, 2003; Westergården et al., 2021). Westergården et al. (2021) demonstrate how this lack of acknowledgement and validation can produce profound feelings of bitterness, anger, shame and loneliness, contributing to the emotional burden of living with CP. Experiences of invalidation can erode trust in one's own body and healthcare systems, reinforcing hypervigilance and heightening the perceived threat of pain (Campbell & Cramb, 2008; Keen et al., 2021). Emotional states such as anxiety and depression are not merely consequences of CP, but interact dynamically with pain processing, influencing attention and interpretation.

Identity disruption is another central psychological consequence of living with CP. Voorhee's (2023) study shows how living with persistent pain destabilises multiple frames of identity, challenging individuals' sense of competence, autonomy and ability to live their lives in the way they expect. Pain experiences become entangled with questions of who one is and who one can be. Through the qualitative studies, individuals highlight how they are prevented from fulfilling community's socio-cultural expectations, they feel discomfort around transforming from a care giver to a care receiver, and there is an effect on their ability to carry out household chores and work duties (Igwesi-Chidobe et al., 2017; Voorhees, 2023; Westergården et al., 2021). This identity-level impact can be intensified

when individuals internalise the disbelief they are faced with, leading to self-doubt and contributing to feelings of isolation.

Coping strategies and pain-related beliefs further shape the trajectory of pain. Individuals adopt a wide range of approaches including avoidance, distraction, pacing or active engagement, and these strategies can significantly impact on pain-related disability and quality of life (Campbell & Cramb, 2008; Igwesi-Chidobe et al., 2017; Keen et al., 2021). Avoidance and withdrawal may offer short-term relief but often contribute towards isolation, de-conditioning, and increased fear of movement (Meulders, 2019). In contrast, active engagement, acceptance-based strategies, and recognising strengths can support better functioning and quality of life (Igwesi-Chidobe et al., 2017; Voorhees, 2023). Underpinning these behaviours are beliefs and attitudes about pain: whether it is seen as a sign of illness, a threat to be avoided, or a constant (but manageable) part of life. These beliefs shape behavioural choices and emotional responses, forming a complex, interdependent psychological system that influences how individuals navigate life with CP.

Psychological Therapies

Psychological therapies form a core component of multidisciplinary Pain Management Programmes (PMPs) in the UK and overall approaches to pain management. These PMPs integrate education, physical activity, and psychological interventions aimed at improving function and quality of life (Cole et al., 2021). Psychological interventions aim to support increased self-management, as well as behavioural and cognitive change (Roditi & Robinson, 2011). Pain management programmes (PMPs) within non-residential settings are the primary intervention for individuals living in the UK who have not responded 'well' to pharmacological and specific psychological interventions (Gauntlett-Gilbert & Brook, 2018). These programmes involve interdisciplinary teams working together within a common model, using cognitive behavioural principles to approach best management practice (Cole et al., 2021). Methods to promote behaviour change and well-being including physical activity and education are used, and individuals are encouraged to practise these skills outside of the programme setting – embedding them into their everyday lives. Some other common techniques used include biofeedback, relaxation training, operant behaviour therapy, cognitive-behavioural approaches, and acceptance-based approaches (Roditi & Robinson, 2011). These programmes recognise the importance of person-centred care where management of CP is most beneficial when individualised, rather than protocol-driven (Nijs et al., 2024).

As explored in the previous chapter, fear-avoidance is a leading psychological theory as to how pain persists chronically (Vlaeyen et al., 2016). This model holds a cognitive-behavioural perspective

whereby catastrophic interpretations of pain trigger protective behavioural responses such as avoidance of movement or activity that can have tangible effects on pain sensitivity, thereby reinforcing the very cycle of pain they are aiming to prevent. While contemporary critique of the fear-avoidance model argues for a more nuanced understanding of how fear, avoidance, and pain interact, it maintains support of the suggestion that maladaptive cognitions and behaviours play a central role in pain persistence (Pincus et al., 2010). Cognitive-behavioural therapy (CBT), therefore, has become a commonly used intervention because it directly targets these psychological processes (Yang et al., 2022). Research demonstrates that CBT can reduce catastrophic thinking, disrupt fear-avoidance patterns, and improve pain-related self-efficacy (Darnall, 2019; de Boer et al., 2014; Vergeld et al., 2021; Yang & Chang, 2019; Zautra et al., 2008). Evidence also suggests that fear-avoidance beliefs may moderate intervention outcomes, with individuals who hold stronger avoidance beliefs benefiting most from CBT-based approaches (Wertli et al., 2014).

While CBT has been shown to be beneficial for reducing pain severity, fear-avoidance, pain-related disability and increasing self-efficacy, there is little known about the longer-term sustainability of these after the intervention has ended (Yang et al., 2022). Further, CBT has been critiqued for its emphasis on symptom reduction and cognitive restructuring, which can inadvertently reinforce the idea that pain-related thoughts must be corrected before meaningful activity can continue (McCracken & Morley, 2014; Vowles & Thompson, 2011). For some individuals, this can reproduce a sense of struggle with internal experiences, and position pain as a problem to be controlled rather than a condition to be lived with (Eccleston & Crombez, 2007; McCracken & Eccleston, 2003). These limitations have contributed to a growing interest in therapeutic approaches that shift the focus from changing thoughts to changing one's relationship with them (Vowles & McCracken, 2010).

Acceptance and Commitment Therapy (ACT) has become increasingly used as an effective psychological approach to coping with CP, and as a suggested improvement on Cognitive-Behaviour Therapy interventions (Feliu-Soler et al., 2018; Hughes et al., 2017). ACT conceptualises *suffering* as arising from attempts to control or avoid pain at the expense of quality of life rather than from the severity of pain sensations themselves (Feliu-Soler et al., 2018; Vowles & McCracken, 2010). Through this therapy approach CP management is conceptualised in terms of psychological flexibility, leading to engagement with valued life activities, and improvements to functioning (Feliu-Soler et al., 2018; Hughes et al., 2017; Vowles & McCracken, 2010). Developing psychological flexibility is further said to allow for individuals to move away from catastrophising thinking and experience a distinction between self and the content of the mind (Scott & McCracken, 2015).

Clinical research, healthcare professionals implementing interventions, and patients receiving treatment have differing perspectives on what measures of success are, therefore it is important to understand the efficacy of any intervention from the patient's perspective as well. When reviewing qualitative literature exploring the use of ACT in CP management, it can be noted that participants often describe ACT supporting a shift in their relationship with pain (Casey et al., 2019; Thompson et al., 2018). This helps to develop individuals' focus towards acceptance and flexibility. An increased engagement in personally meaningful activities is also reported by participants, supported by acknowledging that pain would not be cured (Bendelin et al., 2020). The qualitative literature supports the use of ACT alongside other coping elements, reinforcing that there is no *silver bullet* when supporting people to manage CP (Thompson et al., 2018). It is also highlighted in Casey et al.s' (2019) study that while an acceptance of pain correlates with enhanced fulfilment of life, not all participants in ACT believe that it is possible to *accept* CP. Attitudes towards finding a cure for CP, self-efficacy, and perceived injustice contributed towards these perceptions of acceptance (Casey et al., 2019).

Compassion-based approaches have started to gain attention as another psychological intervention within CP management spaces (Gooding et al., 2020). Informed by evolutionary models, these approaches emphasise the interconnection between mind and body, and align closely with holistic and biopsychosocial understandings of pain (Malpus et al., 2023; Penlington, 2019). Through this lens, shame, self-criticism, and emotional distress are understood as central components contributing to the suffering associated with persistent pain (Smith & Osborn, 2007). Many individuals with CP describe harsh self-judgement linked to productivity, perceived burden, and fears of being disbelieved, which can be enacted through hypervigilance, in turn exacerbating psychological distress (Malpus et al., 2023; Smith & Osborn, 2007). Compassion-focused approaches aim to counter these processes by cultivating kindness toward the self, as well as emotional validation and safety, which encourages individuals to respond to pain with care rather than self-discipline or resistance (Gilbert, 2009, 2014). From a psychological perspective, compassion may facilitate emotional regulation, reduce threat-based responses, and enable more flexible and sustained engagement in social and daily life despite ongoing pain.

Self-compassion is particularly relevant in the context of managing CP because it does not rely on comparison with others or evaluating oneself against a normative criteria. Instead, it involves practices such as reappraisal and a soothing, supportive inner dialogue that fosters a sense of self-

worth independent of achievement or perceived productivity (Gilbert, 2014). This approach to coping is especially important for people living with CP, who often experience disruptions to valued roles and identities, and may internalise negative social messages about capability or legitimacy (Smith & Osborn, 2007). Emerging evidence suggests that compassion-based interventions can meaningfully shift these patterns (Penlington, 2019). In a recent service evaluation, participants identified as 'strivers' – individuals who tend to cope by pushing through or ignoring pain – responded positively to a compassion-focused group programme, showing reductions in depression and anxiety severity, decreased pain-related disability, and improvements in self-efficacy (Malpus et al., 2023). These findings indicate that compassion-based approaches may offer a valuable psychological resource for individuals navigating their lives with CP.

Social

The social dimensions of CP have a marked impact on how individuals are able to navigate daily life, and understand themselves in relation to others. Social isolation emerges consistently across the literature as a central feature of the CP experience (Campbell & Cramb, 2008; Christidis et al., 2025; Igwesi-Chidobe et al., 2017; Kugelmann, 1999). Because CP is largely invisible and consistently inconstant, individuals often struggle to articulate their needs or have their experiences validated, leading to a sense of disconnection and gradual withdrawal. When navigating CP, many individuals withdrew themselves from social situations due to inability to do the things they used to be able to (Campbell & Cramb, 2008; Voorhees, 2023). The invisibility of pain can erode a person's sense of belonging and disrupt participation in the shared rhythms of daily life.

Isolation is further reinforced by the practical implications of constraints imposed by CP. Fluctuating symptoms, fatigue, and reduced mobility can limit participation in work, leisure, family, and community activities (Kugelmann, 1999; Voorhees, 2023). These disruptions impact individuals' ability to maintain social roles and relationships, with the significant consequences for their sense of identity, as discussed previously. Research shows that people often describe a shift from being perceived as capable, reliable or independent, to being seen as burdensome and unpredictable (Voorhees, 2023). Such shifts destabilise multiple layers of identity simultaneously, including one's sense of competence, social worth, and relational positioning.

The social meaning and enactment of CP is also shaped by broader institutional and structural contexts. As Kugelmann (1999) notes, pain discourse is not only medical but also legal and financial. For many, CP becomes entangled with systems such as a workplace reasonable adjustments,

disability assessments, and welfare support (Blake et al., 2025). These systems often require individuals to repeatedly justify or evidence their pain, creating additional layers of employment-related stress and vulnerability (Adams & Salomons, 2021; Wainwright et al., 2013; Wynne-Jones et al., 2011). The ambiguity of pain does not fit easily into these often bureaucratic contexts, contributing to the ongoing stress and burden of illness which individuals living with CP experience.

Interactions with healthcare systems and relationships within this structure also play a significant role in shaping social experiences. Many people with CP report feeling dismissed, disbelieved, or inadequately supported by clinicians, which can deepen feelings of marginalisation and reinforce the sense that their experiences are not recognised or valued (Campbell & Cramb, 2008; Koesling & Bozzaro, 2021; Liddiard et al., 2023). For those whose experiences of pain intersect with socioeconomic disadvantage, gendered expectations, racialised experiences, or other forms of marginalisation like those connected to ageism, these challenges are often amplified (Anderson et al., 2009; Bartley & Fillingim, 2013; Davies et al., 2009; Nicholl et al., 2015; Shetty et al., 2025; Zimmer et al., 2022). Structural enactment or inequalities can limit access to appropriate care, meaningful employment, housing, and social support (Igwesi-Chidobe et al., 2017; Kugelmann, 1999). This further entrenches experiences of isolation and inequalities, reducing opportunities for meaningful participation in social and relational life. Taken together, these social dimensions demonstrate that CP is not experienced in isolation from the social world but is continually shaped by relationships, expectations, and structural conditions. CP reshapes identity and social positioning, influencing how individuals see themselves and how they are seen by others (and systems) (Voorhees, 2023). Understanding the experience of living with CP, therefore, requires attention to not just the biological and psychological processes but also the social environments and power structures which shape the lived experience of CP.

A biopsychosocial approach has implications for how pain management approaches are offered and delivered to people living with CP (Gervais-Hupé et al., 2023; Hulla et al., 2019). Qualitative research highlights that effective coping and pain management is not exclusively shaped by a decrease in symptom severity, but by individuals' feelings of maintaining agency and autonomy, their sense of identity, emotional safety, and access to support (Blomqvist & Edberg, 2002; Budge et al., 2012; Crowe et al., 2017). I take a moment to invite you to engage in your own way with Invitation Two.

Invitation Two: A biopsychosocial (and more) approach

ZINE PROMPT: What are the different ways people manage their pain – biological, psychological, social, relational, creative?

Reflect on your own strategies, however small or seemingly 'normal'. Notice whether your responses feel siloed and stable, or intermingled and fluctuating.

Social support - The Chronic Pain Community

Social support functions as a core component of a biopsychosocial approach to managing CP, whether this be provided through clinical relationships, or by communities and close personal relationships (Gong et al., 2024; McCracken, 2005; Tse et al., 2020). As explored in the previous chapter, managing and living with CP is not an individualised experience and is deeply embedded within social relationships, expectations, and cultural contexts. There is currently little consensus on concepts of what *social support* actually is, making it difficult to review tools which may or may not be embedded into PMPs (Gong et al., 2024). In their review, however, Gong et al. (2024) identified some leading concepts including three fundamental levels of informational, instrumental, and emotional support. What consistently emerges is that social support is a protective factor that can buffer distress, enhance self-efficacy, and improve engagement with self-management practices (Gong et al., 2024). Supportive relationships provide emotional validation and practical assistance, which can counteract the isolation and identity disruption which commonly occurs when living with CP. However, relationships also have the ability to complicate coping with studies showing that solicitous responses, such as excessive attention to pain behaviours, may inadvertently reinforce disability, while punishing or dismissive responses can heighten distress, shame, and avoidance (McCracken, 2005). The quality of social interactions therefore plays a crucial role in shaping whether individuals feel empowered or undermined in their efforts to live and move with pain. Significant others also have an influence on self-management of pain with qualitative studies demonstrating that partners, family, and close friends can either facilitate engagement with pain management strategies, or create barriers through scepticism, overprotection, or conflicting responsibilities (Brown & Newton-John, 2023). These findings help to reinforce the role of social relationships within the biopsychosocial model of pain, highlighting that CP is not experienced or managed in isolation (Ghio & Peters, 2024).

Whilst approaches to CP care are often framed as 'self-management', it is suggested that people living with the condition benefit from connection with others who share similar experiences (Arnott et al., 2023). Studies consistently highlight the importance of being believed and validated by others within the CP experience – forms of recognition that are not always available in the clinical environment or from friends and family who have not lived with CP themselves (Liddiard et al., 2023; Matthias et al., 2016; Tosas, 2021). Peer support groups, whether informal or formally organised, can offer a unique relational space in which experiential knowledge is shared and identities are affirmed (Farr et al., 2021). Efficacy studies support the use of peer-support interventions, with promising and significant impact on quality of life being demonstrated, particularly connected to psychological outcomes, self-efficacy, perceived pain severity, and participants' confidence in actively managing their pain (Matthias et al., 2015; Tse et al., 2020).

Despite their relevance and potential, research into peer-support groups for CP management remains limited (Arnott et al., 2023; Matthias et al., 2016). The limited number of studies that do explore these groups in depth demonstrate the strong value they hold for participants, and the potential for them to be a sustainable element within PMPs (Farr et al., 2021; Khodneva et al., 2021; Matthias et al., 2016; Stenberg et al., 2022). Peer groups are able to provide continuity after completing clinician-managed PMPs, helping individuals sustain self-management practices that often are less adhered to after formal support ends (Farr et al., 2021). People described these groups as spaces of mutual understanding, where they did not need to justify or explain their pain, and where shared meaning-making helped to normalise experiences that had previously felt isolating (Matthias et al., 2016). The groups also enabled sharing of coping techniques and helping each other feel able to master tasks and skills through trusted sources of experiential knowledge (Stenberg et al., 2022). Vitally, these groups can reduce isolation and foster a sense of belonging, which may buffer against emotional distress even when pain persists. Supportive social relationships therefore function as key psychosocial coping resources, reinforcing the view that CP management is relational as well as psychological and physical.

Sources of social support in CP research have traditionally been examined through family, friendship, and workplace connections. However, healthcare professionals (HCPs) are not only clinical experts, but also make up part of the community, or social world, through which CP is interpreted and managed (Fu et al., 2016). Emerging research demonstrates that interactions with HCPs shape how individuals understand their symptoms and make decisions about management approaches which

can also have psychological and behavioural consequences (Bergman et al., 2013; Franklin et al., 2018; Frantsve & Kerns, 2007). For example, studies show that patient-provider communication influences levels of fear, hope, trust, and perceived legitimacy, all of which affect engagement with self-management and adherence to guidance (Jonsdottir et al., 2016; Teh et al., 2009). When communication is dismissive, rushed, or over biomedical, patients report feeling "treated as a number, not treated as a person", which can heighten distress and undermine confidence (Hadi et al., 2017). Conversely, relational and validating communication from HCPs can strengthen agency and foster emotional safety (Jonsdottir et al., 2016; Matthias & Bair, 2010).

This relational approach positions HCPs as key social actors within the biopsychosocial model who are capable of reinforcing safety and agency or conversely amplifying threat and doubt (Kennedy et al., 2024). Multidisciplinary teams are made up of multiple HCPs, which can include nurses, physiotherapists, psychologists, pharmacists and doctors who all play a role in the successful implementation of CP management strategies (Scottish Government, n.d). The relational approach of these professionals can support adherence to management plans, as well as act as a barrier (Fox & Chesla, 2008; Hadi et al., 2017). Evidence from qualitative research shows that collaborative, person-centred partnerships between patients and professionals enhance engagement with self-management (Fu et al., 2016). This demonstrates that social support for people living with CP extends beyond personal relationships and networks to include the relational dynamics of healthcare encounters, which can profoundly shape how individuals manage and live with their pain.

Embodiment - Movement and Chronic Pain

Invitation Three: Getting into the body

ZINE PROMPT: As you read about embodiment and movement, pause and check in with your own body. What sensations are present? How would you like to move your body?

Take a line for a walk across the page. Let your pen wander.

Do your marks reflect your own sensations, or do they echo the experiences described in the text? Or neither?

It is important to recognise that social and psychological processes and behaviours are lived out *through the body*. Bringing the thesis back to the physiological aspects of CP is not to re-medicalise the experience, but to foreground that pain is an embodied phenomenon (Bullington, 2009; Tabor et al., 2017). CP alters the experience of the body within the world, including the perceived possibilities for movement and the body's relationship with space, meaning individuals must negotiate decisions daily about movement and activities (Honkasalo, 1998). Movement becomes a site where physical sensation, psychological meaning, and social expectations intersect, and where individuals navigate identity disruptions, pain-management plans, and family or work obligations with bodies that feel unpredictable and limited. This embodied complexity underpins the need to consider movement as a central component to CP management. Understanding how people inhabit, make sense of, and move with their pain forms a crucial foundation for exploring the role of movement-based practices and embodied coping strategies in everyday life with CP.

Physical activity is widely recommended as a core component of CP management across UK clinical guidelines and multidisciplinary pain services, supported by substantial evidence demonstrating reductions in pain severity and improvements in quality of life (Cole et al., 2021; Geneen et al., 2017; National Institute for Health and Care Excellence, 2021, April 7). Within PMPs, physical activity is supported through behaviour-change techniques that recognise every-day movements, including household chores, as a meaningful domain of therapeutic process (Cole et al., 2021). Across different diagnoses where CP plays a leading part, no specific type of exercise or physical activity modality has been shown to be superior, but it has been evidenced that some of any movement is better than none (Grooten et al., 2022; Häuser et al., 2010; Tuninetti et al., 2025). This evidence supports flexible, personalised approaches that align movement with individual values and goals (Cole et al., 2021; Nijs et al., 2024). Physical activity interventions connected to CP are therefore increasingly framed in terms of paced and adaptable movement, emphasising function and participation over performance or comparison with normative standards (Geneen et al., 2017). Within clinical and rehabilitation settings, movement is often prescribed in graded or structured forms such as through physiotherapy, and is positioned as a means of restoring bodily function or reducing disability (National Institute for Health and Care Excellence, 2021, April 7). When approached in a de-medicalised and more person-centred way, movement becomes more than exercise or fitness; it becomes a psychologically meaningful process through which individuals renegotiate their relationship with pain and with themselves (Meehan & Carter, 2021).

Chronic pain is known to disrupt individuals' relationships with movement due to fears of exacerbating symptoms or causing harm, leading to avoidance of activity as outlined through the fear-avoidance model explored previously in this thesis (Vlaeyen et al., 2016). The threatening status of movement can complicate its role in pain management, and CP also fundamentally alters individuals' relationships with their bodies and, consequently, with movement itself (Crowe et al., 2010). Activities once associated with pleasure or ease may become sites of threat, loss, or frustration (Smith & Osborn, 2007). These disruptions affect everyday activities which underpin a person's ability to enact their identities and social roles as expected (Toye et al., 2013b). Consequently, movement is not a neutral or self-evident coping strategy but one that is emotionally charged (Lundberg & Bullington, 2007). Understanding movement as part of pain coping therefore requires attention not only to physical capacity but also to fear, meaning, and agency.

Qualitative studies indicate that many individuals living with CP experience a loss of trust in their bodies, as the often taken-for-granted rhythms of movement become unpredictable (Honkasalo, 1998; Svenaeus, 2015). Movement becomes an effort, requiring constant decision making and monitoring (Bullington, 2009; Smith & Osborn, 2007). In this context, generic messaging from HCPs or public health campaigns to 'be more active' may feel invalidating or overwhelming, particularly when it fails to acknowledge the embodied uncertainty and identity disruption which accompanies CP. Researchers and clinicians have therefore increasingly emphasised the distinction between exercise as a clinical prescription, and movement as embodied coping and a lived and meaningful experience (Nijs et al., 2024; Piggin, 2020; Rosenfeld & Faircloth, 2004). When approached in ways that emphasise choice, pacing, and personal meaning, movement may support acceptance, self-compassion, and re-engagement with valued aspects of life (McCracken & Morley, 2014). Engaging in physical activity and movement can provide opportunities for individuals to enact self-compassion and values-based living in practice and cultivate renewed trust in their bodies, whether through gentle, creative, or socially connected forms of movement (Damsgård et al., 2011).

Finally, when examining CP management approaches, it is important to recognise that individuals are often viewed primarily through a medicalised, patient-centred lens. Even holistic and multidisciplinary interventions occur within systems that label people as patients or participants, shaping how they understand and inhabit their bodies (Bullington, 2009). Bullington (2009) argues that CP "ruptures the natural connection between body and world," (p.100) producing alienation and identity loss. Re-connecting with movement, and enabling bodies to participate in desired activities, can therefore support identity reconstruction and re-establish connections with the

material and social world (Rosenfeld & Faircloth, 2004). Movement, in this sense, becomes not only a therapeutic tool but a means of re-inhabiting the body and reclaiming agency within everyday life.

Defining Meaningful Movement

Movement, as demonstrated through research and lived experience, is far more than simple physical exertion or clinical treatment (Piggin, 2020). Within the context of CP, movement is an embodied negotiation with the potential to aid in identity reconstruction, fear-reduction, quality of life, and supporting relationships with pain itself. What matters extends past the basic act of being physically active, into *why* people with CP move and *what movement comes to mean* within their everyday lives. This recognition helps to create the conceptual foundation for exploring **meaningful movement** within this thesis. Throughout this thesis, meaningful movement refers to any autonomous bodily or mental action that is intentional and interrelated with the lived experience of CP and therefore the physical world and social environment. This conceptualisation is, in part, informed by Piggin's (2020) holistic definition of physical activity which refers to 'people moving, acting and performing within culturally specific spaces and contexts, and influenced by a unique array of interests, emotions, ideas, instructions and relationships' (p. 72). Such a definition helps to disrupt dominant reductionist framings of movement that treat movement as a measurable output within research and health messaging, rather than a relational and meaning-laden experience.

For individuals living with CP, engaging in meaningful activities often requires engaging with movement despite uncertainty or discomfort. Movement becomes a key site where psychological coping processes such as acceptance, pacing, or self-compassion are translated into embodied practice. It is through movement that individuals test the boundaries of safety, rebuild trust in their bodies, and re-establish a sense of identity and agency. Bodies in movement are central to how we experience the physical and social worlds; perception, cognition, and action are deeply intertwined (Borghi & Cimatti, 2010; Harris et al., 2015). The ability to initiate movement independently is widely regarded as fundamental to human agency and to the experience of meaningful life. Movement is also a form of empowerment and is one of the primary ways we interact with our environments, manipulate objects, and effect change. Myers (2017) argue that humans are drawn to movement and meaning from birth, driven by curiosity and desire to explore, make sense of, and engage in the world. Despite its intuitive resonance, the concept of meaningful movement has received limited academic attention. A systematic search of *Discover, Google Scholar, Scopus, and PubMed* revealed no studies explicitly investigating "meaningful movement" in the context of CP. Existing literature tends to focus on adjacent constructs such as functional movement, movement-related behaviours,

or exercise adherence, which often prioritise biomedical or performance-based outcomes (Geneen et al., 2017; Leese et al., 2024). One example of the few exceptions is Lundberg & Bullington (2007), who found that patients with CP described 'meaningful movement' at the intersection of identity, changing bodily experience, adaptive self-management, and social validation.

The absence of a robust evidence base reflects a broader pattern in research and clinical implementations, which privileges biomedical and behavioural framings over experiential and embodied understandings. As the next section of this thesis argues, this gap is not merely conceptual but epistemological. It raises questions about whose knowledge counts, whose language shapes practice, and whose experiences are legitimised in the production of CP knowledge. Defining meaningful movement, therefore, is not only an analytic task but also a sociopolitical one; it invites an opportunity to democratise ways of knowing and to centre the expertise of those who live with persistent pain.

Chapter Three: Ways of Knowing

Understanding chronic pain (CP) and meaningful movement requires careful consideration of not only what is known, but also *how* knowledge is produced and legitimised. In critical health psychology, questions of knowledge are not neutral but are shaped by underlying assumptions about whose perspectives are valued and how reality is understood (Lyons & Chamberlain, 2017). For those living with CP, their experiences frequently exceed the limits of language, disrupting conventional ways of describing and communicating what is known (Munday et al., 2021; Tosas, 2021). Consequently, traditional positivist approaches to understanding CP have been limited in their ability to interrogate the often messy realities of living with the condition. In order to really understand the embodied experiences of living with CP, we must turn to paradigms which have capacity to capture the meaning-laden nature of it.

This chapter outlines the research paradigm underpinning the study and explains how a constructivist worldview shaped the design, implementation, and interpretation of the research. Constructivism, with its emphasis on multiple realities, co-created meaning, and the situated nature of knowledge, provides the philosophical foundation for the methodological choices made (Crotty, 2020). Within this paradigm, arts-based methodology informed by participatory tenets, alongside reflexive thematic analysis, were used to support co-researchers in articulating and sharing their experiences of meaningful movement while living in CP. These creative and analytic tools also enabled me, as the author, to interpret and present these experiences within the thesis. These approaches were selected for their capacity to surface embodied, emotional, and tacit forms of knowledge that may be difficult to access through more conventional qualitative and quantitative methods (Chamberlain et al., 2018; Harasymchuk et al., 2024; Margolin et al., 2024). They also align with this study's intention to recognise and validate the expertise held by people with CP, enabling their insights to guide both the process and the outcomes of the research.

Ontological and Epistemological Assumptions

This study is situated within the constructivist paradigm, which assumes that reality is layered, intermittent, subjective, and co-constructed through social interaction, interpretation, and experiences (Crotty, 2020; Olsen & Pilson, 2022; Schwandt, 1994). Constructivism is particularly well suited to the study of CP, given that pain cannot be directly accessed or verified independent of the individual experiencing it. Individuals living with CP are continually making sense of their experiences

in relation to prior knowledge, expectations, cultural narratives, and social interactions (Aldrich & Eccleston, 2000; Clur & Barnard, 2025). The constructivist paradigm suggests that knowledge is created through the meanings individuals assign to their worlds and are crucially shaped by their histories, social and cultural contexts, relationships, and embodied experiences (Chapman & Nakamura, 1999; Olsen & Pilson, 2022). Based on a relativist ontology, this world-view and philosophical stance of what knowledge is, and how it comes to be formed, aligns closely with the purpose of this present study. The study seeks to explore and co-construct understandings and narratives through a paradigm which steps away from ingrained neoliberal dominance of individualism and traditional health-related power structures which often purport a single determinable 'truth' (Allen, 1994; Lyons & Chamberlain, 2017; Rogers, 1996). Constructivist approaches can help move understandings of chronic health experiences beyond passive awareness and towards active tools for resisting discrimination (Olsen & Pilson, 2022). I aim to explore how people living with CP understand and articulate meaningful movement, and to position their subjective and relational experiences and interpretations as legitimate forms of valued knowledge.

Constructivist research emphasises the co-creation of meaning between researchers and 'participants', believing that all knowledge is produced through interaction and interpretation (Crotty, 2020; De Oliveira, 2024). This approach rejects traditional ideas of an objective truth and knowledge being held and produced by researchers independently (Murray & Chamberlain, 1998). This subjective way of viewing the world and knowledge-construction is particularly relevant for the present research, which intends to amplify the voices of lived experience and position them as knowledge holders in direct contradiction to dominant biomedical framings (Liddiard et al., 2023; Wallerstein & Duran, 2006). By adopting a constructivist worldview, the study recognises 'participants' as 'co-researchers' and values their accounts of movement and CP as not simply data to be extracted, but narratives and relational embodied knowledge.

This paradigm also aligns with my commitment as a researcher to participant leadership and empowerment - enacted in part through recognising involved individuals as *co-researchers.* Constructivism supports this endeavour by foregrounding the importance of agency, and relational knowledge production, making it well suited to participatory and arts-based approaches, which will be discussed next, that seek to democratise research processes (De Oliveira, 2024). Within this framework, co-researchers are understood not as subjects of study but as co-producers and collaborators whose insights actively shape direction and interpretation of research. This ultimately assists in challenging traditional hierarchies of knowledge whereby academic and clinical voices are

typically privileged over participants and patients. If you wish to, follow the zine prompt in invitation four, and reflect on who is given *the power to know* before continuing to read this chapter.

Invitation Four: The power of knowledge

ZINE PROMPT: If you are still with me, start a new page.

Take a moment to think about who is given the power to *know*? Whose knowledge is legitimised, and whose is dismissed? Add words, shapes, or marks to represent everyday knowledge – how can this be valued on an even playing field within academic, clinical, and political spaces?

Notice if your marks change according to the knowledge production you're considering?

Arts-based Research

Arts-based research (ABR) was employed as the primary mode of inquiry in this present study. ABR is not only a methodological choice but also a philosophical one as it offers a way of engaging with embodied and experiential forms of knowledge, extending beyond language and rational explanation (Bird, 2022; Eliasson et al., 2025; Harasymchuk et al., 2024). ABR aligns closely with the constructivist paradigm outlined above, which assumes that knowledge is embodied, relational, and constructed through experience rather than discovered as an objective truth. Research within (mainstream) psychology has predominantly focused on empirical approaches (Roberts & Castell, 2016). ABR challenges these epistemic hierarchies and conventional research binaries between qualitative and quantitative by enabling creative, sensory, and affective ways of knowing to be articulated (Boyd & Barry, 2024). It assumes an ontology in which knowledge is produced through engagement with materials, images, metaphors, and embodied practices, and an epistemology that recognises meaning as multiple, situated, and co-constructed (Margolin et al., 2024).

Arts-based inquiry can be considered a research practice when it is used to generate new knowledge, rather than simply illustrate existing scientific ideas (Bird, 2022; Leavy, 2020). Much like qualitative and quantitative research approaches, ABR offers a distinctive lens through which to explore the human experience. It does not replace other methods, but compliments them, allowing

researchers to ask different questions and/or access different forms of understanding and articulation. Arts based research also helps to question dominant assumptions about what counts as legitimate knowledge. By resisting the expectation that knowledge must be universal, measurable, or detached to be valid, ABR disrupts epistemologies that have historically served individualistic, neoliberal, and capitalist priorities (Margolin et al., 2024; Sonn & Baker, 2016). Creative practice becomes a form of inquiry in its own right - generating, exploring, and communicating knowledge – rather than merely illustrating pre-existing findings (Leavy, 2020). Through creative processes such as drawing, collage, photography, and storytelling, co-researchers can express meaning visually, verbally, symbolically, and metaphorically, surfacing tacit forms of knowledge that may be difficult to articulate through more conventional methods (Baker & Wang, 2006; Fraser & al Sayah, 2011; Larsen et al., 2018). This approach aligns with constructivist assumptions that knowledge is diverse and deeply personal, and shaped by social, cultural, and political contexts. It positions co-researchers as experts in their own lived experiences and argues they should have appropriate platforms to enshrine this.

Crucially, ABR shifts the research process away from data *extraction*, and toward *co-creation*. Although situated within qualitative inquiry, ABR differs from traditional methods by approaching knowledge production through creative making, rather than the extraction of data from subjects (Bird, 2022). The aim is not to make art *about* research data, nor to provide therapeutic intervention, but to use artistic practice and creativity *as* research. Through creative engagement, co-researchers generate insights, and surface tacit understandings that otherwise remain unspoken or inaccessible – particularly within the academic and clinical discourses (Leavy, 2020). Because ABR centres co-researchers as active agents in knowledge production rather than as passive subjects of study, it has the potential to redistribute power within traditional research dynamics (Cheryl et al., 2025). This redistribution of agency is particularly important in CP research, where individuals often experience systematic injustice, disbelief, and marginalisation within clinical and institutional settings (Buchman et al., 2017; Côte, 2026; Newton et al., 2013). ABR creates space for contradictions, non-linear experiences, and complexities of CP to be expressed in ways that conventional methods often constrain. Additionally, creative methods can amplify the scope and quality of knowledge explored, enabling individuals living with CP to express aspects of their experiences such as identity, that are not easily verbalised (Murray & Gray, 2008). ABR supports expression and agency, empowering co-researchers to articulate their experiences on their own terms (Estrella & Forinash, 2007). In doing so, it contributes to the broader reimagining of whose knowledge counts and how it is produced. ABR enhances research dissemination and often produces

ready-to-share creative artefacts of knowledge (Murray & Gray, 2008). This can be particularly important when reflecting on different cultural understandings of pain. It is important to keep in mind the conflicting history of research when approaching studies which gather and grow knowledge about non-Western communities, particularly when situated within a Western context (Reid et al., 2019). For example, indigenous communities such as Māori have traditionally been subjected to research rather than involved in it, which does not support empowerment and social justice (Hammond et al., 2018). Arts-based research can offer opportunities to work with communities and produce/present knowledge in a way which is decolonising and democratising (Gray & Coates, 2010).

Zines and Research

Zines (pronounced *zeen*, as in *magazine*) resist being pigeonholed into a definitive box and cannot be universally described (Todd & Watson, 2006). They are non-commercial, self-published booklets created through a do-it-yourself ethos for the purposes of sharing personal and political narratives, community building and creative expression (French & Curd, 2022; Piepmeier, 2008; Spandler et al., 2026). Any number of artistic practices can be employed to create a zine, communicating what the makers wish to communicate, in the way they wish to tell their story. Emerging in the 1930s as a self-created outlet for subcultures and gaining traction and influence during the civil rights movement in the 1970s and the punk scene – including feminist punk movement, Riot Grrrl – zines have frequently amplified underheard voices and supported social justice activism (Comstock, 2001; Duncombe, 2017; Matich et al., 2024). While zine cultures are not free from issues of representation, they remain a significant medium for amplifying marginalised perspectives and enabling agency over narrative construction (Ramdarshan Bold, 2017).

Zines have increasingly been a subject of, or used in, research practice as part of ABR approaches as well as within feminist, disability, health and educational paradigms (Ashtari et al., 2022; Creasap, 2014; French & Curd, 2022; Lupton, 2022). They have been used as a means of public engagement or a creative way to disseminate findings, as well as a part of research design (Clark et al., 2026; French & Curd, 2022; Spandler et al., 2026; Way, 2024). Despite this methodology expansion, there remains limited literature on the practicalities of using zines in research practice. Critique also cautions that the introduction of zines into the academic arena risks reducing zines to *outputs* if their ethos is not upheld (Jones, 2024).

Zines disrupt traditional hierarchies of knowledge production by giving everybody a chance to become a creator (Damon et al., 2022). As the medium exists outside of the mainstream, there are no pre-existing rules or expectations of what can be in a zine, allowing for literal blank pages to be filled with multimodal creative narratives. Rather than requiring co-researchers to translate their experience into academic or clinical language, zines allow knowledge to emerge in forms that are meaningful to those creating them (Parsons et al., 2026; Way, 2024). They also reduce the reliance on researcher interpretations when communicating knowledge, further shifting traditional power dynamics within academia. The methodology also aligns with decolonialising praxis due to the creative agency it enables, allowing space for knowledge creation outside of the superimposed borders of coloniality, neoliberalism, and other systems of oppression (Denscombe, 2025; Liu et al., 2025; Parsons et al., 2026). Zine production practices intentionally and actively reject neoliberal and capitalist logics of commodification, favouring more democratic and community-orientated modes of knowledge sharing (Atton, 2002; Duncombe, 2017; Jones, 2024). This redistribution of epistemic authority is an important tool for this present study, which aims to do research in a way that democratises knowledge and empowers co-researchers to say what they want to say, the way they want to say it.

In addition to knowledge creation, zines also help to democratise dissemination and extend this beyond academic audiences (Campbell & Clark, 2023; Gameiro et al., 2018; Valli, 2021). Their low-cost, accessible, and often open-circulation format allows for experiences to be shared, connecting individuals who may feel isolated or stigmatised (Baker & Cantillon, 2022; Duncombe, 2017; Spandler et al., 2026). Zines create alternative media spaces that can convey the realities of marginalised communities and foster connection, solidarity, and empowerment (Atton, 2002; Leteurtre et al., 2023). While zines reflect the situated perspectives of their makers, this subjectivity is a strength rather than a limitation for this present study as it aligns with my commitment to valuing context-dependent, experiential, and co-produced forms of knowing.

Tenets of Participatory Action

This research is further informed and guided by the principles of participatory action research (PAR) including values of equitable participation, social transformation and reflexivity (McGrath et al., 2025). This approach seeks to centre the knowledge, agency, and priorities of communities whose experiences are often marginalised or rendered invisible within dominant research, academic, and political discourses (De Oliveira, 2024). PAR is grounded in the belief that those who live an experience are best placed to understand it, and what it means for them and their lives

(Fahlberg et al., 2026). PAR establishes that research should be conducted *with* communities rather than *on* them.

In this study, PAR provided a values-based framework, actioned through ABR, for engaging people living with chronic pain as co-researchers, enabling them to reframe, articulate, and share their narratives of meaningful movement on their own terms. I am not claiming that this research fully fits the PAR paradigm, rather that it is informed by the core tenets. A key limitation is that co-researchers were not involved in shaping the initial research design, as the use of ABR and zine-making had already been determined. This departs from authentic PAR approaches, where the line of enquiry is established collaboratively with co-researchers from the outset (Cahill, 2007; Wright et al., 2006). As a result, while co-researchers exercised agency within the creative and interpretive phases of the project, their influence on the broader research process were constrained by the decisions I had made in advance as the lead researcher.

A core tenet of PAR is a commitment to the redistribution of power within research processes (Heard, 2023; Parsons et al., 2026). Traditional research models often position academic knowledge as superior and lived experience as secondary; PAR challenges this hierarchy by recognising experiential knowledge as equally legitimate and necessary for understanding complex social and health issues (Beresford, 2013; Cornwall & Jewkes, 1995; Hills et al., 2007). PAR assumes that knowledge and power are intertwined, and that research has the potential to either reinforce existing inequalities or to challenge them (Fals-Borda, 1987). This study responds to a demonstrated gap in chronic pain research, where the voices of those living with pain are frequently constrained by bio-medical framings. By adopting a participatory approach to ABR, the research aimed to create conditions in which co-researchers could shape the content and interpretation of the inquiry.

Participatory action research (PAR) emphasises *action* as an integral component of research. Knowledge is produced with the intention of contributing to change – whether at the level of individual empowerment, community connection, or broader social understanding (Baum et al., 2006; Cahill, 2007; Lykes, 2013). In this study the creation and dissemination of a co-created zine functions as both a research output and an act of knowledge mobilisation, enabling co-researchers to share their experiences with healthcare professionals, policymakers, and wider audiences. This aligns with PAR's commitment to producing research that is descriptive and transformative (Parsons et al., 2026; Reschiglian & Scarcelli, 2025; Sonn & Baker, 2016).

Rationale for Zines and Participatory Action Research Design

The collaborative zine created in this study served as both a method of data generation and a mode of analysis, allowing co-researchers to externalise, share, and interpret their experiences of meaningful movement. Zines' multimodal and tactile properties welcomed the layering of images, texts, colours, and symbolism which enabled co-researchers to represent and re-imagine their fragmented and non-linear experiences. Creative methods also provided space for intersecting oppressions related to race, class, gender, and disability to surface without forcing them into biomedical or positivist narratives. This approach, importantly, helped to legitimise the co-researchers' lived experiences as knowledge through co-constructed creative practice, rather than being viewed as supplementary or anecdotal. As a method, zine-making supported creative autonomy, invited playfulness, and offered a democratic form of knowledge production that aligns with the participatory ethos of the study. Further, the choice of zine-making specifically aligned with PAR values through anti-commodifying approaches to knowledge. Zines draw on do-it-yourself and social justice traditions that intentionally resist institutional advantage and privileging, and value self-determination, accessibility, and community meaning-making. Their use in this study reflected a research commitment to producing knowledge that is grounded in lived experiences and shared in ways that prioritise connection over consumption.

Zine making is also an inherently embodied practice, requiring cutting, handwriting, and assembling publications which requires connection between the maker and their bodies (Piepmeier, 2008). This embodied dimension made zines particularly well suited to exploring CP and meaningful movement, where bodily experience is central yet often difficult to articulate verbally, particularly within more traditional academic discourses (Munday et al., 2023; Padfield et al., 2015). As a research method used within a participatory arts-based paradigm, zines offered a flexible medium through which co-researchers could maintain agency while exploring and communicating their lived experiences in ways that were meaningful to them as the creators (Baker et al., 2024; Leteurtre et al., 2023; Zhuo, 2024). Their multimodal nature allowed co-researchers to combine visual, textual, and symbolic forms of expression, reflecting the fragmented, layered, and often non-linear qualities of CP. As zines do not require coherence they were able to embrace the representation of contradiction and uncertainty which accompanies the experiences of living with CP. In this way, zines also align closely with constructivist and arts-based epistemologies, foregrounding lived experience as a legitimate and valuable form of knowledge. Further, by being informed by tenets of PAR, this research acknowledged that meaning-making is a collaborative, relational, and political process. It positioned co-researchers as active agents in the production of knowledge and aimed to challenge the

structural and epistemic inequalities that shape how CP is understood and therefore responded to through movement.

I was drawn to participatory arts-based research as this approach is grounded in a transformative paradigm that values subjectivity, reflexivity, and the potential for creative practice to foster empathy, awareness, and social change (Lykes, 2013; Margolin et al., 2024). This was considered particularly useful for exploring complex or sensitive experiences – such as chronic pain – because they enable co-researchers to work with metaphor, symbolism, and embodied expression to explore experiences which are characteristically complex and hard to articulate and foreground. These forms of representation can reveal dimensions of experience that are difficult to capture through interviews and surveys alone. Importantly, ABR and participatory tenets can facilitate participation and involvement from groups who are traditionally excluded from academic leadership and research in a broader sense. Zine-making is playful, flexible, and accessible which allows for co-researchers to engage on their own terms, without the constraints of standardised measures or predetermined constructs (Baabdullah et al., 2025)**.** This makes ABR especially well-suited to participatory and co-produced research, where the aim is to democratise knowledge production and centre lived experience as this present study endeavours.

As with all forms of research methodology, despite the unique strengths outlined above, participatory ABR also comes with limitations and presented several challenges. The research process required time and flexibility within this, was resource-heavy, and reliant on extended engagement from all those involved (Phillips et al., 2024). Designing and facilitating artistic activities that truly empower co-researchers requires trust-building, materials, space and in this case collaboration with creative practitioners. These demands required careful planning, clear objectives, and ethical attention to the capabilities and needs of those involved. It was also a challenge for me as lead-researcher and my co-facilitator to not become too emotionally involved in the subject of research in order to remain analytical when necessary (Cahill, 2007). Interpretation also poses challenges within this research approach, as artistic expressions are inherently subjective and without participant involvement in analysis, there is a risk of misinterpretation or researcher-imposed meaning (Dadich et al., 2025). For this reason, ABR could be argued to be most ethically and methodologically robust when embedded within participatory frameworks that allow for collaborative interpretation and shared decision-making – as it has been within this present study.

Reflexivity and Relational Ethics

Within constructivism it is understood that the researcher is an active participant in meaning-making and co-producing knowledge rather than an unbiased observer (Kim, 2014). Reflexivity was therefore essential to engage with while developing, executing, and analysing the research (May & Perry, 2017; Olmos-Vega et al., 2023; Shaw, 2010). This methodological practice acknowledges that the researcher's values, assumptions, and experiences inevitably shape the research process and the interpretations that emerge from it (Holmes, 2020). Reflexivity is an ongoing process of self-reflection that researchers participate in to foreground their own behaviours, thoughts, assumptions and expectations (May & Perry, 2017; Patnaik, 2013).

Throughout this process I engaged in ongoing dialogue with co-researchers and the support facilitator, and creative note-taking to critically examine my influence on the research. These practices supported ethical responsiveness and enabled me to adapt workshop structures in situ in response to co-researcher's fluctuating needs, energy levels, and creative decisions. I have also woven my own reflexive practice throughout this thesis and illustrated my reflections and engagement through the inclusion of my own creative zine-pages. I additionally remained curious and interested in hearing the reflections of co-researchers and people outside the immediate research process but connected through their own experiences of CP or arts-based practice – for example when professionally photographing the zine contributions, asking for the photographer's reflections on what he saw. These practices helped me to remain aware of how my interpretations, expectations, and emotional responses shaped the unfolding research. Reflexivity also supported ethical responsiveness, enabling me to adapt the workshop structure to the fluctuating needs, energy levels, creative direction, and comfort of the co-researchers.

This research seeks to value situated and subjective, and does not aim to produce universal or generalisable truths. This stance aligns with broader critiques of positivist dominance in health research and challenges epistemic hierarchies that determine what constitutes legitimate knowledge (Greenhalgh & Papoutsi, 2018). Epistemology is inherently linked to power; whose knowledge is recognised, valued and legitimised? Who is granted the power *to know* and at what level is this knowledge then enacted. People living with CP frequently report being disbelieved or dismissed, reflecting broader epistemic inequalities. ABR, and zines in particular, offered this study and those involved an opportunity to challenge these hierarchies by redistributing the epistemic authority. By enabling individuals to represent their experiences on their own terms, these methods reduced reliance on researcher interpretation alone and privileged co-researcher's meaning-making.

Readers are invited to engage with this text and stories shared throughout the pages. This is not an expectation, but an endeavour to support an embodied and reflexive engagement with the paper as you read. You are also not an unbiased observer in this research, but an active participant, bearing witness to lived experiences as they move from everyday life into academic discourse.

Chapter Four: The Research Journey – Methods

The primary aim of this research was to co-construct lived-experience narratives of meaningful movement alongside people living with chronic pain (CP). A secondary aim was to support co-researchers to retain agency over the forms of knowledge they produced, particularly creative, embodied, emotional forms, which are often sidelined within academic and clinical discourses. In doing so, the study sought to generate a creative artefact/resource that can be disseminated within and beyond the pain community, enabling dialogue, understanding, and action. This chapter details the research methods utilised throughout the study. The research questions and approach are reiterated, how recruitment unfolded is explained, and the analytical process laid out. In line with the participatory-action tenets guiding this research as illustrated in Figure 4, reflexivity and learnings are interwoven throughout the chapter. These also help to illustrate how the initial research plans changed throughout the course, and why. This chapter will also identify the limitations of the study, acknowledging the methodological and contextual factors that shape the scope and transferability of findings.

Figure 4:

Guiding light



Note. Illustration by the lead researcher of the guiding PAR tenets of this research including; Transformation, equitable participation, agency, autonomy, redistribute power, and reflexivity. Materials include blue paper, collage images, and embossing label maker. The final figure was edited together on Canva.

Research questions

The study aimed to answer the following research questions:

1. How do people living with chronic pain articulate and make sense of “meaningful movement” within their everyday experiences?
2. What forms of collective insight and shared meaning are co-created through arts-based explorations of meaningful movement?
3. Explore how the co-creation of a collective zine creates a space for the democratising of knowledge and challenging stigma of chronic pain and movement.

These research questions reflect the participatory arts-based orientation of the study and the endeavour to democratise the research process and experience. The aim was to creatively and collaboratively work with a section of the CP community to explore and recognise collective understandings of meaningful movement and how it interacts with the experiences of managing and living with the condition. The questions therefore focused on not only individual interpretations of meaningful movement, but also on the shared insights that emerged through co-created artistic processes. By attending to both personal and collective meaning-making, the study aimed to illuminate how creative, community-led inquiry can challenge dominant assumptions about what movement “should” look like for people living with chronic pain, and how alternative narratives might contribute to more inclusive, compassionate understandings of movement, health, and quality of life.

Artistic Collaboration

Arts-based research demands not only methodological rigour but also skilled facilitation to support participants in engaging creatively, expressing themselves authentically, and contributing meaningfully to the co-production of data (Chilton & Leavy, 2020; Zarate et al., 2025). In order to ensure the arts-based components of the study were facilitated with expertise and creative leadership I established a collaboration between myself and an artist-facilitator with an established creative practice and knowledge of research, particularly with zines. This partnership was pursued to help create a safe and generative research environment and increase my own confidence in delivering the workshops. Working alongside an experienced practitioner was deemed essential to uphold the integrity of the creative process and to ensure that the zine-making workshops were accessible, empowering, and conducive to rich data generation.

I initially approached Ess Grange in June 2025 for an explorative conversation about their experiences of collective zine-making and creative/collaborative research spaces. The aim of this initial discussion was to sense-check my budding ideas and to help me craft a realistic and fair collaboration pitch which I planned to use to approach a number of different co-facilitator options. I approached Ess due to their experience in similar artistic and research spaces and their strong sense of inclusion exhibited through their work and their own marginalised identities. Ess seemed so enthused by the conversation and showed such genuine interest and thoughtfulness regarding the topic that I asked them if they might be interested in such a collaboration. We discussed the time-expectations for the project and what I felt I needed from an artistic collaboration – reassurance, session plan support, material preparation support, knowledge sharing regarding editing zines and artistic research, in-person co-facilitation, and for this all to be executed with the shared values of the research design. After agreeing these mutual expectations, Ess signed a confidentiality agreement (Appendix A) to formalise the collaborative relationship and reiterate that we were approaching the study with a shared understanding. This enabled me to include some specific information about Ess and their own artistic practice as a poet, researcher and theatre-maker within my research ethics application.

Once the study and approach was approved by the ethics board end of June 2026 and the group who we would be working with was confirmed in September 2026, the first step was for Ess and I to plan the upcoming sessions. We had an online video call to go through the session plans I had drafted, and then organised an in-person 3-hour afternoon session in October 2026 where Ess and I aimed to emulate the upcoming workshops and collaboratively created a prompt zine (Figure 5). This session enabled Ess and I to see, practically, how each of us worked creatively and Ess was able to use it as an opportunity to exhibit to me how they guide people through a zine-making process. This demonstration and relaxed opportunity to learn was invaluable for me to *"get over the fear"* – something I was about to ask a group of people living with chronic pain to also do. During this collaborative session Ess also was able to share some knowledge and facilitation tips with me, getting ready for meeting the group in November. One piece of advice which later proved to be vital in order to respond to the group environment and needs was to make the session "*squishable"* in order to be able to let go of control. In other words to feel confident enough within ourselves to help the group feel safe and able to bring in themselves at "*where they are at*". This co-facilitation approach also helped mitigate power imbalances, as creative leadership was able to be shared rather than held solely by me, the academic researcher.

Figure 5:

Prompt zine



Note. Prompt zine created by the lead researcher and co-facilitator, Ess Grange, to be used in the workshop sessions with the group. Materials include photographs, dried plants, modelling clay, sketches, collage images, glitter, NHS letter, felt-tips and highlighters. This was edited together on Canva and printed professionally to use within sessions.

We will return to Ess's contributions within the workshop environment throughout the methods chapter, particularly within the zine-making session and collective conversation, as they played an essential role in the cultivation of the safe and encouraging environment.

Procedural Ethics

Given the close work with a group of people who are often perceived as vulnerable and who have a higher likelihood to having experienced discrimination, marginalisation, and inequitable healthcare, a full ethics application was submitted to Massey University. Approval was granted by the Massey University Human Ethics Committee (Reference: OM3 25/31). Ethical considerations were embedded throughout the design and delivery of this research, shaping decisions about recruitment,

facilitation, data protection, analysis, and representation. Throughout this methodology chapter, I have highlighted the ways in which power dynamics, cultural considerations, and the rights and dignity of co-researchers were actively attended to. These included the use of co-facilitation (Ess Grange's support and input), the centring of lived experience expertise, and the creation of a creative, relational environment in which co-researchers could participate on their own terms. The participatory ethos of the project meant that co-researchers were not positioned as subjects of research but as active collaborators whose insights shaped the direction and interpretation of the work.

Ethical considerations also informed the analytical process. When identifying themes, for example, I followed Braun and Clarke (2023) and their conceptualisation as themes as patterns of shared meaning, which aligned with the ethical commitment to honour collective sense-making rather than impose an external and researcher-led analytical framework. This approach ensured that the analysis foregrounded the group's interpretations and protected the integrity of their lived experiences, supporting a participatory and ethically responsive analytic process. Further ethical considerations were central to the conduct of the research and included:

Respecting Time, Energy, and Accessibility

All workshops and interactions with the group were scheduled for during the group's usual meeting time and held in their familiar community space to avoid placing additional demands on co-researchers. Activities were paced in response to the group's energy levels on the day and had the ability to be flexible to differing paces amongst the group. This flexibility was built in directly to accommodate fluctuating pain levels, fatigue, and mobility needs. Participation was voluntary at every stage, and co-researchers were encouraged to contribute in ways that felt manageable and meaningful to them.

Creative Ownership and Informed Consent

This zine-making involved the creation of personal and collective artefacts. Co-researchers retained ownership over their personal creative contributions, and explicit consent was sought from each group member for the inclusion of any images created, text transcript, or audio in the final zine, audio narrative and thesis. All members of the group gave informed consent during the visual contribution workshop. Some co-researchers chose not to include their names or identifying information in the final artefacts, preferring to remain anonymous within public-facing outputs. Others took proactive steps to include their name, initials, or personal identifiers as a way of

asserting ownership over their creative contributions. This variation reflected differing comfort levels and personal preferences, and it also demonstrated the degree of agency co-researchers held over how their work and identities were represented. This approach remained aligned with the ethical commitments of the project: respecting autonomy, supporting informed decision-making, and ensuring that participation did not compromise anyone's privacy or wellbeing. Consent was treated as an ongoing relational process rather than a one-off administrative requirement. Co-researchers were invited throughout the process to amend their contributions, or withdraw at any stage prior to finalisation of the zine and audio narrative.

Dissemination and knowledge sharing

As creative artefacts, the zine and accompanying audio narrative required ethical consideration beyond the conventions typically applied to textual qualitative data. Unlike interview transcripts or fieldnotes, these artefacts were not intended to be anonymised, secured, and destroyed in the same way traditional data often are. Instead, their purpose was to be shared, circulated, and engaged with as expressions of lived experience and as outputs of a collaborative creative research process. Decisions regarding the dissemination and long-term stewardship of the zine and audio narrative were made collectively. Following the group's approval of the final versions, discussions were held with co-researchers and the programme manager from Thriving Stockwell to determine how the artefacts should be shared within and beyond the community. This collaborative decision-making process ensured that dissemination aligned with the group's intentions, respected their ownership of the creative work, and upheld the participatory ethos of the study.

An additional ethical consideration relates to the broader context of arts-based research. Creative and community-generated knowledge is not always afforded the same legitimacy as traditional academic outputs, and there can be slow institutional uptake in recognising such works as "research" or valuing it as credible knowledge (Morris & Paris, 2022). This dynamic carries ethical implications: it risks reproducing epistemic injustice by devaluing the forms of expression and meaning-making that are most accessible and authentic to marginalised communities. By foregrounding the zine and audio narrative as central research outputs, this project sought to challenge these hierarchies and affirm the validity of creative, embodied, and relational knowledge.

Recruitment and Participants

The recruitment for this project was designed in line with PAR principles to engage co-researchers to be actively involved in the research process, rather than recruit participants as data sources

(Fahlberg et al., 2026). ABR informed by participatory tenets typically requires a small, purposefully engaged group of individuals who are willing and motivated to contribute creatively and collaboratively in the research process (Cheryl et al., 2025; Dahal et al., 2024; Spaniol, 2005). Because this research sought specifically to work with people living with CP, recruitment prioritised accessibility, inclusivity, and co-researcher agency. Further, due to following ABR practices, the strategy focused on identifying individuals who were interested in exploring meaningful movement through creative and reflective processes, and who wished to contribute to co-producing knowledge grounded in their own experiences. Recruitment was planned with these best practices and the core tenets of PAR in mind. However, as anyone in community research knows, the plan usually goes out the window and therefore this section points to the initial plan and then in practice what happened.

The initial recruitment strategy aimed to invite people living with CP to take part in the process through a social media and flyer call-out, with the intention of snowball sampling. The recruitment notice (Appendix B) was created on Canva and was shared through personal social media accounts, physically in local libraries and community notice boards, and through outreach emails to pain-specific charities in the UK and a local hospital's pain patient participant group. Although these approaches generated considerable interest from individuals in the project's ambitions and creative approach, they did not translate into recruitment for direct involvement. While disappointing, this was not completely unexpected due to the nature of research when working with people in CP. Fluctuating symptoms, fatigue, distrust in academia, and uncertainty about the outcomes and 'what next' of research can affect willingness or ability to commit to a research process (Hansford et al., 2024; Vader et al., 2021).

As the recruitment approach pivoted, informal conversations with programme leads and service providers working within CP support contexts proved more fruitful. I spoke with a health coach working within the creative health sector, and the programme manager of a local CP peer-support group. These discussions facilitated a connection with an existing peer-support group that met regularly following taking part in a pain management programme (King's Health Partners, 2025). The expert-by-experience leader of this group discussed the research project with the group, informed by a simplified information sheet I sent to her (Appendix C), and group members in turn expressed interest in exploring meaningful movement through the proposed creative, reflective, and community-based methods. This led to the adoption of purposive sampling, enabling the recruitment of a group whose shared experiences, established relationships, and ongoing engagement with CP management made them well suited to the participatory and arts-based nature

of the study. It was particularly beneficial that the group met each week within a community arts space and partook in creative activities as part of their peer-support practices. Recruiting and engaging with an already established peer-support group also aligned with the project's commitment to relationality, accessibility, and participant agency. Members were already familiar with one another, which supported psychological safety and creative openness during the data production process. This supported the relational ethics of the project and provided a strong foundation of trust for outsiders to join the group in a way which allowed for an authentic sharing of power. Additionally, the group's pre-established rhythms and practices provided a natural structure for the collaborative sessions, ensuring that involvement was grounded in community rather than imposed by the researcher.

The Co-Researchers: Community Context

The co-researchers were recruited through an existing peer-support group formed following participation in a co-produced programme delivered by King's Health Partners; *Pain: Equality of Care and Support in the Community.* This programme employed a bio-psycho-social framework, enabling it to deliver a holistic, person-centred approach to CP management (King's Health Partners, 2025; The Tavistock Institute of Human Relations, 2025). Given the significantly higher prevalence of CP among Black women – particularly Black women in Lambeth, South London - the programme intentionally focused on engaging and working with this population (Anderson et al., 2009; Catalao et al., 2022). Over its duration, 1547 people engaged with the programme, with 79% reporting improvements in their abilities to self-manage their CP (King's Health Partners, 2025). Participants also identified persistent gaps in healthcare provision for those with CP, and highlighted the diversity and complexities of personal circumstances .

As part of this broader initiative, a weekly peer-support group was established in partnership with Art4Space[1], a community arts space. The co-researchers involved in the present research project were active members of this group, which used artistic practice as a medium for fostering connection and sustainable change. Through creative expression, group members develop new skills, strengthen coping strategies, and explore the emotional and social dimensions of living with chronic pain. This aligns with existing literature demonstrating that arts-based interventions can enhance emotional resilience, social connection, and self-efficacy among people living with long-term conditions, including CP (Fraser & al Sayah, 2011; Larsen et al., 2018). Notably, one expert-by-experience from the group successfully secured independent funding to sustain the peer-support

[1] https://art4space.co.uk/

activities at Art4Space for an additional year beyond the conclusion of the King's Health Partners programme. This continuation, now formalised as the *PEACE and JOY Community-Led Group*, with ongoing support from Thriving Stockwell, reflects the programme's commitment to co-design, community leadership, and participatory health promotion. It also demonstrates the group's capacity to mobilise lived experience knowledge and community assets to sustain meaningful, culturally relevant support (Ocloo & Matthews, 2016).

Nine women living in South London in the UK took part in this present research project, welcoming me and Ess into their weekly peer-support group. Participation was voluntary, informed, and situated within a context and foundation of collective care and creative agency. While these aspects are seen as a strength for the nature of this research, it also meant that the composition of the group was not determined by me as the lead researcher. Through two workshops and a feedback session, the women contributed artwork and conversation to a collectively created zine and audio narrative. All group members were over 55-years-old, and had varied experiences of CP which affect the quality of their daily lives. The majority (66%) of those who contributed were Black British with the other members from white European and British backgrounds. Due to the fluctuating nature of the persistent pain and associated symptoms experienced by the group, two members took part only in contributing a visual artwork for the zine and were not present at the session to speak about their contributions.

Working with a pre-existing community of women living with CP (represented in Figure 6) required a heightened sensitivity to the relational, cultural, and embodied dynamics present in the group, as well as an awareness of the power I held as an academic researcher entering their established space. Members of this on-going group became the co-researchers for the present study and welcomed me and Ess into their space. Recruitment was therefore embedded within existing group activities, reflecting a relational and trust-based model of engagement aligning with the guiding PAR tenets. Participation emerged organically through conversation, shared understanding of creative practice, and mutual interest in the research aims. Other participatory tenets also emphasised co-production, accessibility, and the ethical imperative to engage communities as active agents rather than passive subjects (Baum et al., 2006; Benjamin-Thomas et al., 2018; van der Velde et al., 2009).

Figure 6:

Peace & Joy Chronic Pain Peer-Support group



Note. Collage representing the peer-support group members created through found images and reflecting on the individuals who made up the group. If you look closely you will see nurturing and connected individuals balancing in their own ways – through having a cup of tea and a chat, or harvesting home-grown fruits.

As the group was already familiar with using art as a medium for expressing their experiences, barriers to meaningful involvement were reduced, and the value of arts-based and lived-experience knowledge was immediately recognised. The use of arts-based approaches enabled me to build trust with the group, as creative practice provided a shared language through which relationships could develop. This enabled the participation of individuals who may otherwise be excluded from conventional research formats due to the realities of living with CP, cultural marginalisation, or mistrust of formal institutions (Cheryl et al., 2025; Parsons et al., 2026).

Invitation Five: Community and social influences

ZINE PROMPT: On a new page, sketch or write about the communities you move within – formal, informal, chosen, inherited. How do these communities shape what you know about pain and movement?

Maybe make a mark or choose a word that to you represents connection, and another that represents disconnection.

Reflections on Working with Community

Reflexivity was essential in navigating the power dynamics inherent in conducting research within a community that has historically experienced marginalisation, disbelief, and inequitable care. I remained conscious of the risk of inadvertently reproducing these dynamics and worked with Ess to ensure that co-researchers retained ownership over their creative contributions, interpretations and narratives. This included being attentive to when to step back, when to offer guidance, and when to invite deeper exploration. By foregrounding lived experience and creative autonomy, the research sought to honour the expertise held within the group and to actively resist extractive or hierarchical models of knowledge production.

It was also important to recognise me and Ess's 'outsider' status as visitors to the peer-support safe space, but also as people who do not experience CP first hand (Heard, 2023). My partner lives with fibromyalgia and as an informal carer for her I have experience in listening and trying to understand her experience from a lived perspective. This prior contact with CP as an outsider looking in may have contributed both positively and negatively to this research. I was transparent with the group from the initial meeting of this lack of first-hand experience, but of a proximity to the CP experience. One advantage of being a 'knowledgeable outsider' is that it allowed me to bring informed understanding without assuming insider authority, and to be able to contribute perspective without dominating meaning-making. This position also allowed me to notice taken-for-granted assumptions within the group and to act as a bridge between community-generated knowledge and academic discourse. At the same time, my partial distance from the real lived experience allowed for critical reflexivity, helping me to remain attentive to power dynamics and avoid over-identification.

Data Analysis Plan

The overall plan was to use collective analysis in continued engagement with the peer-support group, followed by Reflexive Thematic Analysis (TA). Reflexive TA was used to make sense of the zine and accompanying audio narrative, as it allows for meaning to be identified, interpreted, and articulated across diverse forms of data (Braun & Clarke, 2006, 2023). In line with Braun and Clarke's (2023) conceptualisation of themes as patterns of shared meaning, the analysis sought to identify collective sense-making across the dataset. Reflexive TA was selected because it embraces researcher subjectivity as an analytical resource rather than a bias to be eliminated (Braun & Clarke, 2019). This was essential given the participatory and arts-based nature of the study, where meaning is co-produced through relationships, creative process, and reflexive engagement.

More detail on the Reflexive TA processes and how it unfurled will follow later in this chapter. Why I have outlined the plan and approach to analysis here is to help provide the reader context for the ongoing nature of Reflexive TA when guided by PAR tenets. In line with these principles, analysis was not limited to a set point following data production, but rather was ongoing from the initial zine creation workshop – through the collation and editing stages – and into the reactions to the final creative artefact.

Procedure – A Creative Process

This study aimed to create a collaborative zine exploring what meaningful movement meant to people living with CP. The initial plan was to hold one zine-making workshop, followed by a collective conversation whereby co-researchers could attend either in-person, virtually, or through a combination (Appendix D). This original process was designed to bring together a group of unknown people living with CP and to provide the flexibility to engage in the research how best suited them. In response to the research being conducted with an established community, it was essential that the design and delivery of the workshops changed, responding to their needs, capacities, and group practices. This included adapting the original workshop plan and shaping the approach to the pre-existing group structures regarding timings, place and resources available. Even when doing this, the flexibility built into the workshops and process was vital as all plans shifted throughout the process, as illustrated creatively in Figure 7 after Table 1, which acts as a guide to this section of the methods chapter.

Table 1:

Overview of the research process

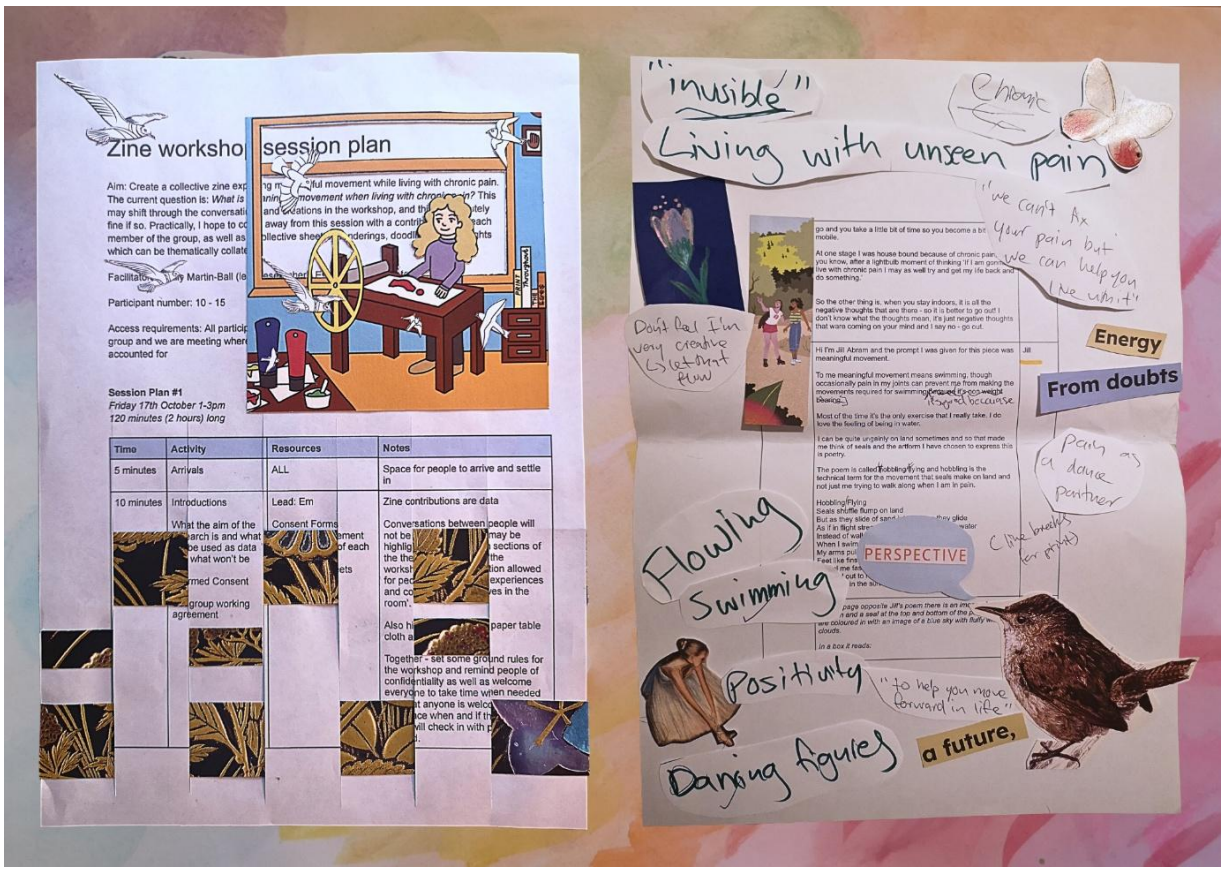
Research Stages	**Aim**	**Details**
Stage 1a *October 2025*	Initial Zine contributions created	• Workshop no.1 (2-hours) • Introduced zines & research • Created individual contributions (A4 pages) • Initial informed consent forms were signed
Stage 1b *October - November 2025*	Digitising contributions and preparing an illustrative first draft of the zine	• Contributions digitised by photographing them • Contributions printed on A3 and in colour individually • Illustrative draft mini zine printed
Stage 2 *November 2025*	Collective conversation to aid in analysis and audio collection	• Workshop no.2 (2-hours) • Conversations about contributions • Audio-recording on a ZOOM (audio recording device) • Additional artistic zine contribution
Stage 3 *November - December 2025*	Collating the zine and audio narrative transcript	• Zine edited in Adobe InDesign • Audio transcribed • Draft audio narrative script written
Stage 4a *December 2025*	Feedback and collecting additional audio	• Workshop no.3 (2-hours) • Feedback and review opportunity for group members • Requests and permission regarding use of raw audio (co-researcher voices) • Re-recording sections of the audio narrative using voice-notes on phones
Stage 4b *December 2025 -January 2026*	Final editing of the zine and audio narrative	• Amendments to the zine on Adobe InDesign • Recorded remaining sections of the audio narrative with three voice-over artists and recording my own voice as the narrator directly into Audacity[2] . • Editing narrative together, including 'cleaning' the audio to align sound levels and bring the narrative together in a cohesive way. • Final version of the zine and audio narrative were sent to Angela and Marta for final approval.
Stage 5 *January 2026*	Printing and disseminating the zine and audio narrative	• Final copies of the zine, with a QR code on the back linking to the audio narrative were printed professionally through an online printing company. • The zine was uploaded to HeyZine.com as an online flipbook. • The audio narrative was uploaded to audio.com to be hosted online for free access. • Thriving Stockwell hosted the zine on their website as a printable PDF for further opportunity of distribution and exhibiting pride in the final creative artefact.

[2] Audacity – a free audio editing software

Research Stages	Aim	Details
Stage 6 *October 2025* – *June 2026*	Analysis and writing the thesis	• Analysis and reflection throughout every stage of the research process, however academic analysis was formalised after the final zine and audio were completed and disseminated. • Supervision and writing continued

Figure 7:

The plan vs. reality: What goes wrong goes right!



Note. Researcher reflections on what deviated from 'the plan'. Materials used include watercolour paints, collage images, cut-out notes from workshops, initial planning documents. Edited together on Canva.

Stage One: Zine-making

Initially one 3.5-hour zine-making workshop was planned to be delivered, which was revised to a 2-hour session in order to fit into the group's usual meeting time at their regular venue - a community and health arts hub in South London. Holding this shorter session ensured that no additional time, energy, or travel burden was placed on co-researchers, all of whom live with CP. While the shortening of the session left less time for extended conversations and reflection, and

comprehensively introducing the concept of zines, it did not impact on our ability to discuss the purpose of the research, gain initial informed consent, and begin the creative process at a pace that felt manageable and respectful of fluctuating pain and fatigue.

A rough workshop plan (Appendix E) was co-created by me and Ess prior to the session. This provided a shared framework and ensured we held a mutual understanding of the key elements required – such as gaining informed consent, establishing a shared initial understanding of "meaningful movement" and generating sufficient creative material for the zine. At the same time, the framework was intentionally flexible. Responsiveness was essential to honour the participatory ethos of the project, enabling us to adapt activities in real time based on the group's energy, interests, and creative flow. This flexibility also supported accessibility, allowing co-researchers to contribute in ways and at a pace that aligned with their physical and emotional capacities on the day.

We covered the central table in the art room with white and blue parchment paper, and a wide range of artistic materials and modes of expression, some of which are illustrated in Figure 8. Providing multiple creative entry points – such as collage, drawing, writing, photography, and mixed-media composition – allowed co-researchers to self-select the forms of expression that felt more meaningful to them. This approach prevented me or Ess from pre-determining what '*should'* be important or relevant, and instead supported autonomy, ownership, and creative agency. It also aligned with arts-based epistemologies, which recognise that different materials and modalities can surface different forms of knowledge (Leavy, 2020).

Figure 8:

Zine-making materials



Note. Some of the tools used within the zine-making workshop are shown in the image. These include watercolours, prompts, glue, glitter, A4 paper, collage materials, photos, embossed labels, and coloured pens. Not pictured but also available was modelling clay, scissors, sketching pencils, ribbon, scrap material, thread, and wool.

In keeping with PAR principles, the workshops did not follow a rigid process. It was ensured, however, that during the workshop all those who contributed artworks for the zine gave informed consent (Appendix F) and made a decision as to whether they wanted to be credited or remain anonymous within the zine publication. The workshop was designed to enable authorship and leadership by the co-researchers, with facilitators guiding rather than directing. To support this, Ess and I shared the specifically created prompt-zine (Figure 5 shown previously in this chapter) and question pages, alongside examples of published zines, demonstrating the breadth of creative possibilities and the freedom co-researchers had in shaping their contributions. These examples served as both inspiration and reassurance, helping co-researchers visualise the potential of the medium while emphasising that there was no “right” way to participate.

The workshop unfolded as a blend of making, talking, reflecting and sharing. Each of the 8 members present at this session made an A4 landscape or portrait page to contribute to the zine. Informed by an introductory discussion on meaningful movement, conversations emerged organically as participants worked on materials, and these discussions alongside the creative artefacts themselves formed an integral part of the data. The artwork also drew on prior group reflections and shared experiences from their completed pain management programme. The structure of the session therefore supported both individual expression and collective meaning-making, enabling the group to explore meaningful movement in ways that were embodied, relational, and grounded in their lived experiences. Each member engaged with the activity in ways that aligned with their own preferences and capacities, while collectively sustaining the safe and supporting environment characteristic of their peer-support practice.

Reflections of Stage 1

Ess helped to play a central role in shaping the workshop environment through their creative collaboration with me as lead researcher. Their practice is grounded in creating calm, encouraging, and inclusive spaces that support people to explore ideas through making. Within this stage of the research process, Ess supported co-researchers to articulate their experiences through zine-making, offering expert guidance, reassurance, and creative prompts while ensuring that co-researchers maintained ownership over their contributions. Their presence helped cultivate a sense of ease and confidence within the group and for me, enabling us all to engage with the creative tasks in a way that felt authentic and with reduced cognitive-load on the logistics and organisation.

Several co-researchers began their creative process by considering what they wished to communicate through their contributions. For example, the poem Hobbling/Flying emerged from a period of quiet reflection and deliberate attention to language and phrasing. Two members of the group responded initially to a written prompt, subsequently selecting images that complemented and extended their text-based reflections. Others engaged in a more exploratory process, spending time searching through the found images and magazines available on the table and allowing these visual materials to guide the direction of their contributions. Due to the location of the workshop being an arts venue and familiar to the group, there were additional materials able to be provided than those which Ess and I brought with us. This meant additional prompts and found items were able to surface – allowing co-researchers to say what they wanted to say in the ways they wanted to articulate them. For example, the images of butterflies which became a central theme in the zine came from a magazine provided by Art4Space. A small number of zine pages were produced with more facilitator support than others. One co-researcher initially expressed reluctance to take part,

stating *"I can't see anything, I don't want to do this."* Through sitting alongside her, exploring different mediums, and gently prompting discussion about how she *"liked to move,"* she ultimately produced a simple yet effective double-page collage. This process illustrates the varied ways co-researchers engaged with the activity and the flexible and responsive facilitation required to support meaningful creative expression.

As facilitators, we adopted an enabling role throughout the workshops, guided by principles of agency and autonomy that underpin participatory research. Rather than positioning ourselves as detached observers, we contributed actively to the creative process by introducing the group to zine-making as a new artistic skill and supporting them in producing their first co-created art piece as a group. Given that all members of the group live with CP, several co-researchers experienced difficulties with tasks requiring fine motor dexterity, such as cutting images, handling tape, or manipulating small tools. In response, Ess and I worked alongside participants, offering practical assistance when needed to ensure they were able to realise the creative ideas they envisioned. Throughout the workshops, we sought to maintain a balance between providing structure and guidance and allowing the group to shape the direction of their contributions, thereby honouring participatory ethos of shared decision-making and creative autonomy.

Having Ess involved as a co-facilitator also created space for ongoing reflection and dialogue between us (myself and Ess) as practitioners. Before and after the workshop, we engaged in structured and informal discussions to reflect on group dynamics, emerging themes, and moments of significance within the creative process. These conversations helped surface nuances that might have otherwise gone unnoticed had I been the sole facilitator, and supported reflexive decision-making about how best to adapt sessions for the needs and direction determined by the group. This artistic collaborating ultimately increased capacity to meet co-researchers where they were, and to attune to the personalities and energies present in the room – something that was essential for building the trust required to support meaningful creative engagement. This trust was reciprocal: while we relied on co-researchers to contribute in ways that felt authentic to them and to share the narratives they wished to foreground, they relied on us to facilitate a process that honoured their autonomy and upheld the supportive ethos of the peer-group environment. This reflective and supportive partnership both between Ess and I, and us both and the group, aligns with participatory tenets, which emphasise shared learning, responsiveness, and the co-creation of meaning throughout the research process (McGrath et al., 2025).

Stage Two: Collective Conversations

Art and pain are both deeply subjective, shaped by personal histories, embodied experiences, and social contexts. In keeping with the participatory arts-based orientation of this study, it was essential that co-researchers retained ownership over how their creative contributions were presented and interpreted. Rather than me as the lead researcher interpreting and analysing the zine independently, a collective conversation was planned with the group to explore what the collated zine looked like, and what contributions communicated. This session enabled the group to explore what meanings were embedded within the zine's pages, decide on how the contributions wove together, and how they wanted readers to understand their work.

This collective conversation was planned to act as a collaborative and co-analysis exercise, enabling co-researchers to identify the themes emerging from the zine and to articulate the significance of their creative choices. By discussing the zine together, the group shaped the interpretive direction of the research, ensuring meanings attributed to their work were grounded in their own lived experiences rather than imposed through an external analytical lens. This approach aligned with the PAR principles guiding the research and emphasised shared meaning-making, relational accountability, and the redistribution of interpretive authority. It also supported the ethical importance of the group maintaining agency over what knowledge they chose to share through the research process, and ensured they maintained their authority over their stories.

A second 2-hour workshop was planned for another peer-support session, 4 weeks after the zine-making workshop in Stage 1 of the research process. The time between sessions allowed time for the original contributions to be professionally photographed (rather than scanned), in order to digitise them and printed copies of these were delivered to the group in the intervening weeks so they had time to review and reflect on their creative contributions. Ess and I had again drafted a flexible session plan which remained malleable to what happened on the day. Questions to guide the conversation were agreed, although it is important to note these were merely enquiries and did not *have* to be answered as specific questions:

- Can you describe what you have created?
- Why did you choose to make what you did?
- Can you tell me a little more about your experiences of movement and pain?
- What makes movement meaningful to you?

The collaborative conversation session was held around the same table where we had created the zine contributions, and we again covered this in blue and white parchment paper to enable creative note taking and doodling if people wished. With the printed copies of each professionally photographed zine contribution as a visual aid, we spoke with each co-researcher who was present about what they had created and why. We had initially aimed to hold this as a group conversation, however, upon arrival it became evident that a whole-group discussion would not be feasible, requiring an immediate shift in approach. I therefore engaged with co-researchers individually, using one-to-one conversations to explore the meanings they wished to convey. Although this adaptation meant we were unable to collectively shape the overarching narrative of the zine or identify shared themes as a group, these conversations were able to be collated into textual elements for the publication, ensuring that the final narrative reflected the messages the co-researchers wished to foreground.

These conversations were recorded using a ZOOM audio recorder, with the group's consent, and later transcribed. One additional member of the group who had not been present at the initial workshop wanted to contribute creatively and so reflected on the creative contributions and conversations being had and responded to these, in part beginning the theming of the data. Feedback during this session indicated that the group were satisfied with the proposed flow of the zine and valued this opportunity to reiterate and clarify some of the implicit messages embedded in their creative work.

Reflections of Stage 2

While this stage intended to facilitate a collective conversation as a group reflection practice, Ess and I had to respond to the energy of the group on the day. It eventuated that the date of the collective conversation coincided with Angela's birthday, the leader of the group. Angela arrived late due to traffic and earlier birthday celebrations, including having a birthday haircut, and as such her entrance with trays of food to share disrupted the group conversation that had begun. It was impossible to get the group back to the table collectively, with members excited to wish Angela happy birthday and share the Caribbean buffet which had appeared. This exhibited the importance of having a *squishable* plan and guiding principles that both Ess and I were aligned with, as it enabled us to pivot on the day and instead speak with people on a 1-2-1 basis and still enable them to share their reflections and narratives connected to their contributions.

Throughout these conversations, and hearing individuals' reactions to the zine so far, enabled the first inklings of themes to emerge. Some reflections Ess and I both had from this session were the

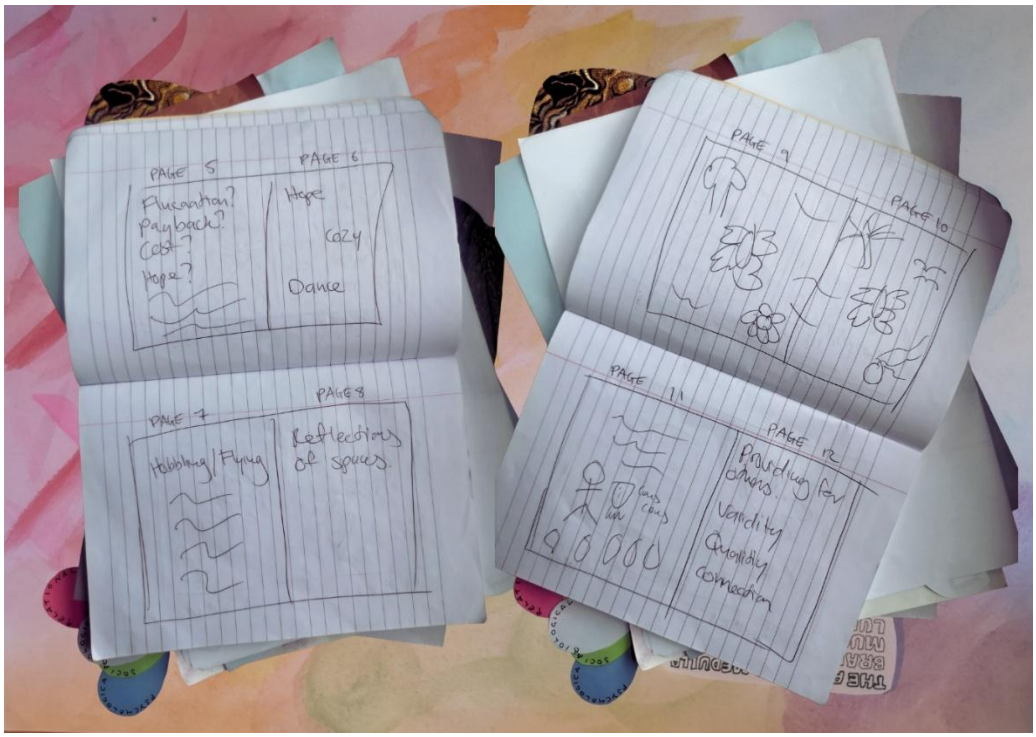
playful and restorative role movement seemed to play for many members of the group. The energy in the room was palpable, reflecting what some referred to as embracing the good days and doing things while they could. It would have felt inappropriate to try and change the natural course of celebration which had entered the room along with Angela and her birthday. Instead, resounding requests for Angela's birthday to feature in the zine somewhere influenced the editing stage and overall feeling of celebration within the zine pages.

Stage Three: Collating the Zine and Audio Narrative

The next step in the production of the collective zine was to collate the individual contributions alongside the verbatim quotes from the collective conversation into a cohesive zine publication which included the co-researcher's voices woven throughout. The audio from Stage 2 was firstly transcribed by ear in Microsoft Word. Then, using InDesign as an editing software, and following threads of the conversations, I collated the zine into a first draft. I approached this by first sketching out a flow to the contributions and reflecting on the initial themes emerging from conversations (example shown in Figure 9). This was to help determine how contributions might be accompanied by verbatim quotes to strengthen and enhance the communication from the group. It also was to visualise, for myself as editor at that point, how the zine might move from one page to the next in a way that made sense to a reader.

Figure 9:

Pages from researcher's notebook – sketching the zine



Once the zine was collated, the transcript from the collective conversation was drafted into a narrative that accompanies the final zine. This script used as much verbatim dialogue from the Stage 2 discussions and descriptions of the creative contributions as possible. Where connecting phrases or further description was needed I wrote a script, staying aligned with the pace and style of the co-researchers and essence of the group.

Reflections of Stage 3

The collation of the zine and audio narrative were very much an iterative and evolving process. My role as lead researcher and co-facilitator shaped how the final zine and audio narrative was co-produced. In keeping with arts-based and participatory approaches, it is important to acknowledge the influence I had on the data which was produced. My presence in the workshops, the decisions I made about structure, pacing, and the level of support offered, as well as the interpretive choices involved in assembling the zine and audio narrative, all contributed to the creative artefact produced. While my primary aim was to uphold the participatory and lived-experience leadership ethos of shared authorship and reciprocity, the research was inevitably co-constructed through my interactions with the co-researchers, my methodological commitments, and my own assumptions about meaningful movement and chronic pain.

Remaining reflexive about these intersecting influences was essential, particularly making editorial decisions on their behalf in the production of the zine and collating of the audio narrative. Also it is worth noting that the collating process continued my close contact with the creative data which had been produced, contributing to the ongoing data analysis and understanding of the group members and their stories as I was engrossed in their contributions. This reflexive stance informs the thematic analysis that follows in the chapter, which seeks to honour the perspectives and intentions of the group while acknowledging the interpretive lens through which I came to understand their contributions. It also mirrors the stance we hope readers will adopt when engaging with the group's narratives and creative expressions.

Stage Four: Feedback and Editing

To ensure that the group had full opportunity to review and approve the developing zine publication, I returned for a third session. On this occasion I brough with me an A4 print-out of the complete draft of the zine, along with an A3 print-out of audio narrative script, so that co-researchers could assess how their contributions were being represented. The tangible print-outs enabled us to make annotations and edits in the margins as co-researchers saw fit. Owing to health-related constraints and availability, not all members were able to provide feedback on their individual pages. In these instances, contributions were anonymised and the visual artwork was described in the audio narrative through direct description of the contributions, rather than through additional interpretation. This approach ensured that all contributions were included ethically and respectfully, while maintaining fidelity to participant's original expressions.

The audio narrative script was checked with the group, and it was confirmed, in person, if people wanted to have their actual voices edited into the audio or not. There was a mixture of responses to this with the result being about 50/50. For members of the group who were unable to be part of the collective conversation due to personal reasons, and still wanted the opportunity to participate, I offered them my WhatsApp number to enable the sending of voice clips describing their contributions and adding to the overall discussion. The audio was then edited together using Audacity, with myself as the lead researcher and three actors voicing the anonymous sections of the script. This audio component allows readers to listen to the group's reflections while engaging with the visual artefacts, creating a multimodal experience that mirrors the relational and dialogic nature of how the zine was created. Further, it brings the images and stories to life in a way that supports the building of empathy and recognising the humans behind the data. Importantly, it ensures that

the knowledge articulated through the zine is communicated in the way the co-researchers intended – foregrounding their voices, interpretations, and priorities.

The Zine Title

It was during this final feedback session that the group collaboratively developed the title of the zine (Figure 10). Titling a collective project is inherently challenging, and this complexity was heightened by the presence of eight distinct perspectives on how best to encapsulate the overarching message. Through an iterative process of drawing out key words and themes that participants felt were central to the zine, the group arrived at the title "Chronic Pain – the invisible dance partner."

Figure 10:

Front cover of the zine



The key words and themes were recorded on a blank sheet of A3 paper as I spoke with each co-researcher throughout the feedback session. One co-researcher emphasised the importance of making visible the invisibility of chronic pain, noting that "people often say that there's nothing wrong with you when you can't see the pain we are in." Others stressed that the title should avoid implying that chronic pain was something they had "overcome" or "cured," instead reflecting its ongoing presence in their lives and the ways they had learned to live alongside it. This emphasis on invisibility highlights the social and embodied tensions group members encounter, particularly the dissonance between their internal experiences and external perceptions. The attention drawn to the invisibleness of chronic pain helps to condense both the unpredictability and the intimacy of chronic pain, illustrating how it moves through the body and mind affecting everyday life in ways that are deeply felt and yet often unseen.

The metaphor of chronic pain as a dance partner emerged organically from discussions with co-researchers. Presenting chronic pain as a dance partner helps to articulate the relational and dynamic nature of living with chronic pain, positioning it not as a static symptom but as an ever-present companion that shapes, constrains, and sometimes enables movement. The metaphor captures the continual negotiation required to navigate daily life with chronic pain. At times chronic pain can be an amenable partner allowing co-researchers to take the lead moving with relative ease and autonomy, and at other times disrupting the rhythm, dictating the tempo/pace, and asserting control. The title therefore reflects both the embodied realities of living with chronic pain and the dynamic, relational nature of the group's experiences of moving in a meaningful way while living with their conditions. As such the title not only reflects the group's shared narrative but can also serve as an interpretive anchor for understanding the nuanced, relational, and embodied dimensions of meaningful movement within the context of living with chronic pain.

Stage Five: Printing and Disseminating the Zine

After a final approval from Angela and Marta as leaders of the group, I sent the zine off to the printers, uploaded an online version to HeyZine[3], and uploaded the audio narrative to audio.com[4]. The completed zine and audio narrative served as an act of reciprocity to the group for what they had generously shared with me as an outsider. The act of returning the completed zine and audio narrative to the group can be understood as a central component of the participatory and relational ethics underpinning this project. In arts-based research the production of a data artefact is not solely

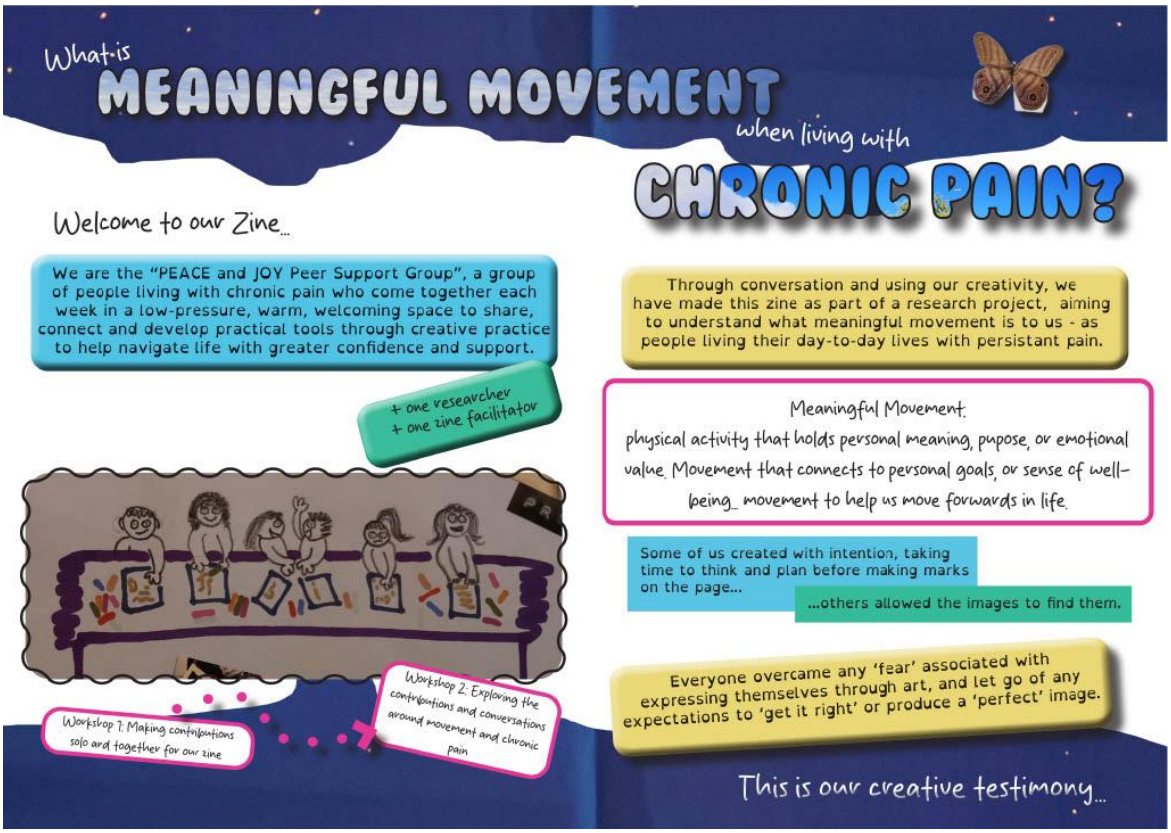
[3] HeyZine – an free online publishing platform
[4] Audio.com – a free audio hosting website

a methodological output but also a relational gesture – one that acknowledges co-researchers' time, energy, creativity and emotional investment. By offering the finished publication back to the group, the research process moves beyond extraction and more traditional research approaches, enabling co-researchers to see their contributions fit together into a tangible, cohesive collective narrative.

Encountering the finished "creative testimony" enabled the co-researchers to see and hear their stories reflected back to them, whether through their own voices or the verbatim performances of the voice artists. The opening pages of the zine, shown in Figure 10, helped to reiterate the co-produced nature of the zine, ensuring there was a shared ownership of the publication. The returning of the work to the group also functioned as a form of validation, allowing co-researchers to witness their experiences, voices and creative expressions being taken seriously and represented with care. This moment of recognition appeared to foster a sense of pride and ownership over the collective work. One participant's response, *"I love it, I really, really love it,"* upon receiving the printed zine, underscored the significance of the co-creative process and the shared power that had been cultivated throughout the project. The pride and emotional resonance expressed by group members highlight the significance of this exchange, illustrating how co-created research artefacts can foster a sense of ownership, empowerment and recognition. The final artefact thus became not only research data and output but also a tangible expression of the group's agency, creativity, and collaborative authorship.

Figure 11:

Chronic pain – the invisible dance partner: Pages 1&2



Step Six: Data Analysis

The data produced and under analysis in this study occurred through a combination of creative contributions, conversational exchanges, an approved audio narrative, and observational notes generated during the zine-making workshop, the conversation and audio workshop, and feedback session. In keeping with arts-based and participatory methodologies, data were not "collected" in a traditional extractive sense but were co-produced through the creative and relational processes that unfolded within the workshops. This approach aligns with the constructivist assumption that knowledge emerges through interaction, reflection, and shared meaning-making rather than through the extraction of discrete units of information (Kim, 2014). To reiterate the data under analysis, the primary data sources under interpretation included:

- Individual zine pages (contributions from the group)
- The zine as a collated whole publication
- The narrative transcript and audio edit – collated from the transcripts and conversations recorded with the group

The collaboratively generated insights and reflections on the zine contributions from the collective conversation served as the analytical starting point. Rather than treating the zine and audio narrative as data to be interpreted solely by myself, the group's reflections were centred from the outset. This participatory grounding shaped how I approached the traditional stages of thematic analysis, guiding the identification of themes and informing the interpretive framework used. While I endeavoured to be led by co-researchers in the analysis, as the author of this thesis I utilised subjectivity to make sense of and understand their lived experiences. These sessions and the discussions with Ess following the workshops helped illuminate how the creative process was functioning as a site of meaning-making and how our facilitation choices influenced co-researcher's sense of agency, safety, and expression options. This shared reflexive dialogue aligned with the participatory principles underpinning the study, emphasising equality, curiosity, mutual trust, and respect. Overall the analysis process was iterative, layered, and grounded in the principles of arts-based and participatory qualitative research.

The analytic process began long before any formal coding with familiarisation of the data starting within the collective conversation and continuing throughout the zine and audio collating and editing process (Byrne, 2022). This early familiarisation in the workshops allowed me to encounter the data through the group's interpretations, emotions, and creative choices and shaped how I approached the material throughout the process. As I moved into the collation of the zine and audio narrative, I became even further immersed through repeated reading, re-reading, and editing, gradually forming a holistic sense of the emotional, aesthetic, and conceptual textures of the data. In arts-based research, meaning is carried not only in words but also in form, colour, symbolism, and process, and this multimodal nature of the zine-making guided my early reflections (Barone & Eisner, 2012).

Coding unfolded as an organic and evolving process, consistent with reflexive TA (Braun & Clarke, 2023). Insights deepened over time as I moved back and forth between the zine, audio narrative, and my own reflexive notes. Attending to visual, verbal, and relational dimensions, I explored recurring imagery, motifs, artistic choices, and expressions of meaningful movement. Codes were not fixed entities; they shifted, expanded, and were repeatedly renamed and reorganised as my understanding grew. Reflexivity was essential here, with each analytical decision shaped by my positionality, emotional responses, and ongoing dialogue with the data and the group.

As coding developed, I| began grouping related ideas and noting patterns of shared meaning. These early clusters were colour-coordinated in an excel sheet alongside images of the zine contributions to support the gradual construction of themes. Reflexive TA positions the researcher as an active agent in theme development; themes do not simply emerge, but are built through interpretive engagement. I followed the conceptualisation of themes as shared meaning, reflecting the aim to identify patterns of collective sense-making across the dataset (Braun & Clarke, 2023). Although co-researchers did not participate in formal coding, their earlier reflections, workshop conversations, and creative decisions significantly shaped the analytical direction. Using their own words to articulate themes ensured alignment with the participator ethos of the study and preserved co-researcher agency within the academic interpretation.

Throughout this process I attended to both similarities and differences across contributions. While the analysis sought shared meaning, it also honoured the individuality of each creative expression and the multiplicity of experiences within the group. This approach aligns with reflexive TA, which values nuance and complexity rather than forcing consensus. Themes were reviewed through an iterative process of stepping away from the coding spreadsheet and returning with a fresh perspective. I revisited the zine and audio narrative to sense-check themes against the full dataset. This recursive movement between closeness and distance helped to ensure coherence, distinctiveness, and fidelity to the group's interpretations. Although there were no formal academic co-analysts the participatory grounding established in the process continued to guide decisions about theme boundaries and emphasis.

Once the thematic structure felt coherent, I refined each theme to articulate its central concept and its relationship to the broader analytical narrative. The final analytical task involved weaving the themes into a coherent narrative that reflected both collective and individual insights. This narrative is presented in Chapter Five, alongside a presentation of the zine contributions and excerpts from the audio narrative, to honour the multimodal nature of the data and to ensure that the co-researcher's voices remain central to the interpretations. In this sense, the presentation of themes is not a final step but a continuation of the reflexive, relational analytic process that shaped the study.

Chapter Five: The Zine – The Creative Artefact and Testimony

The zine embodies the group's collective insights, emotions, and experiences of meaningful movement. Therefore, the findings presented here should be read in dialogue with the zine created by the co-researchers and accompanying audio narrative. The zine is not an illustrative add-on or a supplementary artefact; it is central to the analysis and a primary site of meaning-making within this research. So, please, take a moment to read the zine[5] in its entirety (please follow the link, or footnote for best experience) and listen to the audio narrative or read the transcript (listen to the audio through the link or read the transcript in Appendix G). These artefacts provide an important foundation of engagement for you as the reader of this thesis. The thematic analysis presented in this chapter is therefore best understood as a conversation between the zine, the audio narrative, and the written thesis text.

In the pages that follow, I will present eight themes which emerged throughout the collaborative and reflexive process of creation. These themes reflect the creative artefacts themselves, following the artistic movements and decisions the co-researchers took throughout the process, as well as the stories which surfaced and my own experiences of collaborative working. Each theme is presented descriptively, alongside pages of the zine with illustrative notes, aiming to foreground the voices and expressions that shaped it, authentically. The wider implications of these insights for chronic pain (CP), meaningful movement, and democratising knowledge through arts-based approaches, are explored in more depth in the discussion.

Invitation Six: The findings aka the zine

When reading the zine and listening to the audio I encourage you to consider:

1) What resonates with you?
2) What pages do you visually enjoy the most?
3) What did the audio do?

Look back over your own zine pages so far. What resonates? What jars? What feels familiar or not?

[5] https://heyzine.com/flip-book/2126ea9919.html

What is 'Meaningful Movement'?

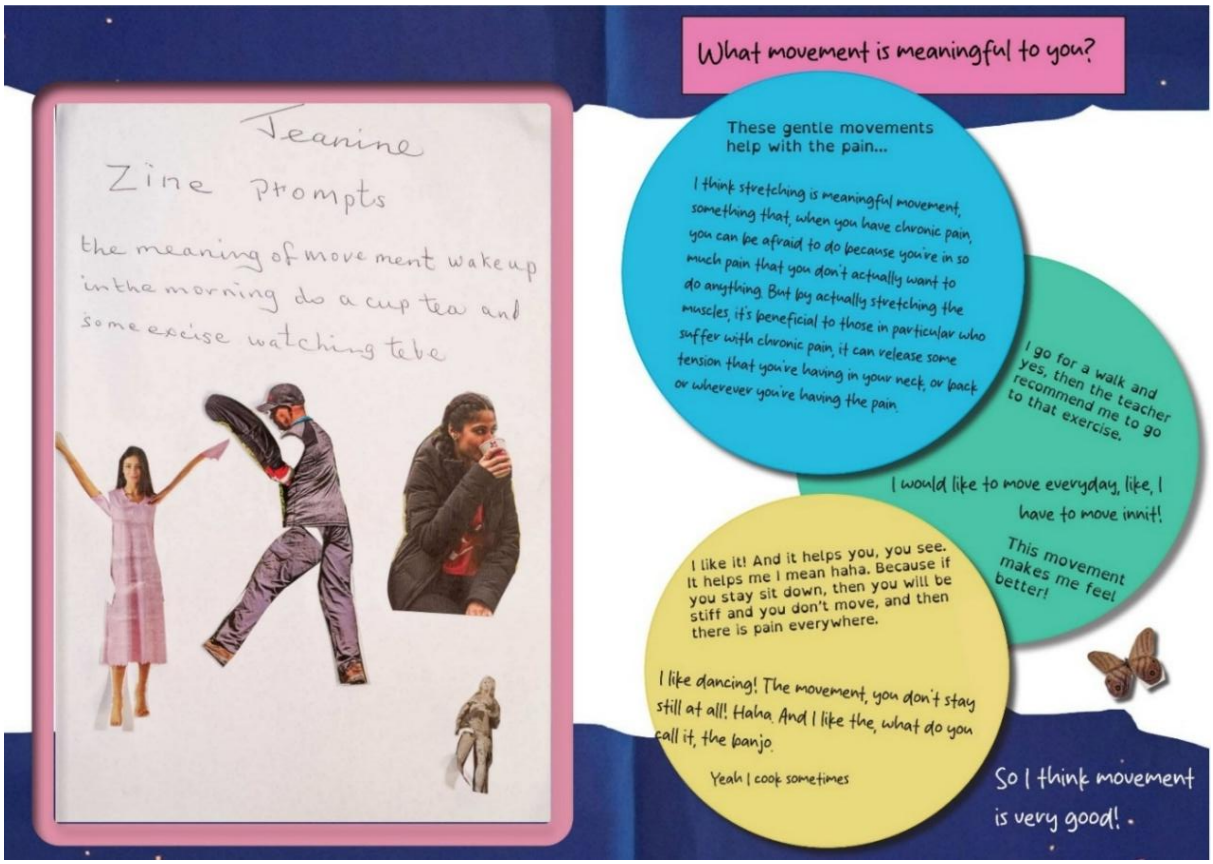
Through the research process a series of overarching themes were identified within and across zine contributions and reinforced through the audio narrative and conversations had. These themes, in part, stemmed from a series of words identified by the group; *Common everyday movements emphasising continuity, Providing for others: movement and identity, Engaging with nature: importance of being, doing and enjoying outside, Cyclicality of pain: moving through the cycles, Metamorphosis: changing relationships with movement and finding new meaning, Optimism: joy, hope and dance, Self-compassion: never give up on hope,* and *Connection and community.* These themes reflect the recurring ideas, metaphors, and embodied experiences expressed by the co-researchers throughout the research process.

Common Everyday Movements Emphasising Continuity

The first theme to emerge was ***common everyday movements***, reflecting the centrality of everyday movement in enabling people living with CP to participate in their daily lives. Across the zine contributions and audio narrative, co-researchers highlighted ordinary activities such as cooking, walking to the shops, gardening, getting out of bed, and attending the peer-support group as meaningful forms of movement. *"Meaningful movement is the art of using my body in different ways to carry out my daily activities"* one of the co-researchers stated. Images, text and audio all included everyday activities and illustrated the importance of these in contributing to quality of life for the co-researchers. One co-researcher explained how she regularly walks as part of her daily movements, and aimed for a certain number of steps to keep her active: *"I can say I do longer walks, I have my watch here, I watch my steps. I try and make five-thousand steps"*. The same co-researcher illustrated how social and cultural rituals can also aid in staying active through the everyday or routine movements they encourage: *"I am a catholic so I go to church and one night I go to choir practice. So I keep myself busy."* These routines and the actions which accompanies them were not presented as trivial, but rather described as significant achievements which shaped the co-researcher's sense of capability and continuity in their lives. As one co-researcher noted (Figure 12), even the simple act of *"waking up in the morning, do a cup of tea"* carried weight and value. For her, this routine was not only a task, but a marker of being able to begin the day on her own terms.

Figure 12:

Chronic pain – the invisible dance partner: Pages 3&4



Note. Page three shows a contribution created by a co-researcher. Jeanie has responded to the zine prompts through writing what the "meaning of movement" is to her. She has cut out found images of people, manipulating their limbs into stretching positions. Page four shows text highlighted in colourful circles which move across the page. These verbatim quotes from co-researchers highlight some of the activities and movement practices that they find meaningful and are important to them.

This theme also encompassed the regularity of movement and its role in pain self-management. Co-researchers emphasised the importance of maintaining consistent and habitual movement to prevent stiffness and manage symptoms. *"I would like to move every day and I have to move, innit"* one co-researcher explained, underscoring the necessity of movement as part of her daily routine. Rather than avoiding movement due to pain, many described an ongoing negotiation whereby they had to balance discomfort, pain, and the desire to remain active. One co-researcher described that *"Just like when you're working sometimes, you can't really move um like you [want to], but you go and you take a little bit of time so you become a bit more mobile."* There was a sense of internal negotiation at times, or necessary balance, and by using every day or common activities as a chance to move, it meant that co-researchers' could achieve two things – get a cuppa, go

shopping, or even come to the peer-support group while also moving to prevent more or worse pain.

"This, this old woman, this is me thinking 'oh what am I going to do today' – and I said 'oh no, let me get up and go to the kitchen and start cooking.'"

Others echoed this sentiment, describing how inactivity could exacerbate pain; "*otherwise you just, you just seize up and you can't do anything."* Another explained *"So I don't sit at home, because if I sit there I feel my muscles become a bit restricted and so it's better for me to move around. So, that's my solution for my sciatica!"* Another co-researcher substantiated this further by saying *"because if you stay sit down, then you will be stiff and you don't move. And then there is pain everywhere."* These accounts highlight how movement required physical and emotional effort, as individuals continuously assessed what their bodies could or could not do, and how movement could help them stay mobile. The emphasis on everyday movements illustrates how they function not only as a practical necessity to be able to interact with the world, but also as a strategy for sustaining autonomy and mitigating the impact of CP.

Movement for these participants was inspired by the common everyday activities that many would take for granted. In the context of living with CP, the ordinary is reconfigured with seemingly simple movements becoming a site for negotiation, meaning-making, and the ability to remain part of the world. The emphasis on common, repeated actions suggests that meaningful movement is not defined by intensity or novelty but by the capacity to maintain participation in daily life and ritual. This reframing challenges dominant cultural narratives that equate movement with performance or productivity, instead foregrounding the value of small, sustained acts that support wellbeing and agency.

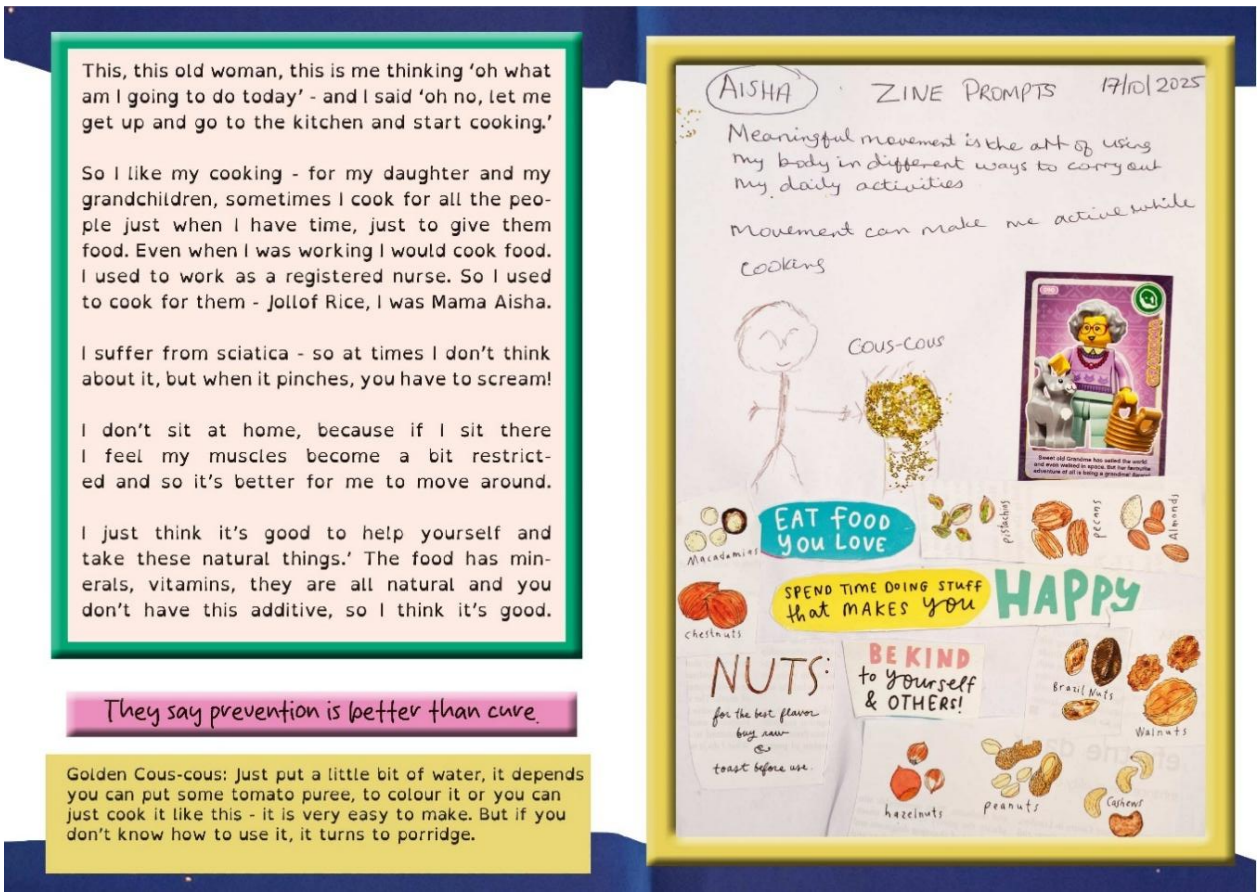
Providing for Others: Movement and Identity

Providing for others is something that powerfully emerges from the zine contributions. For several co-researchers movement was motivated not solely for personal need but a desire to care for family, friends, and the peer-group community. This outward facing purpose appeared to support co-researchers in remaining active despite the challenges of their CP. One group member described how cooking for her family encouraged her to leave the house, even if she was *"walking down the road slowly to go to the shops."* The act of preparing a nourishing meal offered both a reason to move and a way to maintain her identity as someone who gives care, rather than someone defined

by needing care (Figure 13). Another care-researcher elucidated the physical toll of getting to the peer-group session, *"I mean I haven't been doing much walking and I found when I was coming it was really painful walking down the road, because I thought 'I've never felt like this before' but the walking bring the pain on and I felt pain everywhere. And I just thought, god, what is going to happen to me."* Despite the pain she was feeling, the co-researcher fought through to make it to the group session because showing up for others helped her to feel more connected. These stories are particularly significant given the isolating nature of CP, which can generate emotional distress, frustration, grief, and a sense of disconnection from both one's own body and from others. Providing for loved ones and being part of a collective support group where members rely on each other, enabled these co-researchers to sustain relational ties and preserve a valued sense of ones' self.

Figure 13:

Chronic pain – the invisible dance partner: Pages 5&6



Note. The contribution on page 6 of the zine has been created by one of the co-researchers to demonstrate what was important to her: food and care through cooking. Aisha has written part of her response to the zine prompts and then filled her page with found images of nuts and seeds, words that resonated with her, finishing off the contribution with a dazzle of golden glitter to help her cous-cous shine. Page 5 includes her verbatim description of what is happening in the image opposite, and explaining what motivates her – and a recipe for her golden cous-cous recipe.

Another co-researcher further illustrated this theme through her drawing of *"my little garden."* Across the workshop sessions, she regularly arrived with something she had grown or baked – rosemary, thyme, banana cake – to share for others to enjoy. Although she was modest about these offerings, the group often responded with delight, praising her baking and eagerly taking their share of whatever she had brought that week. Not only does the act of gardening support this member to remain mobile and cultivate life outside of herself; *"when sometimes your fingers you can't, they're not so great and you go out [to the garden] and you try anything, to do something and it's not as bad, you know"*, but it also enables her to contribute to the peer-support group in tangible, nourishing ways. Through cultivating plants and preparing food, she enacted care, generosity, and participation while also reinforcing her role within the community and offering a form of embodied connection that extended beyond verbal expression. In this way, providing for others became both a motivation for movement with CP, and a meaningful expression of identity, community, and reciprocity. These exchanges created a warm, familial atmosphere within the peer-support group, reinforcing the sense of mutual care that underpinned their relationships. It was common, while working with the group, to hear one member refer to another as their *"guardian angel"* or *"life-saver,"* expressions that reflected the depth of appreciation and interdependence that had formed with the group.

This theme highlights how supporting and providing for others becomes a meaningful driver of movement when living with CP. It reframes activity as a relational and identity-affirming practice beyond the objective physical act of moving your body allowing the members to do activities they like and show care. One of the co-researchers explained how her experience of being house-bound and then finding a *"way out of the darkness"* had led her to want to motivate and support others who may feel the same: *"I tell that to others and encourage others when I see them, even on crutches, cause I was on crutches too so that the hope will never fade away."* The opportunity to pay it forward and focus on helping others following her own difficult experience keeps this co-researcher moving despite her bad days – like pushing through to be at the group sessions, even when the movement and energy required for engagement feels hard sometimes. The motivation to sustain movement for the co-researchers in this group was not solely driven by the view of wanting to improve individual conditions, but rather motivation interacted with the desire to nurture, contribute, and connect with others. In this sense cooking for family and friends, nurturing life, and exhibiting generosity functioned as embodied forms of agency, countering the isolating effects of CP. These acts enabled co-researchers to inhabit roles which felt purposeful and valued, rather than

positioning them as the receivers of care and burdensome to others. This relational orientation complicates dominant narratives that often frame CP primarily through loss or limitation, instead illustrating how movement can be anchored in reciprocity, contribution, and the maintenance of social bonds.

Engaging with Nature: Importance of Being, Doing and Enjoying the Outside

Engaging with nature emerged as another theme, offering co-researchers both opportunities for physical activity as well as a source of relaxation, grounding, and accomplishment. For many, going outside was not framed as exercise, but as a way of being in the world. As one group member explained, *"I like to do it when the sun shines, or just doing it sometimes when I am not feeling, great – so I go out there and try."* Her description helps to capture the both the tentative effort of *"trying"* and the quiet pleasure of being among living things especially on a sunny day (Figure 14). The zine itself is also filled with recurrent imagery of plants, birds, butterflies, open water, and other natural settings, reflecting how strongly nature and being outside resonated with the group.

Figure 14:

Chronic pain – the invisible dance partner: Pages 7&8



Note. Pages 7 and 8 became a double spread within the zine due to the landscape image the co-researcher sketched. Using coloured pencils the co-researcher sketched her garden and added the annotations to ensure viewers would be able to recognise what produce she was growing. The same co-researcher asked for the words "an important space for people to garden with others, relax, socialise, and take part in creative activities." The words the surround the image are the co-researcher's description of what she has drawn.

Many group members had gardens, even modest ones – *"just a few boxes really,"* – but it was not just about tending their own gardens that was important, but being outside in any form was important. Gardens were valued because they were easily accessed and could be enjoyed even on difficult days. Gardens and gardening offered a sense of creativity and creating, allowing co-researchers to embrace activities that brought pleasure, such as growing tomatoes or simply sitting amongst the plants and keeping the cats from damaging their beauty. One member drew her garden, and narrated it with pride: "I have drawn some rosemary, which is a herb, um, this is pumpkin and that's my sunflower plant. I did have it, it's real." Stepping out into the garden was a place to feel calm, purposeful, and connected – a small but meaningful space where movement and enjoyment could coexist.

For several group members, leaving the house and spending time outside in nature was described as essential for supporting their mental wellbeing. As one co-researcher put it plainly: "*when you stay indoors, it is all the negative thoughts that are there – so it is better to go out!"* Another reflected on the emotional shift she experienced when outdoors: *"[when you are out] you forget the pain, and then when you come back home you get pain again!"* These accounts highlight how nature and the outside world functioned not only as an environmental backdrop for movement, but as an active contributor for emotional regulation, motivation, and a sense of vitality. Being outside offered a temporary reprieve from both physical discomfort and the psychological weight of CP.

This theme highlights how nature operates as a restorative space for people living with chronic pain, offering a counterbalance to the physical and emotional constraints they experience. Movement in natural environments was not framed as exercise in a conventional sense, but as a gentle, accessible way of reconnecting with the body and interrupting cycles of rumination or isolation. The repeated natural imagery throughout the zine suggests that co-researchers locate meaning and comfort in the out-of-doors, positioning nature as both a motivator for movement and a companion in their self-management practices. In this way, nature becomes embedded in the group's capacity to keep moving whilst in pain, enabling agency and intertwined with wellbeing.

Cyclicality of Chronic Pain: Moving Through the Cycles

The **cyclicality of chronic pain** emerged as a prominent theme shaping how co-researchers approached movement. They described how symptoms fluctuate, with periods of relative ease punctuated with flare-ups which make movement difficult or inaccessible. During these episodes, many avoided physical activity for fear of exacerbating their pain, which in turn contributed to a cycle of reduced strength, flexibility and stamina. As one co-research explained, *"occasionally pain in my joints can prevent me from making the movements required for swimming"* capturing how even valued activities could regularly become out of reach. These fluctuations caused a sense of urgency on the good days. When it was Angela's birthday she told us that she was celebrating by doing as many things as possible because *"you've got to do it when you can!"* Others echoed this tension – the push and pull of wanting to move, and fearing the consequences. One researcher described this internal conflict clearly: *"When you have chronic pain you can be afraid to do [stretching/moving] because you're in so much pain that you don't actually want to do anything… but by actually stretching the muscles, it's actually beneficial."* Her words highlight how frequently *"bad days"* disrupted the activities group members enjoyed or hoped to do, and how movement was continually negotiated in relation to fluctuating symptoms.

This fluctuating nature of CP was also expressed visually throughout the zine. Co-researchers used imagery that evoked cycles and repetition: gardens shifting through the seasons, daily rituals such as cooking dinner or making a morning cup of tea, and butterflies symbolising transitions. These images collectively illustrate how co-researchers understood their experiences as continually shifting rather than stable or linear. One recurring ritual was the task of chasing cats from the garden (Figure 15). During the workshop, the co-researcher who created this page spoke about wanting to *"chase the cats out her garden,"* but her *"legs don't move like that,"* so she chose a bold image of a superhero with no legs to represent the energy she wished she had. Group members also spoke about how the fluctuating nature of their CP made it was difficult for others to see or understand – the invisibility of these cycles adding another layer of challenge to their daily lives.

Figure 15:

Chronic pain – the invisible dance partner: Pages 9&10



Note. This visual contribution from a co-researcher was produced following initial resistance due to feeling not so good on the day of the workshop. The image is simple yet impactful with the co-researcher choosing images from a magazine for me to cut out for her and then layering them on the bold background of a garden in bloom. The words at the top of the pages reflect how the co-researcher was feeling that day – she spoke about wanting to chase the cats out her garden, but her legs "don't move like that" and so that's why she chose a strong image of a superhero character with no legs to represent the energy she wished she had to shoo the unwanted cats. The other verbatim text on the page reflects what other members of the group mentioned about the more difficult periods of their movement journeys while living with chronic pain.

This theme underscores how living with CP disrupts linear understandings of progress and managing conditions, instead situating movement as a form of self-management within a dynamic ebb and flow. Co-researchers' accounts reveal that meaningful movement is not able to be a stable or predictable practice, but that it must adapt to pain rhythms, emotional states, and fluctuating capabilities. The cyclical imagery in the zine suggests that the group conceptualises their CP journeys not through narratives of recovery or decline, but through ongoing negotiations and movements. This reframing challenges dominant biomedical narratives that emphasise consistency and improvement, highlighting instead the importance of physical and emotional flexibility in navigating CP and movement.

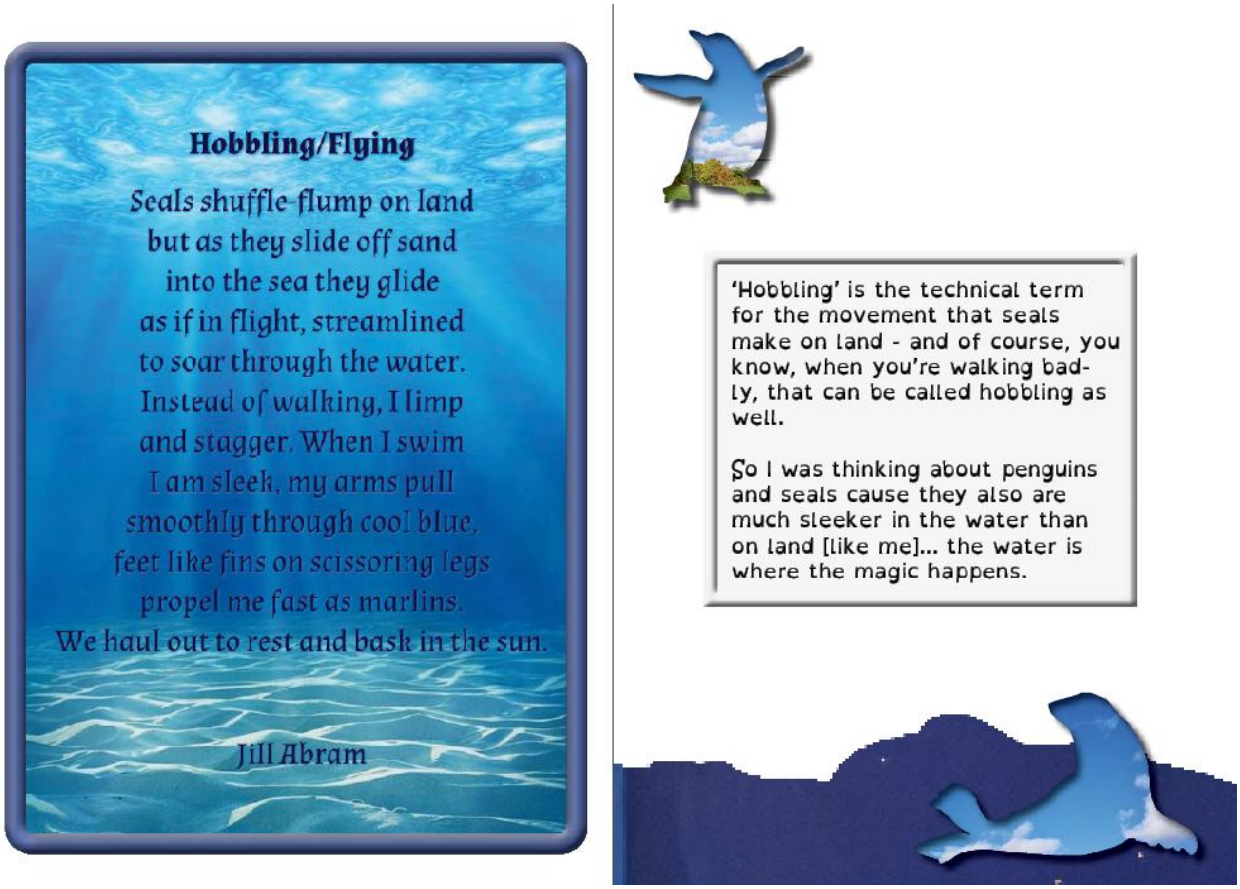
Metamorphosis: Changing Relationships with Movement and Finding New Meaning

The theme of **metamorphosis** emerged through contributions and co-researchers' reflections on how CP continually reshapes their capacities, routines, and relationships with movement. Some of this transformation was tied to the cyclical nature of pain, some reflected the shift from a life lived without CP to one often dictated by it so they were transformed from their past selves, and some was transforming the ways in which they could move despite the pain. Many of the researchers described a period of uncertainty before receiving a 'name' for what they were experiencing. They recalled the struggle to articulate their experiences or feel heard by healthcare professionals. It was only once they were given the words *chronic pain* that they could begin to make sense of what was happening to their bodies and start to adapt. Having a name enabled the co-researchers to learn about the condition affecting their lives and to explore what they could do to help manage it, such as moving in different ways of adjusting expectations they once held for themselves. In this way, metamorphosis was not just physical but psychological and social, involving shifts in identity, understanding, and the strategies they used to navigate daily life.

One co-researcher explored the idea of transformation through the juxtaposition of *hobbling* on land due to pain and *flying* through the water with relative ease (Figure 16). *"To me meaningful movement means swimming"* she explained. The co-researcher explains that "as in the water is where the magic happens" she chose to place her poem, carefully composed within the first workshop, on an image of a calm underwater scene. The way the light bounces and suggests movement and gives a sense of serenity was a purposeful decision to evoke these feelings for the viewer of the zine. The shift that occurs when she enters a more supportive environment was described as *magical*. In water, buoyancy reduces the weight and strain placed on painful joints and limbs, enabling her body to move with a pace and grace that is otherwise inaccessible to her. This physical transformation is accompanied by a psychological one: in water, she moves from feeling like someone who 'staggers' and may be perceived as vulnerable or unwell, to feeling like a person unburdened by limitations. The imagery of metamorphosis – echoed throughout the zine through butterflies and other symbols of change – captures this profound sense of becoming, where movement is not fixed but continually re-imagined in response to the different states of chronic pain.

Figure 16:

Chronic pain – the invisible dance partner: Pages 11&12



Note. Jill spent time contemplating and very purposefully wrote this poem during the zine making session. She typed it up herself and chose the background which she felt fitted best with her vision. She then talked to me about the metaphor of animals that live in water and on land, and how different their movements are depending on the environment.

The contrast between hobbling on land and flying in water illustrates how environments radically reconfigure what movement feels like, what the body can do, and how individuals perceive themselves. This transformation is not merely physical but it is deeply tied to identity and self-worth. In water, the co-researcher experiences a temporary suspension of the limitations that shape her day-to-day life, allowing her to inhabit a version of herself which feels freer and less defined by the pain she experiences. This metamorphosis and moment of transformation for the co-researcher, challenges static or deficit-based understandings of pain, revealing instead the dynamic process in which people adapt, re-imagine, and find new forms of expression.

The recurring images of butterflies throughout the zine also reinforced this sense of ongoing becoming, suggesting that meaningful movement is not fixed but continually reshaped through changing contexts. The co-researchers were drawn to the images of butterflies which were intermingled with other found images for collaging. They each individually chose the images of the butterflies to include, and spoke about how they were drawn to them because of their beauty, perceived lightness, and particularly how they transform from a caterpillar through to a butterfly. *"Where you first have chronic pain, you know you're a caterpillar crawling or trying to crawl, or trying to walk and then you go into this dark place and it takes a while for you to accept that you have chronic pain and once you do accept chronic pain you can come out at the other end by um, trying to get on with your life. Things that you'd stopped doing you can now begin to do again"* one of the co-researchers explained. This description helps to capture and illustrate the emotional and physical shifts that accompany CP. The movement between capability/limitation and hope/frustration.

The theme of metamorphosis offers a powerful lens through which to understand how group members navigate the shifting terrain of chronic pain. Their stories and accounts highlight that movement is not a stable or predictable practice but one that must be constantly reimagined in response to pain rhythms, emotional states, and changing environments. Having to trial and learn new strategies, with each day being an unknown means there is a constant challenge they are faced with. Metamorphosis captures this dynamic process of adapting and finding new ways of expression and ways that one is perceived in the world. Much like how a caterpillar and butterfly are usually judged differently to one another. Metamorphosis aligns with the process through which co-researchers continue to craft meaning, agency and identity in the midst of chronic pain. As one group member put it, *"I'd like them [anyone viewing the zine] to see it's a process that you're going to, that you go through but you can come out at the other end, even if you're living with chronic pain."*

Optimism: Joy, Hope and Dance

The zine exudes **optimism** and gratitude, reflecting the group's commitment to find joy and possibility even when living with persistent pain. The peer-support group's name - *PEACE and JOY* – was not merely symbolic; these values were woven through the stories and artistic contributions the co-researchers chose to share. *"I would have liked to put more colours on my zine page - this is about joy in movement and God,"* one of the co-researchers explained. She had already covered her zine page in colours, but felt like she wanted more in order to emphasise the role of joy and faith in

the ways she meaningfully moved (Figure 17). Joy danced off the pages through the choices of bright colours and thematically in the repeated encouragement to *"spend time doing things that make you happy,"* highlighting how participants intentionally sought out forms of movement that felt good and emotionally uplifting. For many, joy and optimism was not accidental and rather an intentional practice of seeking out movements that felt good, and accessible even on the bad days. It is important to note that this optimism coexisted with the pain, and did not replace it. They spoke, instead, about taking part in *"something that is joyful"* and that this was an important part of what motivated them to move.

Figure 17:

Chronic pain – the invisible dance partner: Pages 13&14



Note. What was striking to me was the sense of joy, hope and tenderness in the stories shared and the relationships between the group members – which was extended to us as facilitators. These pages show the abundance of colour, glitter, and movement which the co-researchers chose to communicate with. Page 13 was created by a co-researcher using her gaming name 'Sunishi' and she explicitly chose the images of birds, flowers, glittery patterns, golden stars and patterns because of the colour and joy they portrayed. The other important message which Sunishi wanted to communicate was the important role which God plays in her relationship with chronic pain: *"God got me to know and love myself."* The verbatim quotes on page 14 are not only from Sunishi, but other members of the group who also referenced their relationships with God and spirituality.

Dancing emerged as a particularly resonant example of joyful movement for many of the group members. One co-researcher explained, "*Dancing is something that naturally makes you happy. You can never see anyone dancing and they are miserable. It's something that brings joy to their life."* Another added, *"I like dancing… If I can, I try to. [I like] the movement, you don't stay still!"* For many, dancing offered a way to temporarily shift attention: *"If you are enjoying it you forget the pain."* These reflections highlight how movement associated with pleasure and expression could momentarily soften the presence of pain and reconnect individuals with a sense of vitality.

This sense of joy was not naïve or dismissive of difficulty. Rather, it was grounded in acceptance and a deliberate orientation toward what remained possible. As one co-researcher put it, *"I put 'gratitude' because sometimes you have to be thankful."* Another described the emotional and relational significance of dancing: *"It says that it's more than a dance class, it's a lifeline. And I believe that because um when you are in that dark place of sort of, and in chronic pain, when you dance to your favourite music it brings you back to life again. It brings you back to life."*

This theme illustrates how optimism functions not as forced positivity but as an embodied strategy for navigating CP. Co-researchers' emphasis on joy, gratitude, and pleasurable movement suggests a reframing of meaningful movement away from obligation or therapeutic prescription and toward emotional nourishment and self-affirmation. Dancing, bright colours, and references to enjoyment signal a refusal to let pain wholly define their identities and experiences. Instead, co-researchers foregrounded moments of lightness and connection that coexist alongside difficulty. One group member captured this beautifully when she explained that what she loved about dancing was *"the movement, you don't stay still anything,"* before adding with a grin, *"I like the, what do you call it, the banjo! [And is that important?] Yes it is!"* Her giggle and the way she almost danced in her seat as she recounted the sound of a banjo conveyed a playfulness that was as meaningful as the words themselves. This orientation of acceptance and finding the joy aligns with broader understandings of resilience in chronic illness, where acceptance and joy are not endpoints but ongoing practices that help individuals sustain engagement with life, community and movement. Optimism, in this context, becomes a form of resistance – an insistence on finding meaning, pleasure, and possibility within the constraints of CP.

The Invisible Dance Partner was collaboratively chosen as the title for the zine. The working title, *Moving With Pain*, was unanimously rejected by co-researchers as they said it felt too flat, clinical

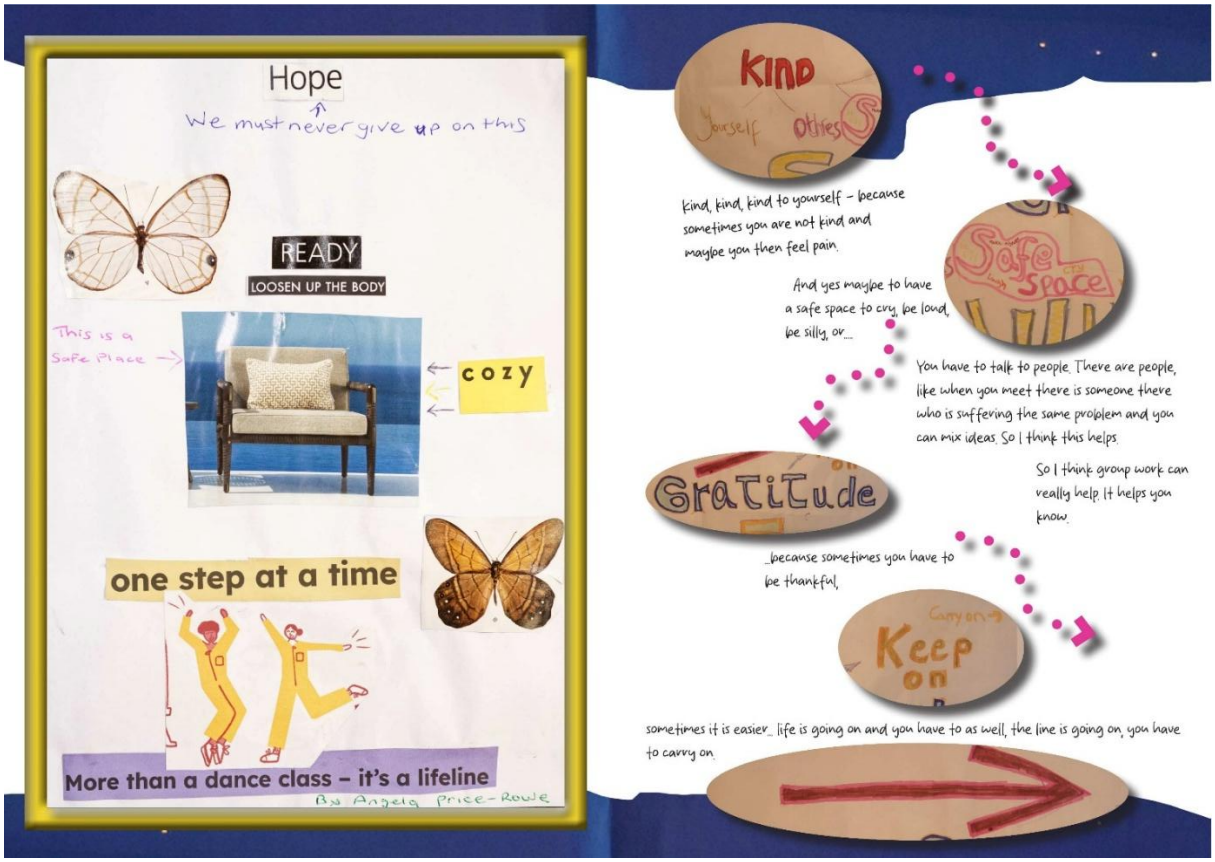
and far away from their lived experiences. They were clear that the title needed to include *invisibility*, reflecting the hidden, often misunderstood nature of CP, and also that there was something that conveyed its constant presence – always with you, shaping your steps whether you wanted it to or not. At the same time, they wanted the title to hold something uplifting, something that reflected the joy, humour, and playfulness which emerged throughout the workshops. Dance had already surfaced as a powerful symbol of hope and expression, so weaving it into the title felt natural and authentic to the group. As the group explained, a dance partner can step on your feet, pull you off balance, take the lead when you don't want them to, or refuse to follow the steps you have been practicing. But a dance partner can also, in moments of synchronicity, bring joy and a sense of being carried. Chronic pain and meaningful movement, they suggested, is much the same; unpredictable sometimes clumsy, overwhelming, but also occasionally allowing moments where movement felt possible again, even transformative, even if temporarily.

Self-Compassion: Never Give up on Hope

Self-compassion emerged as an essential theme in how co-researchers navigated and made sense of chronic pain. Co-researchers described self-compassion as a practice that fosters resilience, reduces stress, and supports their capacity to keep moving. This was expressed explicitly through phrases such as *"kind, kind, kind to yourself – because sometimes you are not kind and maybe you then feel pain,"* as well as through the gentle placement of images and soft visual motifs throughout the zine (Figure 18). Self-compassion was closely tied to recognising personal limits and acknowledging that, at times, stepping back is necessary. Mindful rest and pacing were described as vital strategies that enable co-researchers to sustain movement over time.

Figure 18:

Chronic pain – the invisible dance partner: Pages 15&16



Note. Page 15 was contributed by Angela, the expert by experience leader of the peer-support group. She created the page through collage, allowing the images to find her as she sifted through the materials on the table. Angela has added images of butterflies to her contribution as she flet a great affinity with them, and the process they go through from caterpillar to cocoon through to butterfly. Page 16 shows cut-out sections of the reflection page one co-researcher made during the collective conversation held. These were the main theme she identified as coming through all the other contributions. Using coloured pens she doodled on the white paper on the table-top, and then explained to me what she had drawn – which is what the verbatim text explains.

> *"Also my page has a chair in it, that is a safe place for people with chronic pain. This chair is a cosy chair. It looks nice and it actually feels really comfortable for when we need to sit down to rest our achy bodies."*

This imagery reflects how rest was not framed as failure or inactivity, but as an intentional, compassionate act that supports ongoing engagement with movement. The theme of self-compassion also connects strongly with the earlier emphasis on optimism. The group members expressed a supportive, understanding attitude toward themselves, recognising that small, everyday

actions count as meaningful movement. Movement did not need to be big, extensive, or intense to matter; instead, listening to one's body and accepting that capacity fluctuates allowed for consistency across the ups and downs of chronic pain. As one co-researcher shared, *"The top of my page actually begins with the word Hope and I've always said to myself and to others, we must never give up on hope. It's something that you must always think that you can do."* Another added, *"He's holding something precious… or she's holding that when they're in pain, and showing people that there's something there that can be used,"* highlighting how compassion also extends to recognising one's own value and potential even in moments of difficulty.

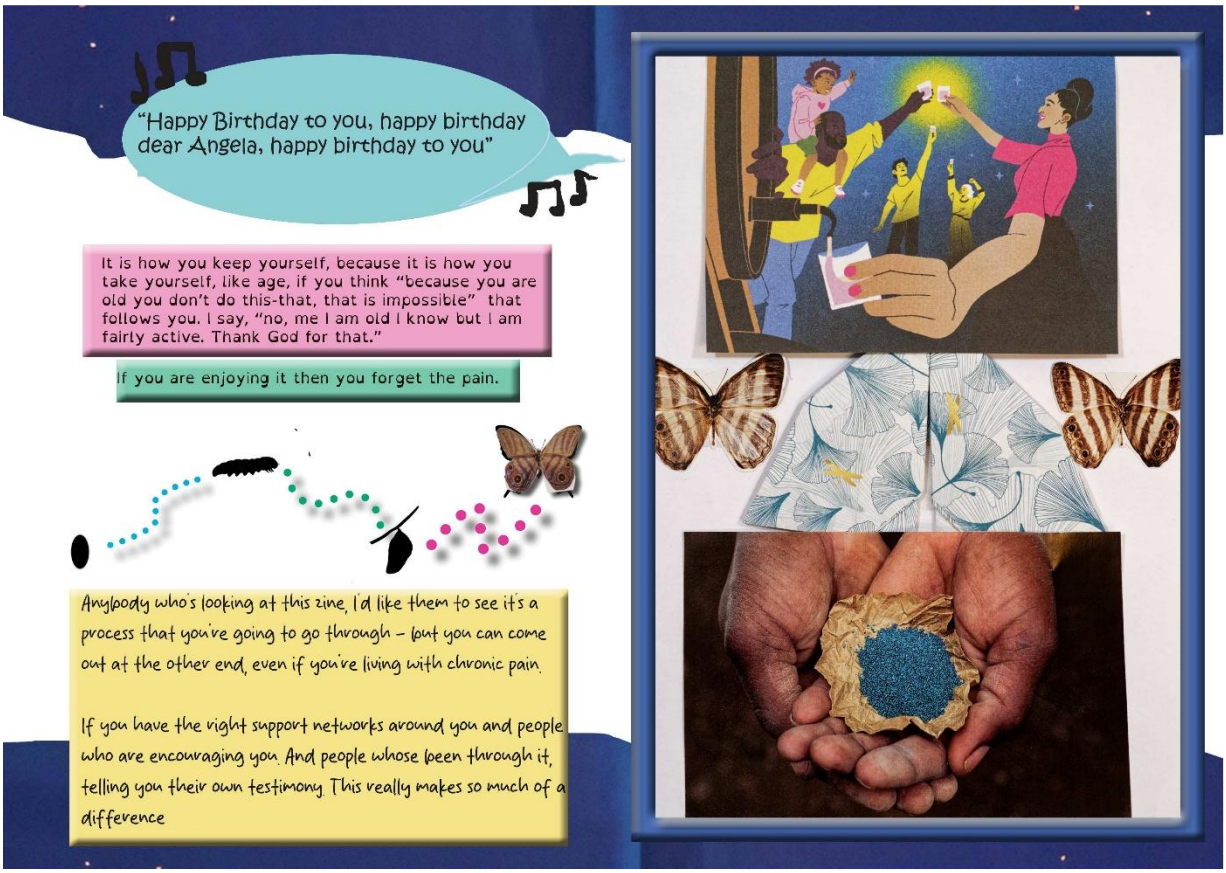
This theme reveals how self-compassion operates as both an emotional and embodied practice within the context of moving with chronic pain. Rather than pushing through pain or striving for productivity, co-researchers emphasised gentleness, pacing, and acceptance as meaningful forms of movement. Self-compassion becomes a counter-narrative to dominant neo-liberal and capitalist cultural expectations of endurance and constant activity, offering instead a framework in which rest, slowness, and attentiveness are understood as legitimate and necessary. The imagery of cosy chairs, hopeful words, and precious objects suggests that co-researchers cultivate internal and external spaces of care that support their ongoing engagement with life and movement. In this way, compassion is not simply an attitude or approach, but a relational practice – towards oneself, one's body, and one's fluctuating capabilities – that ensures sustainable, meaningful movement.

Connection and Community

Connection and community emerged as essential elements enabling meaningful movement for co-researchers. Living with chronic pain can be profoundly isolating, and participants emphasised the value of being part of a group where others genuinely understood their experiences (Figure 19). The PEACE and JOY Peer-support Group offered emotional and psychological relief, creating a space which can help individuals cope with the challenges of chronic pain and support one another through a mutual understanding. As one co-researcher explained, *"If you have the right support networks around you and people who are encouraging you. And people's whose been through it, telling you their own testimony – this makes so much of a difference."*

Figure 19:

Chronic pain – the invisible dance partner: Pages 17&18



Note. Page 17 begins with the group singing happy birthday to Angela. It was requested that this was included in the zine. The verbatim quotes are from a number of co-researchers and highlight the importance of defying stereotypes/dominant expectations and also recognising that living with chronic pain, and accepting it, is a process which can be made easier with the help of others who have also experienced it. Page 18 is the final co-researcher contribution in the zine and was made up of collage images, continuing the motif of butterflies throughout. She has also included an origami moth in the middle, which she was drawn towards due to the folds and movement it offered her image. "He's holding something. Holding something precious - or she's holding that when they're in pain, and showing people that there's something there that can be used."

The zine itself represents the first time the group created something collaboratively, and when viewed as a whole, the importance of connection becomes unmistakable. One participant was drawn to an image of people gathered in celebration, noting, *"It's like they're having a party… it looks like they are having a good time, so they are moving around a lot."* Across the pages of the zine there are images of people dancing together, symbols of spirituality, and references to family and caregiving which all reinforce the significance of shared experience and collective energy. As another co-researcher reflected, *"so I think group work can really help – it helps, you know."*

The ability to talk openly with others who live with chronic pain enables group members to exchange ideas, learn from one another, and generate new strategies for coping. One co-researcher clearly stated this: *"Yeah it is better than when you just sit down there and you don't even know what to do. You have to talk to people. There are people, like when you meet there is someone there who is suffer the same problem and you can mix ideas. So I think this helps."* Through connection, participants found not only emotional support but also motivation, inspiration, and a sense of belonging that made movement feel more possible and more meaningful.

This theme highlights how meaningful movement is not solely an individual endeavour but a relational one. For co-researchers, connection functioned as both a motivator and a form of embodied support, counteracting the isolation that often accompanies chronic pain. The collaborative process and creation of the zine demonstrates how shared creativity can foster solidarity, collective identity, and mutual encouragement from trusted sources. The celebratory imagery, and request for "*Happy Birthday dear Angela"* to be included in the zine, suggests that movement becomes more joyful, more accessible, and more sustainable when experienced alongside others. In this way, connection is an active force which helps shape how group members understand their pain, their capabilities, and their possibilities. Community becomes a site of healing, learning and co-creation – an essential component of meaningful movement within the context of chronic pain.

Invitation Seven: Interpreting creative data

ZINE PROMPT: What do these findings tell us about meaningful movement and living with chronic pain?

Add your own interpretations, agreements, disagreements, or questions. How do they fit within the wider body of literature – or your world?

Summary

As we immerse ourselves in the zine contributions, and listen to the voices and narratives interwoven in the audio narrative, meaningful movement with chronic pain reveals itself as something kind, rhythmic, and deeply human. It is not static, or defined through single physiological acts, but is dynamic, relational and contextual – shaped by bodies, environments, relationships, and beliefs. Movement for this group of co-researchers lives within the quiet rituals of everyday lives, in the hands that cook the golden couscous for others, in gardens tended, and seasons turning. The group's reflections on metamorphosis highlight how changing contexts can transform what movement feels like, while the themes of optimism and compassion reveal the emotional practices that sustain movement even in the face of persistent pain and the challenges it brings. Finally, the zine shows how movement with chronic pain is underscored by connection and community. This acts as motivation, a source of learning, and shared understanding.

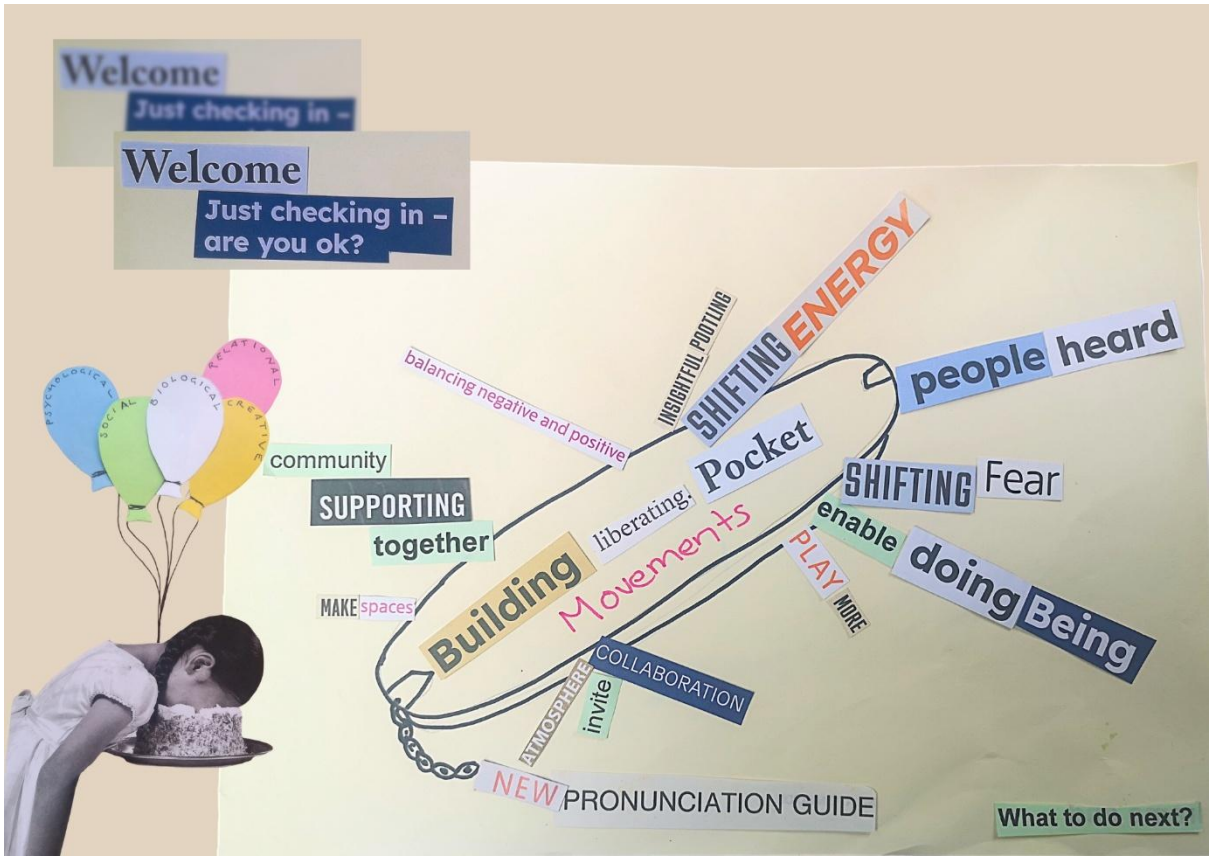
Together these thematic findings offer a rich, multi-layered tapestry of movement that is not linear or perfect, but cyclical, relational, and alive. They demonstrate the power of creative, participatory methods to surface embodied knowledge that might otherwise remain unarticulated. In keeping with participatory and arts-based approaches, this chapter has focused on articulating what emerged from the creative work and research process. The discussion that follows considers the broader implications of these insights, and how they contribute to an alternative narrative and understandings of chronic pain, meaningful movement, and knowledge production.

Chapter Six: So What Does This Mean…

As I approach the final chapter of this thesis, feeling a little like the girl in the image below – overwhelmed – I am also so proud of what the co-researchers have been able to achieve and more focused on the colourful balloons which reflect the joy, creativeness, and community that this whole research process has meant, and the knowledge and tools the group have created (figure 20). I encourage you to re-read the zine or listen to the audio to re-immerse yourself in the research before reading the summary of findings to follow.

Figure 20:

What's the point of all this?



Note. Personal reflective zine-response. Materials used include colour post-it notes, biro pen, collage images and edited on Canva. The image on the righthand side depicts a Swiss Army Knife with the tools and knowledge which was produced within the group, and that they have cultivated for themselves (and others).

This study explored *meaningful movement* in the context of chronic pain (CP), through participatory arts-based practice, while also legitimising lived experience as knowledge. This final chapter summarises the findings in a section titled 'Meaningful movement.' In order to acknowledge the

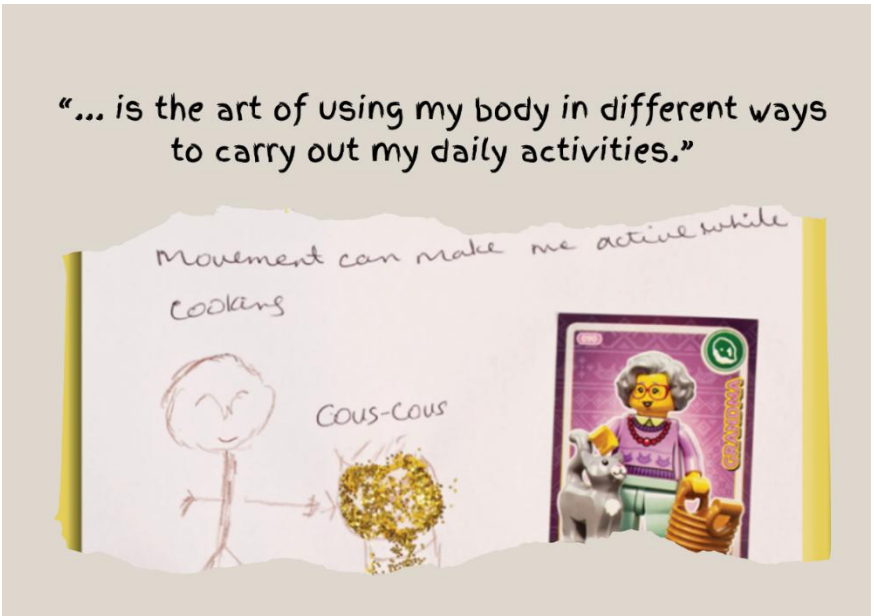
action enabled through this research approach I also highlight the dissemination of the zine and how this contributed to the impact of the research. I then discuss the findings in relation to the biopsychosocial model and outline the limitations of this framework. Lastly the strengths and limitations of the present study are considered alongside recommendations for future study and action.

Meaningful Movement

The zine-making enabled co-researchers to articulate experiences of chronic pain (CP) and explore meaningful movement in ways that are often difficult to express within clinical and academic frameworks. A significant element of analysis and understanding is situated within the collaborative zine and accompanying audio narrative, which serve as the main sites of meaning-making. I have therefore included selected quotes and visual snapshots from the zine edited together to form a figure, to support this discussion and ensure that co-researchers' voices are heard throughout (Figure 21). These are intended to be read within the flow of the discussion and not require over clarifying.

Figure 21:

Common everyday movement - snapshot of the zine and audio narrative



The thematic analysis in Chapter Five reveals the overarching themes of *common ever day movements emphasising continuity, providing for others: movement and identity, engaging with nature: importance of being, doing and enjoying outside, cyclicality of pain: moving through the*

cycles, metamorphosis: changing relationships with movement and finding new meaning, optimism: joy, hope and dance, self-compassion: never give up on hope, and *connection and community* which emerged from co-researchers' creative contributions and the participatory research process.

Movement and physical activity are main characters within the stories of those living with CP. This study demonstrates that movement is meaningful and the *meaning* of movement shifts past being a synonym for physical activity or exercise, but instead refers to the ways that movement holds emotion and personal purpose. Movement emerged not just as a clinical prescription, but as a lived and relational experience as demonstrated through the examples of how people articulated and identified the ways in which they moved.

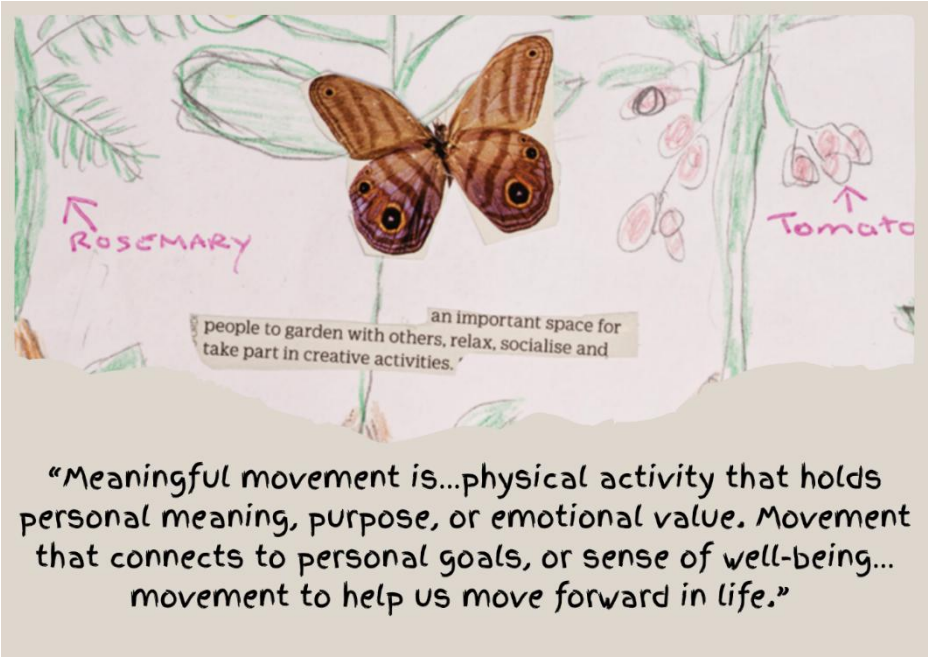
Co-researchers framed movement as meaningful when it supported their ability to partake in everyday activities such as cooking (figure 21 above) as well as helped them to accept their condition and engage in enjoyable and life-encouraging movement. There was also an illustration of where movement enabled co-researchers to transform within the moment, for example the shift from hobbling in pain on land – to gliding through the water with relative ease. Through co-researchers' narratives and metaphors, movement is shown to be a meaningful process through which identity is renegotiated and their sense of self is reconstructed in the context of CP.

Meaningful movement was deeply embodied, shaped by sensations, rhythms and necessary negotiation of symptoms. The collaborative zine revealed that meaningful movement often emerged in small, gentle, or creative forms. This was demonstrated through simple stretching, stepping outside into the garden, and dancing all being described as ways co-researchers engaged in movement to support their managing of their symptoms and their emotional wellbeing. There were no grandiose demonstrations of physical vigour like running a race, climbing mountains, or winning a sports tournament which shifted the narrative away from more mainstream measures such as intensity and duration of movement. This highlighted that meaning attributed to movement is seemingly humble and mirrors the invisible nature of CP. Meaningful movement, in the eyes of those living with CP, is often overlooked in clinical measures of what is determined as physical activity of significance in the context of managing CP. It is difficult to measure and articulate such an embodied experience and feeling as meaningful movement, but through the creative process, co-researchers were able to demonstrate emotion and tacit forms of knowledge to demonstrate that meaningful movement is an emotionally grounded concept, shaped by identity, community and creativity.

Rather than following a predictable trajectory of improvement, movement was depicted as cyclical; illustrated through the recurring motif of butterflies, life-cycles, and the recognition of the need to rest and enact self-compassion on the harder (more painful) days. The zine contributions resisted dominant sociopolitical narratives of linear recovery or a return to 'normal', instead presenting movement as a meaningful way to remain connected relationally and socially, helping to accept the pervasive reality of living with CP and finding ways to live quality and meaningful lives despite this. Figure 22 illustrates this with the zine snapshot showing an example of the garden as a place of connection and relaxation, and the quote explaining that movement is not about 'getting better' but rather about "*moving forward*" with pain. Other co-researchers explicitly shared they had learnt through their pain management programme that their pain was chronic and therefore not curable, but that they had been taught ways in which to live with it. This learning was reflected in the way they approached talking about their pain together, and impacted on their thought-process when asked *"what is meaningful movement"* as part of this research.

Figure 22:

Moving forward with meaning – snapshot of the zine and audio narrative



The creative process surfaced moments of joy, playfulness and experimentation in both the research process and the illustrations of meaningful movement. These forms of movement are rarely acknowledged within CP research and research practices themselves can be tiresome for members of communities who often come under traditional 'observation'. The collaborative zine-making informed by participatory-action tenets of co-researcher agency and disrupting power imbalances

helped to demonstrate how research can be both practical and enjoyable. Members of the group voiced a strong sense of ownership over the creative artefact produced, and the narratives shared. Joy was expressed not despite pain, but alongside it, illustrating that meaningful movement can coexist with pain and discomfort. The reader can observe the joy in the zine, shown through the bright colours chosen, the specificity of dancing due its role in making movement enjoyable, and taking advantage of when one's body allows you to move how you want to by *"doing stuff that makes you happy".*

When taken together, these findings show that meaningful movement is an embodied, emotional, relational, and identity-laden process that transcends traditional measurements of physical activity. The study demonstrates that meaningful movement can be shaped by creativity, community and personal purpose which are dimensions that can be overlooked within clinical practice.

Democratising Knowledge – Creative Dissemination

One of the main strengths of this project was the methodology and the relational values which scaffolded the implementation of it. A key strength of arts-based research (ABR) is that it often leads to research outputs which can be used to engage diverse audiences with the knowledge produced (Murray & Gray, 2008)**.** Distributing the zine and audio narrative formed the final step in the research process, and was important as part of the participatory process. The co-researchers and other members of the group were all presented with a professionally printed copy of the zine to keep as a tangible artefact of what they had created together. The group leaders also proactively shared the finished zine and audio with the National Centre for Creative Health[6] to be considered for their *Creative Health Research Round-Up 2025* as well as organising a celebration event to 'launch' the zine and use it to offer an opportunity for reflection and reconnection for group members, the healthcare professionals who worked with them through the pain management programme, and local system leaders such as councillors. Further, the zine and audio narrative were hosted on the Thriving Stockwell website[7] including a downloadable version of the zine for home printing to further the sharing potential of the artefact and resource. Lastly, the zine was archived within the Wellcome Collection's zine library[8], further enshrining the creative testimonies in the academic and creative health cannon.

[6] https://ncch.org.uk/
[7] https://www.stockwell.org.uk/2026/01/19/moving-through-pain-a-zine-created-by-the-peace-joy-chronic-pain-peer-support-group/
[8] https://wellcomecollection.org/works/au3cu2mq

This act of dissemination and archiving helped to extend the work beyond the peer-support group and the present academic space, and into wider networks that shape the co-researcher's lives. While the process of creation of the zine and the individual contributions to the publication and the audio narrative allowed for the group to articulate their experiences, values, and embodied knowledge, the circulation of the products allowed these expressions to be witnessed, digested, and responded to by others. In this sense distribution was not simply dissemination; it was a continuation of the collaborative ethos that underpinned the entire project. What follows is a reflection on the impact and significance of dissemination as the final phase of the research process.

The zine as a piece of research within itself was accepted and included in the National Centre for Creative Health's Research Round-Up (2025). This demonstrates how the co-researcher's creative work resonates beyond the immediate context of the project and academic thesis. The round-up highlighted the zine as an example of participatory creative health practice, positioning it within the category of *creative health communication and literacy*. This section of the report focused on "knowledge mobilisation designed for lived experience and public audiences rather than academic or system stakeholders and the democratic co-creation of artistic health communications with communities" (National Centre for Creative Health, 2025, P. 17). Such recognition situates the zine not only as a creative artefact but as a meaningful contribution to the growing field of creative health research.

The round-up authors explicitly acknowledged the value of the stories the group chose to share, noting: "Rather than framing pain solely as a medical problem to be fixed, the narrative presents it as an ever-present companion that must be acknowledged, adapted to and worked with over time" (National Centre for Creative Health, 2025, P.20). This interpretation aligns closely with the themes identified in the present study, particularly the cyclical nature of chronic pain, the role of acceptance, and the transformative potential of meaningful movement. The report further emphasised the communicative power of the zine, stating, "Its strength lies in demonstrating how creative expression can make lived experience visible in ways that clinical language often cannot. The piece offers readers and listeners insight into the complexity of chronic pain, helping audiences better understand the subjective realities of pain and the potential role of creative practice in health communication" (National Centre for Creative Health, 2025, P.20).

This inclusion in a national round-up, and the authentic interpretation by the author which I had no personal influence in, affirms the value of lived experience knowledge and demonstrates how creative health and research outputs can communicate complex experiences such as chronic pain in ways that are accessible, emotionally compelling, and grounded in community expertise. Importantly, it also signals that the insights generated by the co-researchers hold relevance for wider audiences, including practitioners, policymakers, and researchers working at the intersections of health, creativity, and social care. These implications will be articulated more directly at the conclusion of this chapter.

Alongside the national recognition, the zine was also able to generate impact at a local level. A sharing event was organised by Marta and Angela as leaders of the group (both peer and programme delivery leaders), hosted at a local GP practice which was involved in the initial chronic pain management intervention the group formed from. Healthcare professionals, local councillors, and some other members of the local community were invited to attend, representing a significant relational moment between the co-researchers and those who shape their local health and wellbeing infrastructures. At this event the zine was exhibited on A3 posters, copies were shared with attendees with instructions on how to print their own or distribute the online resource (Appendix H), and a number of the group who contributed had the opportunity to speak directly with practitioners and decision makers about their experiences of chronic pain, the value of the peer-support group, and their contributions to this collective health resource.

This gathering helped to transform the zine and audio narrative from a static creative artefact, into a relational tool – one that facilitated dialogue, fostered empathy and invited reflection from all in the room on how CP is understood and supported within primary care and community settings. While the experiences shared are personal to those who contributed to the zine and are not meant to share universal truths about living with CP, the narratives shared were specific to the Lambeth location as it is the context and environment where the co-researchers move and manage their CP. For the co-researchers, the event offered a rare opportunity to articulate their experiences on their own terms, using the zine and their contributions as both a creative anchor and a form of self-advocacy. For attendees, it provided an entry point into the lived realities of CP and movement that extended beyond clinical language or diagnostic criteria.

In this way, the zine's journey through national spaces and local settings embodies the very notion of meaningful movement that sits at the heart of this project. Reactions to the zine and audio narrative

highlighted the power of co-created artefacts to communicate lived experiences of CP in ways that offer alternative narratives which are accessible, affective, and resonant. Those who encountered the creative artefacts commented on the warmth, colour, and emotional honesty – qualities that invited engagement and building of empathy with the shared stories and story-tellers. This aligns with broader literature on arts-based research, which suggests that creative outputs can act as boundary objects, travelling across worlds (contexts) and opening up dialogue between groups who might not otherwise connect, somewhat similar to the way in which dance can communicate across culture and spoken language (Groot & Abma, 2021). This is particularly resonant from the point of view of those whose voices do not often have a platform to be heard in different contexts.

For the co-researchers, sharing the zine carried a sense of pride and visibility. Several expressed that seeing their words, drawings, and ideas collectively in print and collated with care and respect, made their experiences feel validated and valued. The act of sharing the zine to others became a form of advocacy, allowing group members to communicate aspects of CP that they often found difficult to articulate verbally. In this way, distribution functioned as an extension of the group's collective voice, amplifying their knowledge and insights and challenging dominant narratives that frame chronic pain solely through deficit or limitation and through clinical language.

When friends, family, and colleagues viewed the finished zine, their responses as 'lay' people also underscored the relational nature of the project. People reflected on their own experiences of pain, caring for someone with CP, or what movement was to them and what it *could* be, creating a ripple effect of connection that extended beyond the original group. This suggests that the arts-based approach taken in this study and the following creative dissemination fostered empathy and shared understanding, contributing to a more nuanced conversation about CP (Chilton & Leavy, 2020; Leavy, 2020). It demonstrates that this approach to research can generate impact not only through its findings but through the artefacts it produces and the relationships those artefacts help to cultivate. Ultimately, the distribution and reactions to the zine illustrates how knowledge created collaboratively and through creative practice can continue to move – circulating, resonating, and prompting reflection long after the workshops and production have ended and before a finished research thesis has embedded the work into the academic canon.

Together, the national recognition, local sharing event, and other personal responses to the zine illustrate how arts-based research practices which are informed by participatory tenets can move fluidly beyond the boundaries of the academic research setting. The zine becomes a moving artefact,

carrying the voices, insights, knowledge, and creative expressions of the co-researchers into new spaces. Its circulation demonstrates the immediacy of potential of creative dissemination to:

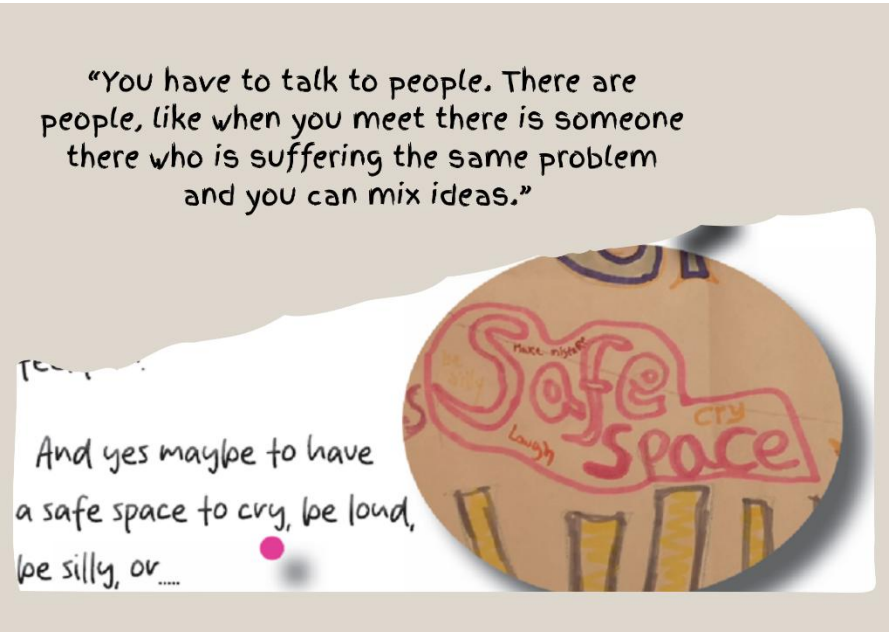
- Mobilise lived experience knowledge
- Foster connection across professional and community boundaries
- Influence understanding and practice
- Amplify voices that are often marginalised in health discourse

Communicating Chronic Pain

The process of this present research consistently pointed to the need to find and allow for alternative ways of communicating chronic pain (CP) and how it can be managed. There is a need to be able to express the shifting, embodied realities of living with CP to healthcare professionals and to family and friends. Importantly, co-researchers' expressed how having a community who "*just get it"* with who they could communicate freely in the same language, allowed them to feel seen, heard and accepted as illustrated in Figure 23. Finding places, people and spaces where it feels safe to be authentic and not have to "*overexplain"* themselves, were seen as vital by the group in managing their CP sustainably.

Figure 23:

A shared understanding – snapshot of the zine and audio narrative



Communicating CP is often constrained by the limits of language, the invisibility of the condition, as well as the structural conditions that determine whose accounts and ways of expressing are believed

and validated (Munday et al., 2021; Tosas, 2021). These findings reinforce longstanding critiques that the experience of CP exceeds the expressive capacity of clinical and academic language, particularly as symptoms fluctuate, contradict each other, or can resist coherent narrative form. Co-researchers shared experiences during conversations and dissemination of the zine, of repeated dismissal and disbelief, highlighting how invisibility intersects with epistemic injustice, shaping how suffering is acknowledged and made visible (Tosas, 2021). In the same way, co-researchers highlighted feelings of relief when they first entered the pain management programme, describing feelings of being heard, believed, and seen – sometimes for the first time. This recognition helped to create conditions of safety that enabled feelings of trust, leading to self-expression and ultimately more open engagement in the creative process.

The findings also helped to highlight the benefits of using non-medical language and creative communication practices for articulating chronic pain. The zine-making process and the permission granted to experiment with language (both visual and verbal) allowed co-researchers to express themselves how they wished to. Metaphor, imagery, and symbolic representation emerged as central communication tools, enabling co-researchers to express emotions and sensations of CP that were difficult to verbalise (Main, 2014; Margolin et al., 2024). The use of arts-based and participatory research practices helped to reveal dimensions of pain and movement in ways often obscured in traditional research paradigms, supporting decolonising and community-centred approaches (Denscombe, 2025; Seppälä et al., 2025). Zine-making particularly enabled co-researchers to express sensations and emotions which can be difficult to put words to, instead using visual metaphor, humour, and symbolism to communicate what cannot easily be spoken (Margolin et al., 2024). The flexibility of zine-making and the open creative invitation allowed individuals to articulate themselves in ways which felt authentic, resulting in a spectrum of contributions which were at once deeply personal and widely relatable. Personalities were enabled to shine through the pages with contributions which were honest, earnest, playful, and raw – challenging the expectation that pain narratives must be coherent or clinically legible in order to be valid.

The multimodal nature of zines allowed co-researchers to communicate contradictions and complexity without forcing resolution. Co-researchers used techniques of layering images, juxtaposing colours, and combining different creative modes, enabling them to represent the non-linear, cyclical, and often tumultuous temporality of chronic pain. These creative choices, and the opportunity to make them, helped to express the lived realities of moving with CP more authentically than linear narrative forms, illustrating how CP can be simultaneously debilitating while

individuals remain hopeful. The collective zine and the narratives demonstrate how creativity and creative communication can hold complexity in ways that verbal accounts alone cannot.

Zine-making formed the central arts-based method through which data were co-produced in this study. Their accessibility, flexibility, and emphasis on creative autonomy make them particularly well suited to participatory informed research with communities whose voices are often overlooked or constrained within mainstream discourse (Baker et al., 2024; Way, 2024). Throughout the workshops, zine-making provided a multimodal, tactile, and relational medium through which co-researchers could explore and articulate their experiences of meaningful movement while living with chronic pain.

Biopsychosocial Model and Chronic Pain

The biopsychosocial model is widely regarded as the clinical gold-standard for understanding and managing CP, emphasising the interconnection of physical, psychological, and social dimensions (Cole et al., 2021; Turk & Monarch, 2002). The model recognises the importance of attending to people's physical experiences of pain, often through pharmaceutical prescriptions and physical therapy, but emphasises that these must be supported in tandem with psychological approached that address the emotional and cognitive effects of living with persistent pain (Malpus, 2019; National Institute for Health and Care Excellence, 2021). It also highlights the need to consider the social and environmental contexts that shape pain, including workplaces, social support, and relationships (Blake et al., 2025; Kapos et al., 2024). These three dimensions play a part within clinical practices to enable function and quality of life but are also intertwined with the embodied experience of pain (Geneen et al., 2017; Honkasalo, 1998). The findings of this study echo and support the turn towards a biopsychosocial model of CP, highlighted through the foregrounding of meaning and intersecting experiences within the zine contributions (Gatchel et al., 2007). Notably the co-researchers' narratives resonated most strongly with social and emotional (psychological) dimensions of the model.

Biology – Physicality And Chronic Pain

Individuals did use physical-therapy type language including *"become a bit more mobile", "hobbling", "stretching the muscles",* and *"the teacher recommend me to go to that exercise," s*howing that the language and communication of pain is still often grounded in biomedical language. Physically and creatively, on the other hand, the co-researchers pointed to embodied nature of pain and there was a clear absence of any discussion of pharmacology or

biomedical-led approaches in how they move while in pain or manage their conditions. Figure 24 highlights that meaningful movement is not prescriptive and instead relates to small but significant movement that intersects with day-to-day life.

Figure 24:

A stretch can be just enough – snapshot of the zine and audio narrative



Physically meaningful movement is shown to mean capability and continuity, which is in line with biomedical treatments where movement is prescribed (National Institute for Health and Care Excellence, 2021). However, what is notable is how the co-researchers did not articulate moving when *in* pain (which is often how CP experiences are labelled), but that they moved *despite* the pain. Balancing stillness, discomfort and desire to move all have to be considered when looking at the physical aspect of pain management. The results continue to point to the inadequacy of a purely biomedical and disease/injury approach to understanding CP (Gatchel et al., 2007; Turk & Monarch, 2002).

Psychological Impacts

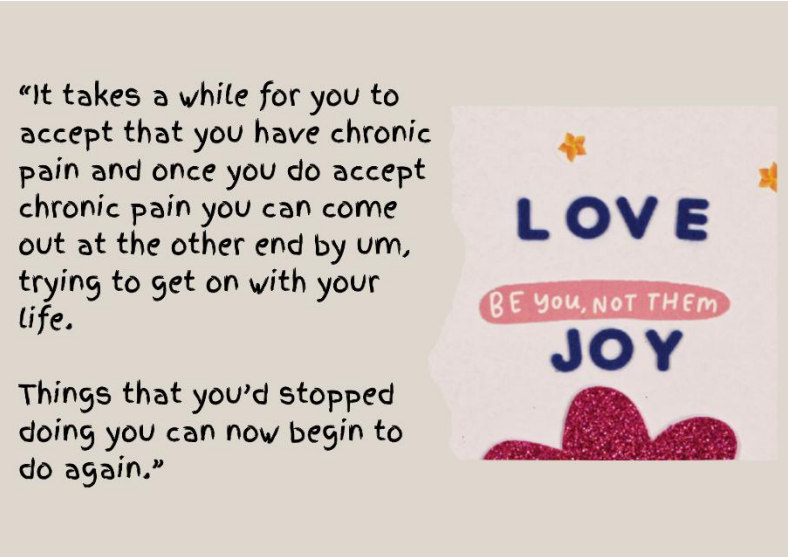
With regards to the psychological dimension of the biopsychosocial model, the findings point to the core role of identity shifts when living with CP as well as the fear and anticipation of pain, but also how coping well was tied very closely to connection, hope and optimism.

Narratives surfaced the anticipation of pain, bodily vigilance, and loss of confidence which also echoed an embodied predictive processing approach (Kiverstein et al., 2022). The zine-making process created space for co-researchers to illustrate how fear of pain exacerbation shaped

movement choices in new ways. One group member reflected that: *"[stretching is] something that, when you have chronic pain, you can be afraid to do because you're in so much pain that you can't actually want to do anything"* while another noted *"If you stay sit down, then you will be stiff and you don't move, and then there is pain everywhere"*. Thus psychologically the findings resonate with the fear-avoidance model, particularly in the ways the co-researchers depicted hesitancy towards movement at times and the recognition of physical deconditioning when one does not move the body (Meulders, 2019; Zale & Ditre, 2015). Group members took the model beyond just recognition of this detrimental cycle, however, and also illustrated how they individually counteracted to break the fear-avoidance cycle (Meulders, 2019). Co-researchers described the understanding that just trying *"anything, to do something"* and talking to themselves to *"get up and go to the kitchen and start cooking"* helped to keep them moving even when *"not feeling great"*. The zine contributions, as highlighted in Figure 25, further demonstrated the pain management approaches of pacing, self-compassion and acceptance as ways to understand and live with CP through the fear-avoidance framework.

Figure 25:

Acceptance, self-compassion and identity – snapshot of the zine and audio narrative



It is widely recognised that living with chronic conditions affects identity, yet few studies specifically explore how CP reshapes the self. Existing literature does, however, highlight that CP disrupts every-day life and alters individual's ability to continue in the social and relational roles they expect to (Voorhees, 2023). Less is known about how individuals actively reconstruct identity in response. As Figure 25 (above) highlights, the destabilising impacts of identity disruption was evident within the group, but so too were the self-determined changes to self through acceptance and self-compassion.

The current findings strongly illustrate how experiences of CP and the motivations to move meaningfully are intrinsically intertwined with identity. Voorhee's (2023) study found that living with persistent pain destabilises multiple frames of identity, challenging individual's sense of competence, autonomy and ability to live their lives in the way they expect to. However, the co-researchers in this project demonstrated a strong thread of holding onto, or reclaiming, existing identities which were separate to their CP identities. Examples of this were illustrated through being seen as *"Mama Aisha",* supporting and providing for family and others in the peer-support group, being a gardener, and the religious identities connected with God as a protector and father. There were times when pain had an impact on their ability to carry out household chores and work duties which has been shown in other research (Igwesi-Chidobe et al., 2017; Voorhees, 2023; Westergården et al., 2021). What this present research helped to surface was how connection and community helped to work against internalised feelings of isolation or self-worth.

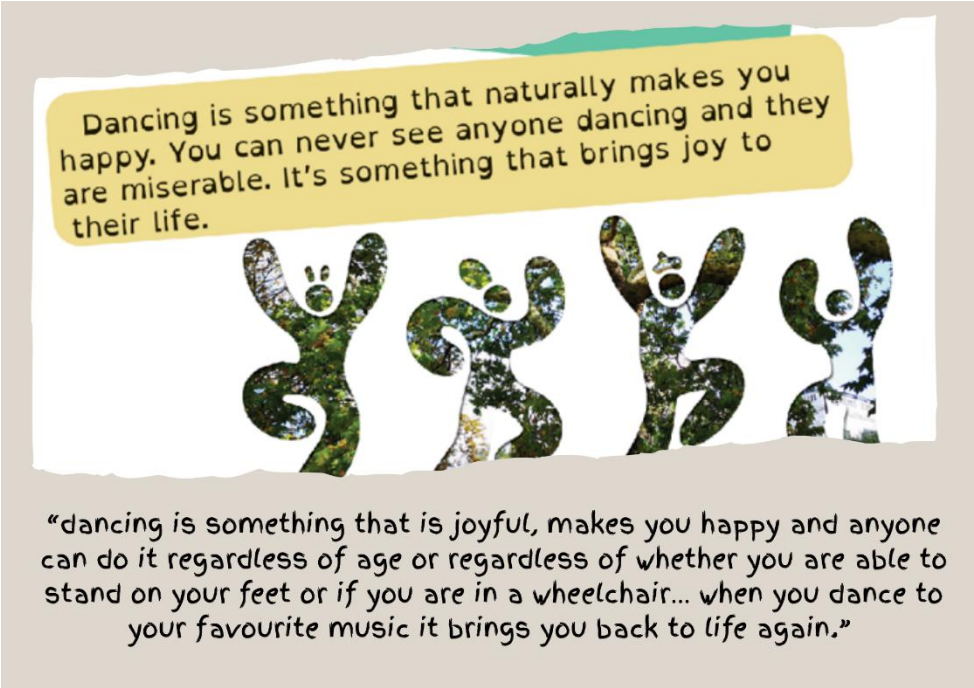
The creative representations also illustrate how identity is negotiated through movement, rest and relationality. While other research has showed that fluctuating symptoms, fatigue, and reduced mobility can limit participation in work, leisure, family, and community activities (Kugelmann, 1999; Voorhees, 2023), this present study extends existing work on identity reconstruction by showing that creative practice can help by allowing individuals to *show* important aspects of their personality and identity in ways that a verbal assessment cannot capture. Identity can feel like an incredibly personal and intimate thing to discuss, but one that is vital to understand when approaching CP management and support from a person-centred lens (Voorhees, 2023). Aligning with other examples of arts-based research which utilise zines as a knowledge creation and democratising tool (Baker & Cantillon, 2022; Parsons et al., 2026; Spandler et al., 2026), this project's zine-making provided a flexible, multimodal space where co-researchers could experiment with different versions of themselves while maintaining agency over expression of their identities. One member was hesitant to take part in the zine activity at first, expressing frustration at the pain she was feeling on the day of the workshop as well as her affected eyesight preventing her from seeing the creative materials in the way she wanted to. She expressed that she "liked to chase the cats out her garden" and then quickly corrected herself to explain that her "legs don't work" so instead she actually throws items in the direction of the cats to scare them away. Page 10 and 11 of the zine illustrates what she produced for her final contribution. This adds to the understanding of how pain can affect how people truly wish to be able to act in their everyday lives. Pain was seen as

a barrier to the individual, and so in order to have the same outcome she had to adapt her dance steps to join CP's tempo.

Chronic pain is often synonymous instinctively with suffering, exhaustion, and isolation, and these experiences have been shown to become internalised in ways that shape identity and mental health (Campbell & Cramb, 2008). The findings of this present study, however, complicate this narrative due to exhibiting an element of playfulness and joy throughout the creation process and the finished pieces of art. These emotions are not often centre-stage, or even permitted to be explored, within dominant discourses of CP (Thompson et al., 2024). People living with CP often describe how the condition positions them in the identity of patient, problem or a burden, particularly in clinical contexts where they must repeatedly justify their pain to be believed (Malpus et al., 2023; Smith & Osborn, 2007). This repetition is not only exhausting, but can also narrow the emotional and identity options available to them. In contrast, the arts-based approach to this research created the space for co-researchers to inhabit alternative identities, not just as co-researchers (instead of participants) but also as artists, knowledge-producers, and meaning-makers. This shift opened up possibilities which traditional academic research and clinical spaces often forecloses. The zine revealed joy, hope, tenderness, and playfulness as seen in Figure 26 through the demonstrations of dance and the feelings that are embodied through movements like this, but are often overlooked within a research context. The recurring metaphor of dance flowing across the pages of the zine, and throughout the melody of the audio narrative, was particularly striking. Dance symbolised not only enjoyment but also autonomy and exploration, suggesting the ability to relate to one's body with curiosity rather than fear. In this way, the creative process supported identity reconstruction by allowing co-researchers to reclaim emotional experiences, and express parts of themselves, that CP can make feel out of reach.

Figure 26:

Dance the pain away (for now) – snapshot of the zine and audio narrative



Social – community and peer support

Social isolation emerges consistently across the literature as a central feature of the CP experience (Campbell & Cramb, 2008; Christidis et al., 2025; Igwesi-Chidobe et al., 2017; Kugelmann, 1999). However, this entire research process has highlighted the valuable antidote to this offered through peer support and community. The creative data, and research process, moves the experience of living and moving with CP beyond individualised explanations and co-researchers consistently described how relationships and social/cultural expectations and influences shaped their movement choices. Figure 27 showcases an image which a co-researcher was specifically draw to as it looked like *"a party"* or a family as she said. In this sense, the zine, audio narrative, and themes presented through the creative artefacts as well as the process of creation, align with relational and culturally situated models of CP which emphasise the importance of those around you and the quality of the relationships you hold (Okolo et al., 2024).

Figure 27:

The antidote to isolation: community – snapshot of the zine and audio narrative



Chronic pain is a profoundly relational experience, impacted by feelings of belief and dismissal from others (Werner & Malterud, 2003; Westergården et al., 2021). Peer-support groups therefore offer a unique a unique and powerful context where meaning-making, identity reconstruction, and emotional safety can unfold in ways rarely accessible in clinical and dominant social settings (Farr et al., 2021; Matthias et al., 2016). This study was accomplished through working with a peer-support group, and so the findings reflect the shared and relational experiences of the individuals within the collective. While the group preceded the current study, the environment played a crucial role in shaping the creative process and the meaning that emerged from the zine. The power of shared experiences was particularly visible in the relational moments that unfolded during the workshops. When one co-researcher was at first hesitant in her ability to contribute she started by doodling a small sketch of herself cooking. The gentle, enthusiastic responses from those around her, especially the group's delight in her golden couscous, offered a form of validation which encouraged her in her contributions. This moment is an example of where peer-support can create a sense of validation and permission; permission to express yourself, to take up space, and to contribute your voice without judgement (Stenberg et al., 2022). For many of the co-researchers, being believed by peers and relational micro-affirmations helped to counteract the cumulative effects of epistemic injustice (Buchman et al., 2017; Tosas, 2021). Encouragement, like that displayed with the golden couscous, did not simply feel good but actively expanded on what felt possible to express, demonstrating how permission is socially produced rather than independently generated. The peer-support group

provided a space for validation when articulating experiences of CP and movement outside of standardised and normative measures.

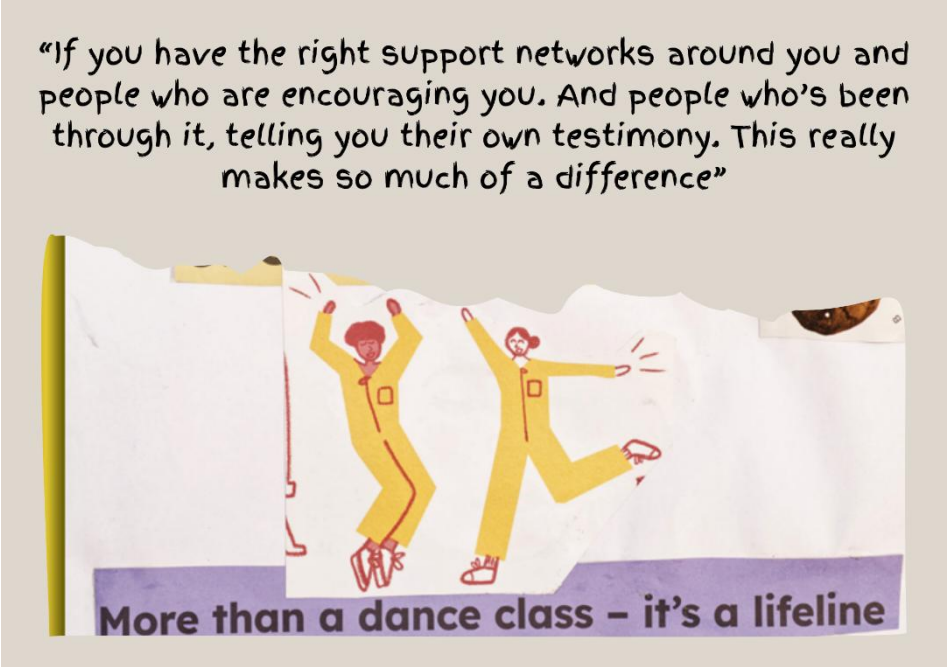
Co-researchers repeatedly described the peer-support group as a space of emotional safety, where they were able to express vulnerability without feat of judgement. Being welcomed into the group to co-create the research zine meant that my research could also be practiced from within this safe space with an existing foundation of trust and validation (Wallerstein & Duran, 2006). The feelings of safety exhibited through the group stood in stark contrast to the exclusion co-researchers had faced elsewhere and as an antidote to the fear experienced when living and moving with CP (Kapos et al., 2024). These experiences of exclusion were not incidental but reflected broader structural conditions such as ableist and neoliberal assumptions about productivity, gendered expectations around coping, and the cultural narratives and prejudices which doubt pain or do not recognise it within cultural settings (Bourke, 2014; Voorhees, 2023). In this context, peer-support was shown to actively do more than provide a space of comfort; it also enabled creative risk-taking, identity expression on a deeper level due to an existing shared-understanding amongst the group, and the emergence of hope and positivity (Stenberg et al., 2022). The encouragement co-researchers offered one another illustrated an extension of permission to do what you can when you can and helped to transform hesitant marks on the page into fuller, more confident contributions. This helps to illustrate how shared experience can foster a sense of community which softens the emotional labour of living with CP and expands what feels possible (Toye et al., 2013a).

The peer-support group provided strong supporting evidence for handing power to those with lived experiences to help to sustain the positive effects of pain management programmes and enable people to not just learn how to move with their condition, but to embed ongoing movement into their everyday lives and provide a space for ongoing support (Farr et al., 2021). Peer-support shaped how co-researchers understood meaningful movement, particularly when they saw their experiences reflected in others. Seeing how others creatively express how they engage in meaningful movement enabled and encouraged co-researchers to imagine new possibilities for themselves. Taking part in a dance class together and moving together in a creative way, as expressed in Figure 28, exemplifies how co-researchers see group activities as life affirming. Peer-support therefore acted as a catalyst for re-imagining movement not as an individualised struggle, but as a relational practice shaped by encouragement, shared testimony, and collective experimentation. This relational framing is particularly important given how fear and isolation can constrain movement when living with CP. Taken together, these findings help demonstrate that

peer-support is not merely a nice-to-have extra within chronic pain management practices but rather a transformative relational resource that fosters safety, expands identity, and enables new forms of embodied possibility and meaningful movement.

Figure 28:

Doing things together – snapshot of the zine and audio narrative



Overall the findings support understandings of pain (and therefore moving with pain) as a multisystem process shaped by emotion, relationships, and context rather than solely biological damage (Hulla et al., 2019; Lee et al., 2014).

Intersectionality; Moving Beyond the Biopsychosocial Model

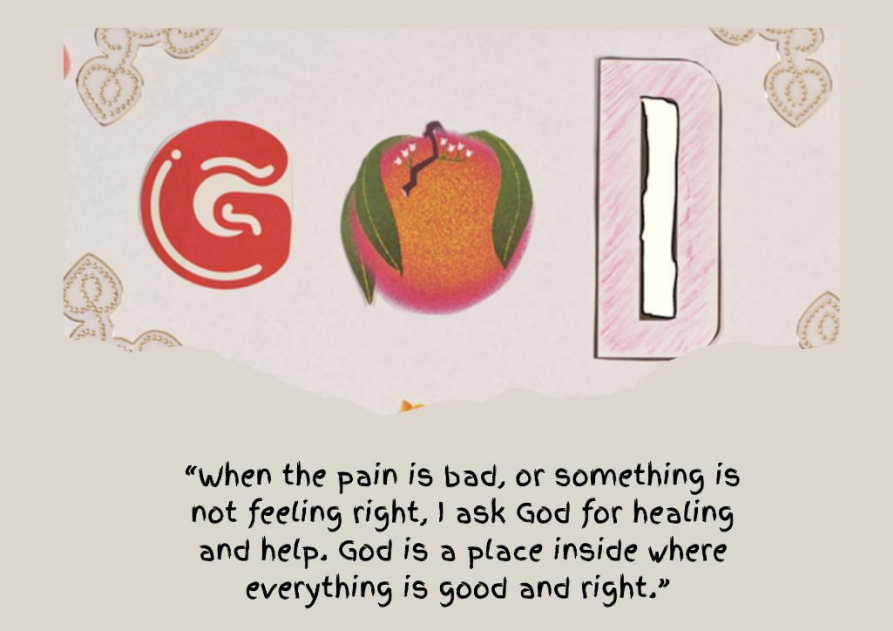
While these biopsychosocial models provide useful frameworks, the co-researchers' narratives and creative contributions reveal a more fluid and entangled experience of CP than the three-part structure implies. The findings of the study illustrated how movement with CP is continually enacted through sociocultural worlds rather than contained solely within the individual body.

Religiosity and faith is brought into the picture, adding an element of spirituality and ritual to the experience of living with and managing CP, something which is often missed within biopsychosocial framings – but an integral part of cultural models such as Te Whare Tapa Whā which approaches health through a Māori worldview (Durie, 1985; Lewis et al., 2024). While no members of the group

were Māori, there was clear resonance with taha wairua (spiritual health) and taha whānau (family health) which were expressed through acknowledging the role of *"god"* and *"family"* within their pain health journeys and as motivators for movement and condition management. This is further reiterated in Figure 29 whereby a co-researcher explains that God is also a constant companion alongside her pain, but instead works to help alleviate her discomfort. The group members explicitly referred to each other and the group as their *"chronic pain family"* and it was apparent through the ways in which the group related to one another and treated one another that this intimacy and family-like connection was a vital part of their CP experiences and contribution to their quality of life.

Figure 29:

Spirituality and a helping hand – snapshot of the zine and audio narrative



The biopsychosocial model does not fully capture the importance of communication within the experience of moving with and managing chronic pain (Aldrich & Eccleston, 2000). Nor does the model adequately account for the embodied nature of movement, which involves far more than physical function (Bullington, 2009; Tabor et al., 2017). Within the biopsychosocial framework movement is typically positioned as a physical component, yet for people living with CP *meaningful movement* becomes a site where physical sensation, psychological meaning, and social expectations intersect. Individuals must navigate identity disruptions, pain-management plans, and family or work obligations with bodies that feel unpredictable and limited. The model also struggles to accommodate the non-linear temporality of CP. Chronic pain is lived cyclically, unpredictably, and

often in tension with dominant expectations of progress, stability, or recovery (Bunzli, Smith, Schütze, et al., 2015; Crowe et al., 2010). These rhythms shape how people move, rest, plan, and participate in daily life, but are not easily captured within a framework that assumes relatively fixed domains. Cultural influences are similarly under-represented. Typically culture and spirituality are considered social elements, however this tends to underplay their significance. Culture can be tied to identity, relational norms, communication styles, and understandings of the body – dimensions that may not be encompassed within Western approaches to holistic health (Antunovich et al., 2024). The biopsychosocial model's Western epistemological roots can therefore limit its ability to recognise diverse ways of making sense of pain, movement, and wellbeing. Finally, the model has been critiqued for its tendency to individualise responsibility, emphasising personal coping while underplaying structural factors such as socioeconomic inequalities, racism, and gendered expectations (Aldrich & Eccleston, 2000; Tabor et al., 2017). These broader determinants profoundly shape how CP is lived and managed, yet sit largely outside the model's conceptual boundaries.

Strengths and Implications

The strengths of this research as illustrated throughout the discussion, also point to some practical implications for people living with chronic pain, practitioners supporting these people, and policymakers and funders who shape the system around them.

For people living with chronic pain

- Seek out, or create relational space (e.g., peer-support groups) where experiences are validated, shared, and understood without judgement or explanation.
- Use creative expression (drawing, collage, storytelling, movement) as a tool for communicating pain, exploring identity, and making sense of fluctuating symptoms.
- Recognise meaningful movement as personal and adaptive, not as a fixed routine or productivity goal. Movement can be relational, playful, and responsive to the body's rhythms. Meaningful movement can be almost *anything you want it to be.*

For healthcare professionals

- Adopt and nurture relational, person-centred approaches to movement and pain management, recognising that fear, identity, and social context shape how people move and what motivates them to move.

- Integrate and embrace creative practices (e.g., visual metaphors, body mapping, narrative tools) into consultations to support communication and understanding of invisible experiences.
- Acknowledge, aloud, non-linear pain trajectories and avoid framing movement as a linear progression or solely as physical therapy.
- Actively validate lived experience as a legitimate form of knowledge that can guide treatment planning.

For policy makers and funders

- Recognise chronic pain as a social, relational, and embodied experience, not only a biomedical or behavioural issue
- Invest time, resources, and space in community-based peer-support groups (such as the PEACE and JOY group) as essential infrastructure for chronic pain support.
- Shift away from productivity-centred narratives that position people with chronic pain as failing to contribute to society; policy must reflect the ongoing, fluctuating nature of CP and the small but significant movements people can make as part of living a good quality of life.
- Fund creative health initiatives that amplify lived experience voices and improve communication, visibility, and understanding around invisible conditions.
- Support participatory and arts-based research that returns value to communities as it goes, and produces accessible, democratic forms of knowledge.

This research demonstrates the depth of knowledge residing within communities and the transformative potential of creative, participatory approaches (Sonn & Baker, 2016). Arts-based methods offer access to forms of insight that remain obscured in traditional research and produce outputs that can be shared widely and meaningfully (Campbell & Clark, 2023; Gameiro et al., 2018). The study contributes to a growing movement to democratise health knowledge, centre lived experience, and reshape how chronic pain is understood across personal lives as well as policy and practice.

Boundaries and Limitations

There are several limitations and boundaries to this present project. As with all participatory and arts-based research, the study was heavily shaped by the co-researchers, my co-facilitator Ess, and myself (Baum et al., 2006; Leavy, 2020). The group was an existing group which is a strength in terms of trust and shared history, but it also presented a boundary to the research findings . This does not

invalidate the group's testimonies, rather it underscores that the knowledge produced is situated and should not be read as universal. The group of co-researchers held prior knowledge of movement with CP and management techniques due to the pain management programme they had taken part in prior to the research commencing. This was beneficial for the execution of this study but is highlighted as difficult to reproduce should another research wish to replicate this study. But it should also be noted that community work should be grounded in the community so this is not really a limitation, but rather a boundary to note.

Time and effort were additional constraints to this study. Participatory arts-based approaches require sustained relational work, flexibility, and iterative collaboration. The project unfolded within the limits of a Master's-level timeframe, which inevitably shaped the depth of co-analysis, the extent of creative exploration, and the opportunities for longer-term follow-up. Also, as I was completing this study while working full-time there were time constraints on the amount of time I had available to weave my commitments and cognitive-power. Some collaborative possibilities, such as deeper co-interpretation or extended dissemination, were constrained by these temporal boundaries and limitations rather than a lack of interest or value.

Working with people living with fluctuating and chronic conditions brings inherent challenges to sustaining participatory engagement. Energy levels and pain flares impacted attendance to the workshops and ability to participate while in the room. The flexibility of the workshops were able to respond to this, however, these lived realities meant that there was not consistent engagement across all workshops from the same members of the group. These fluctuations are not limitations of the co-researchers, but rather realities of CP that must be ethically and relationally accommodated in participatory design (Eccleston & Crombez, 2007).

Finally, the collaborative zine-making approach generated rich, multimodal insights, but they also require interpretation (Leavy, 2020). The zine and audio narrative were co-created, yet this final analytic narrative was written by me (Ozkul, 2020). This introduces an inevitable interpretive boundary: while I worked to honour co-researcher's voices, the themes and framing ultimately reflect my analytic decisions, shaped by my positionality, training, and relationship with the group.

Future Research Opportunities

This study supports several clear avenues for further research into *meaningful movement* as an embodied, emotional and identity-laden concept. First, there is a need to examine how meaningful

movement is understood and enacted across diverse and underserved communities who are more likely to experience chronic pain, including women, indigenous cultures, trans and non-binary people, older people, and working class people. Research should explore how cultural norms, intergenerational knowledge, and community-specific understandings of the body and identity shape movement possibilities and constraints. Extending this work beyond the UK would also allow for comparative insights into how different health systems, cultural contexts, and sociopolitical conditions influence experiences of chronic pain and movement.

There is also strong potential to investigate meaningful movement in relation to other invisible or fluctuating conditions, such as fibromyalgia, chronic fatigue, long COVID, endometriosis, and autoimmune disorders. These conditions share similar challenged around visibility, stigma, and fluctuating capacity, making them excellent ports of further enquiry through creative practices into how movement becomes meaningful, resisted, or reclaimed.

Further research should also examine how meaningful movement can be integrated into clinical practice and community health programmes. This includes exploring how clinicians might use relational, creative, or narrative tools to support conversations about movement, fear, pacing, and identity. There is scope to test how meaningful movement frameworks could complement existing pain management approaches, particularly in multidisciplinary or community-based settings.

The zine's reception highlights further opportunities for creative health communication research. Such work could examine not only the impact of creative artefacts on empathy and understanding, but also how they shift power dynamics and open new forms of dialogue. Future studies could evaluate how co-created artefacts – such as zines, audio pieces, or visual narratives – can be used in:

- Clinical training and reflective practice
- Pain management education
- Service design and quality improvement
- Public health campaigns
- Cross-sector dialogues between lived experience communities, practitioners, and policymakers

Finally, there is significant scope to explore how participatory and arts-based research methods can be scaled, adapted, or embedded within health systems internationally. Future studies could investigate how these approaches reshape practice, policy, and public understanding of chronic pain,

while also examining the ethical, relational, and logistical considerations of sustaining creative collaboration over time. This includes exploring models of co-research that are enjoyable, empowering, and generative for participants, while also producing rigorous and impactful academic knowledge.

Closing

I wish to leave you in the same way the thesis begun – with creative reflection. To conclude a participatory arts-based study with a conventional conclusion would feel incongruent. The insights shared within this academic artefact were shaped through colour, metaphor, texture, shared stories and creativity. As this thesis draws to a close, ending with a creative piece feels appropriate to honour the collaborative spirit of the project and mirrors the ways the co-researchers expressed what could not be captured in words alone. The image presented in Figure 30, and the poem which follows this, brings us back to a creative mode of knowing. They are gestures of reciprocity and authentically supports the democratising of lived experience knowledge through artistic communication and zine-making while also being a final moment of moving with the work. I also leave you with a final invitation.

Final Invitation

I invite you, one final time, to gather the thoughts, sensations and questions that have surfaced as you have read.

Take a blank A4 page and fold it into a zine (Appendix I for instructions).

If you have engaged creatively throughout this thesis and have contributions of your own – take a moment to look back at the journey you have come on with me and the co-researchers. Cut and paste these onto the fresh pages of your zine, or doodle/write your own closing reflections on this research.

Let your own creative response become part of the ongoing movement this thesis hopes to inspire.

Figure 30:

Guiding light illuminates



Note. Collage created by me, Emily Martin-Ball. Materials include collage images cut from magazines, calendars and books, along with paper. Editing was done in Canva where some of the layering was made possible including the inclusion of the shining lights.

The ocean can be volatile and serene

waves of nausea overcome me while the subtle movement lulls me to sleep

storm clouds scatter rain

as the individual, micro, drops

merge into the body of water below

turning into currents and spray

…but

I have an umbrella!

And what is that it has below?

A rudder, with sunshine at the helm

Golden threads connect the sky and the creatures often overlooked in the dark

What is usually hidden, from which one flees…

…Surfaces…

drawn by the light shone

and comes carrying secrets to be shared

of how to survive the shifting tides

with grace

and together.

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Appendices

Appendix A

Artist Confidentiality Agreement - signed

School of Psychology
Massey University
Private Bag 102-904
North Shore

MASSEY UNIVERSITY
TE KUNENGA KI PŪRIHUROA
UNIVERSITY OF NEW ZEALAND

COLLEGE OF HUMANITIES AND SOCIAL SCIENCES

What is Meaningful Movement when living with chronic pain? An arts-based exploration.

CONFIDENTIALITY AGREEMENT

I Ess Grange (Full Name - printed)

agree to keep confidential all information concerning the project '*What is Meaningful Movement when living with chronic pain? An arts-based exploration.*' including if the project title changes throughout the process.

I will work collaboratively with the lead researcher, Emily Martin-Ball, to facilitate the data creation, and uphold co-researcher confidentiality, privacy, psychological safety and autonomy. I will not retain or copy any information involved in the project, except for a final copy of the zine and audio analysis narrative.

Signature: **Date:** 18/6/25



Format for Confidentiality Agreement (2015) Page 1 of 1

Appendix B

Recruitment Notice



Note: This recruitment notice was made on Canva and disrupted on social media, as an attachment to mails, and printed for display on local notice boards.

Appendix C

Simplified Introduction/Information Sheet

What is Meaningful Movement when living with chronic pain? An arts-based exploration.



Kia ora (hello), I'm Emily and I'd love to introduce myself to you. I am a 34-year old New Zealander living in London. I am a (non-professional) performer and creative and spend much of my time connecting with nature and my community through hiking, choir singing and movement. I live with long-term conditions myself, and care for others who experience chronic pain in different ways. I am currently studying towards a Masters in Health Psychology by distance, through Massey University (based in New Zealand), It is through my Master's research project that we have come to meet.

What's the idea?

I would like to create a 'zine' with you! I am inviting people who live with chronic pain to take part in an arts-based research project, exploring what 'meaningful movement' means to them. You do not need to have a diagnosis of chronic pain or a specific condition to take part.

Pronunciation of Zine: 'Zeen' like the end of 'magazine'

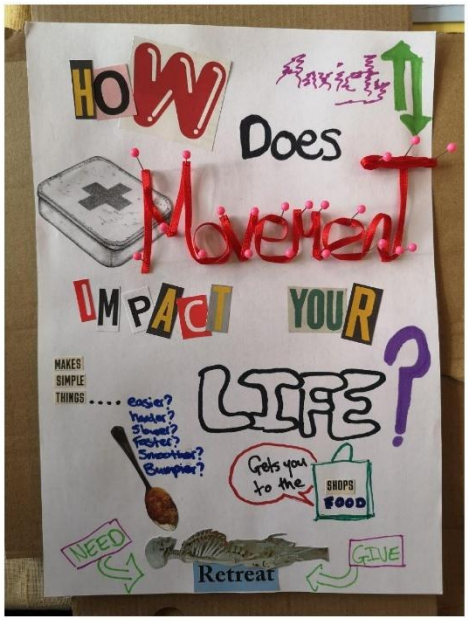


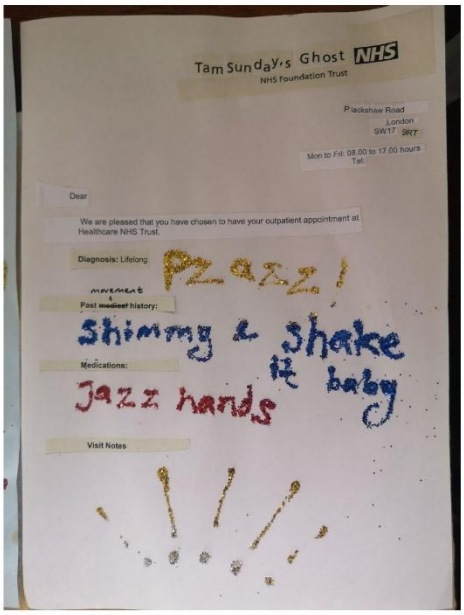
Together, we'll create a collective zine to express and redefine what meaningful movement is while living with chronic pain. A zine can't really be described in one way, but they are often self-published booklets or magazines, made up of different forms of artistic communication from poetry, and written stories to collage and sketches.

What's involved?

1. A co-facilitated workshop where each person will create a page or more to contribute to the collective zine. You can use whatever form of artistic expression you like and we can use one of your group sessions at Arts4Space and agree how long the session will be before we schedule it in
2. I (Emily) and my co-facilitator will collate your contributions into one zine, and share this back to you for feedback and approval
3. We will hold another in person workshop at Arts4Space. This time, together as a group we will talk about what you have created and you will have the opportunity to talk more about your contribution. This conversation will be recorded
4. I (Emily) will edit together an audio description of the zine with your words and share this with you for your feedback and approval.
5. We will decide, together, as a group where the finished zine and audio will go next.

Some examples of what our prompts will be:





Question: How does movement impact your life?	Question: If you could write yourself a prescription for movement, what would it look like?

Appendix D

"What is involved?" Section of the information sheet

<u>What is involved?</u>

You can participate in the zine workshop and collective conversation either **in-person, virtually,** or through a **combination**. The core process is the same for all co-researcher contributors: **Initial phone call -> Zine creation -> Collective conversation**.

The following outlines the process based on how you participate.

In-person contributions

1. *Initial phone call (15 - 30 minutes):*

   After you express interest, I will contact you to arrange a phone call. I will ask about your experiences of chronic pain and a bit about what meaningful movement means to you. I'll also provide details about the study and answer any of your questions. Consent forms will also be emailed in advance and discussed during this call.

   - If there are any concerns at this point, or necessary adjustments for the workshop, this will be a good opportunity to discuss them.
   - This call will be audio-recorded (with your permission) for memory and transcription. You may pause or stop the recording at any time and no data will be recorded during the paused period. You may also ask for any information to be redacted from the conversation.
   - You are welcome to have a support person with you during the call, and use speakerphone if preferred.
   - The call can take place at home of in any private setting that ensures your comfort and confidentiality.

2. *Zine Workshop (3 hours):*

   You'll join 6 - 10 other co-researchers, myself, and a zine facilitator at an accessible venue in London. Together, we'll create contributions for a collective zine. Basic materials will be provided, and you are encouraged to bring items that feel meaningful to your experience and will help you explore the topic (e.g., prescriptions, magazine clippings, craft supplies, movement log).

   - If unfinished during the session, you'll have one week to complete your contribution and return it (physically or digitally).
   - The full collated zine will then be shared with all co-researchers. You'll have **2 weeks** to review it and suggest any changes before giving your approval.

3. *Collective Conversation (90 minutes):*

   Around three weeks later, you'll be invited to a group conversation at a similar time and location. This session is an opportunity to reflect on the zine-making process, share insights, and collectively interpret the collated zine.

   - The discussion will be audio-recorded for transcription and used to create an audio narrative interpretation of the zine.
   - You may choose to leave the room at any time, or ask for a pause if necessary.
   - Once edited together, you'll have **2 weeks** to review and approve the final audio narrative. If no response is received, your approval will be assumed.
   - A summary of findings will be available to you on request.

Virtual/distance contributions

1. *Initial phone call (up to 30 minutes):*

As with in-person participants, we'll begin with a phone call to discuss your experiences of chronic pain and the research process. Consent forms will be emailed in advance and reviewed during the call.

- If there are any concerns at this point, or necessary adjustments to enable your participation, this will be a good opportunity to discuss them.
- This call will be audio-recorded (with your consent) for memory and transcription. You may pause or stop the recording at any time and no data will be recorded during the paused period. You may also ask for any information to be redacted from the conversation.
- You are welcome to have a support person with you during the call, and use speakerphone if preferred.
- The call can take place at home of in any private setting that ensures your comfort and confidentiality.

2. *Zine Contribution (self-directed - 2 weeks:*

   You will receive a recording of the in-person workshop facilitation and a written instruction guide to help you create your zine contribution at home.

   - You'll have **2 weeks** to complete your contribution.
   - I can provide materials as discussed in our phone call and offer support as needed.
   - You can return your contribution via post (pre-paid envelope provided) or by email as a high-quality digital file.
   - Once the zine is collated, it will be shared with all co-researchers for review. You'll have **2 weeks** to approve or request edits.

3. *Collective Conversation (90 minutes):*

   Approximately three weeks after the zine deadline, a group Zoom session will be held to reflect on the process and co-analyse the zine.

   - The session will be audio-recorded with your consent and used to create a collective narrative interpretation.
   - Once edited together, I will share the audio narrative with you and you'll have **2 weeks** to review and approve.
   - A summary of findings can be provided if requested.

Appendix E

Draft Workshop Plan

Zine workshop session plan

Aim: Create a collective zine exploring meaningful movement while living with chronic pain. The current question is: *What is meaningful movement when living with chronic pain?* This may shift through the conversations and creations in the workshop, and this is absolutely fine if so. Practically, I hope to come away from this session with a contribution from each member of the group, as well as a collective sheet of ponderings, doodlings and thoughts which can be thematically collated.

Facilitators: Emily Martin-Ball (lead researcher), Ess Grange (facilitator)

Participant number: 10 - 15

Access requirements: All participants over 50 years old - as this is an already formed peer group and we are meeting where they usually meet any major access needs are already accounted for

Session Plan #1

Friday 17th October 1-3pm

120 minutes (2 hours) long

Time	Activity	Resources	Notes
5 minutes	Arrivals	ALL	Space for people to arrive and settle in
10 minutes	Introductions	Lead: Em	Zine contributions are data

	What the aim of the research is and what will be used as data and what won't be Informed Consent Set group working agreement	Consent Forms Collective agreement (confidentiality of each other) Information sheets	Conversations between people will not be used as data but may be highlighted within certain sections of the thesis - for example 'the workshop nature of creation allowed for people to share their experiences and co-construct narratives in the room'. Also highlight the brown paper table cloth and pens Together - set some ground rules for the workshop and remind people of confidentiality as well as welcome everyone to take time when needed and that anyone is welcome to leave the space when and if they wish. Emily will check in with people if needed. "Participation in this project is voluntary, however, I hope that you all enjoy being part of the project and get something out of it for yourselves. I would also like to hear from you what you would like to get out of these sessions and where you might like to see our finished product be shared."

			Encourage everyone to move as they wish in the space while creating, and have conversations.
15 minutes	Check-in moment Led group movement or breathing	Lead: Ess	Pen in hand - check into the space Kick off with a led [breathing] exercise to bring everyone into the space together and setting up
5 minutes	Introduction to Zines - what they are, a little history	Lead: Ess	
5 minutes	Introduction to Meaningful movement and the purpose of the study	Lead: Em	
5 minutes	Explanation about how the rest of the workshop is going to run and setting out what people are going to be asked to create	Lead: Ess	
75 minutes	Zine contribution creation	Lead: Em & Ess	All group members to work on their contribution to the zine

			Brown paper on top of the table/tables so people can doodle thoughts Prompts and questions in zines and distribute them around the table. Emily and Ess floating around group to join in conversation and continue to prompt if needed Music (playlist requests)
10 minutes	Closing and Check-out	Lead: Emily	Check in with how everyone is going, where they are at. Everyone who is comfortable doing so can get up and walk around the table to view others' creations so far and ask any questions of one another. With a Pen - end on Ess then Em Maybe a chance to return to some of the doodles from the brainstorming/creative exercises? Discuss next steps with everyone - Emily will be back next week so we can continue on our work and finish the zine off.

			If people would like to take any aspects of their work home as they might like to continue working on it this week - please do but please bring it back! If not, Emily will look after it for the return next week.

Session Plan #2

Friday 24th October 1-3pm

120 minutes (2 hours) long

Time	Activity	Who	Notes
5 minutes	Arrivals	ALL	Space for people to arrive, complete any paperwork like remaining consent forms etc.
10 minutes	Re-Introductions & check-ins	Emily	
10 minutes	Led group breathing exercise	Recorded?	Kick off with a led breathing exercise to bring everyone into the space together and setting up
10 minutes	Creation check-in	Emily	See how people are getting on with their contributions and allow time for people to discuss their creations with one another. See if any themes or shared understandings are starting to emerge.
45 minutes	Zine contribution creation continues	ALL	Continue with contributions. This can be relatively flexible and relaxed with people taking breaks as they need

10 minutes	Break	ALL	Move around the space if wanted/needed
20 minutes	Collation input	Lead: Emily	Collectively see how the group feels the contributions feed into one another and flow. Is there a strong 'audience' coming out of the contributions? Do we want to share a working draft of the zine at the BHM celebrations next week? If so - what do you want to share?
10 minutes	Thanks, next steps, farewells (for now)	Lead: Emily	Thank people for their time and contributions, remind of next steps in the process. I will aim to have the final zine collated within the next week and printed to share with you all by 14th November. 14th November I would love to be able to hear from you what you make of the finished product. What you are telling people through the art. What you want people to know when they are reading the zine etc.

Appendix F

Example consent form

School of Psychology
Massey University
Private Bag 102-904
North Shore

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

COLLEGE OF HUMANITIES AND SOCIAL SCIENCES

What is Meaningful Movement when living with chronic pain? An arts-based exploration.

PARTICIPANT CONSENTFORM – INDIVIDUAL

Please read and confirm your understanding of thestudy by ticking the boxes

1. I have read or have had read to me, and I understand the 'Information Sheet' …… ☐
2. I have had the details of the study explained to me, my questions have been answered to my satisfaction, and I understand that I may ask further questions at any time…….. ☐
3. I have had enough time to decide and I understand that taking part is my choice..... ☐
4. I understand that I have an obligation to respect the privacy of the other members of the group by not disclosing any personal information that they share during the workshop..... ☐

5. To be completed and revisited at each stage of the study. Circle the ones you agree to:
   - I agree/do not agree for my creative contribution to be used in the collective zine
   - I agree/do not agree to my participation in the collective conversation being sound recorded and used in the audio narrative.
   - I agree/do not agree for my name to be credited in the final creative work

Declaration by Participant:
I_____ [print full name] _____ hereby consent to participate in this study.

Signature: _____ Date: _____

Additional notes from any revisits to this consent form:

Appendix G

Audio Narrative Transcript

Zine Page	Script	Speaker
Page 1	*Hello, and welcome to our zine about meaningful movement when you live with chronic pain.* *It's nice to meet you.* *You are welcome to tune-in to our stories while you read, or just sit-back and listen.*	*Narrator*
Page 2/3	We are a peer-support group of people living with chronic pain. We come together each week in a low-pressure, warm and welcoming space to share, connect and develop practical tools through creative practice to help navigate life with greater confidence and support. *Plus one researcher* Plus one zine facilitator *There is a drawing on this page, showing six people sitting at a table. Scattered around are art supplies like coloured pens. Each person has a piece of paper in front of them, with their own marks on the page. This is us, making the zine you hold in your hands right now.* Workshop number one; making contributions solo and together for our zine. *Workshop number two; exploring the contributions and conversations around movement and chronic pain.* Through conversation and using our creativity, we have made this zine as part of a research project, aiming to understand what meaningful movement is to us – as people living their day-to-day lives with persistent pain. Wh*en we say 'meaningful movement' - we are talking about physical activity that holds personal meaning, purpose, or*	V1 *Narrator* V2 *Narrator* V3 *V4* Narrator *V3*

	emotional value. Movement that connects to personal goals, or sense of well-being… movement to help us move forward in life. Everyone overcame any 'fear' associated with expressing themselves through art, and let go of any expectations to 'get it right' or produce a 'perfect' image it says in a yellow box. *In a blue box it says: Some of us created with intention, taking time to think and plan before making marks on the page – leading into an overlapping green box – others allowed the images to find them.* 'This is our creative testimony – from the people who live it.' *This invites you to turn the page...*	V4 *Narrator* V4 *Narrator*
Page 4	*Page 4, The artist explains her contribution* The meaning of movement, waking up in the morning, do a cup of tea and um, some exercise and watching tele. *There are some cut out collages below this writing on the page, where the artist has stuck images of people in different shapes. Some look like they are floating above the page, and are throwing a shadow on the paper.* This one is having a cup of tea. And these ones are doing exercise. Haha. I don't know this one, I forgot this one. I like these movements, for the pain and for the exercise. They make me feel better.	*Narrator* Co-researcher 1 *Narrator* Co-researcher 1
Page 5	*What is meaningful movement? It says in a pink box.* Over the top of colourful circles; blue, green and yellow, we tell you how we like to move. *These gentle movements help with the pain*	*Narrator* V4 *V3* Co-researcher 2

	Stretching is meaningful movement, something that, when you have chronic pain, you can be afraid to do because you're in so much pain that you don't actually want to do anything. But by actually stretching the muscles, it's actually beneficial to those in particular who suffer with chronic pain, that it can release some tension that you're having in your neck, or back or wherever you're having the pain.	
	I like it! And it helps you, you see. It helps me I mean haha. Because if you stay sit down, then you will be stiff and you don't move, and then there is pain everywhere.	*V4*
	I would like to move everyday, like, I have to move innit!	V2
	This movement makes me feel better!	*V3*
	I go for a walk and yes, then the teacher recommend me to go to that exercise.	Co-researcher 1
	I like dancing! The movement, you don't stay still at all! Haha. And I like the, what do you call it, the banjo.	*V2* V4
	Yeah I cook sometimes	*V2*
	So I think movement is very good!	Narrator
	Next page…	
Page 6	This, this old woman, this is me thinking 'oh what am I going to do today' - and I said 'oh no, let me get up and go to the kitchen and start cooking.'	Co-researcher 3
	So I like my cooking - for my daughter and my grandchildren, sometimes I cook for all the people just when I have time, just to give them food. Even when I was working I would cook food. I used to work as a registered nurse. So I used to cook for them - Jollof Rice, I was Mama Aisha.	
	I suffer from sciatica - so at times I don't think about it, but when it pinches, you have to scream!	
	I don't sit at home, because if I sit there I feel my muscles become a bit restricted and so it's better for me to move around.	

	I just think it's good to help yourself and take these natural things.' The food has minerals, vitamins, they are all natural and you don't have this additive, so I think it's good. *This writing is in a green frame, in a pink box below it reads -* They say prevention is better than cure. *In a golden box we see some instructions to make Golden Cous-cous:* Just put a little bit of water, it depends you can put some tomato puree, to colour it or you can just cook it like this - it is very easy to make. But if you don't know how to use it, it turns to porridge.	 *Narrator* V4 *Narrator* V4
Page 7	*On the opposite page is Aisha's artwork. She starts off her piece by writing* meaningful movement is the art of using my body in different ways to carry out my daily activities. Movement can make me active while cooking. Here I have drawn a person, that's me, cooking cous cous *The cous cous is golden and sparkling* There is a picture stuck there and that's me, grandma, walking down the road slowly to go to the shops with the cat. I am going to get food to cook. These are nuts, and the fruits it's good for your health you know, because it is what we put in us. You get in trouble for yourself if you don't eat properly. *Aisha has used collage as her artform and has stuck many pictures of nuts below her self-portrait cooking the cous cous.* *Eat food you love – it says, spend time doing stuff that makes you happy, be kind to yourself and others. Nuts.* *Turn the page…*	*Narrator* V4 *Narrator* V4 *Narrator*
Page 8/9	*This page is a double spread. In the middle is a green oval and on top of that a beautiful sketch done with coloured pencils.*	*Narrator*

	I have drawn some rosemary, which is a herb, um, this is pumpkin and that's my sunflower - sunflower plant. I did have it, it's real. Um, and these are tomatoes. *The words around the sketch, in a circle, read:* This is my little garden, but really it's in some boxes... but that's my garden... and they are a bit high so I can get into them - otherwise getting down is too low... And I like to do it when the sun shines, or just doing it sometimes when I am not feeling, great - so I go out there and try and… *Turn the page*	V3 *Narrator* V3 *Narrator*
Page 10/11	Sometimes the pain can stop me from doing what I want to do.....like chase the cats out of my garden! *On this next page there is another, simple collage. This piece was made with help to cut out the pieces, and create an image which shared the story.* The main background shows a magazine spread of a lush garden. The artist has added some additional plants, like tomatoes and pink flowers to highlight the plant-life in the garden. *On top of the plant sits a lounging black cat – or is it the cat being thown out the garden by the superhero comic-book figure who has an angry expression, and accusing finger pointing at the cat?* *To the right of the image there are three yellow boxes with the words:* When sometimes your fingers you can't, they're not so great and you go out and you try anything, to do something and it's not as bad, you know. Just like when you're working sometimes, you can't really move like you would do, but you go and you take a little bit of time so you become a bit more mobile. *At one stage I was house bound because of chronic pain, but you know, after a lightbulb moment of thinking 'If I am gonna live with chronic pain I may as well try and get my life back and do something.'*	V2 *Narrator* V2 *Narrator* V3 *Co-researcher 2*

	So the other thing is, when you stay indoors, it is all the negative thoughts that are there - so it is better to go out! I don't know what the thoughts mean, it's just negative thoughts that ware coming on your mind and I say no - go out.	V2
Page 12	*Hi I'm Jill Abram and the prompt I was given for this piece was meaningful movement.* *To me meaningful movement means swimming, though occasionally pain in my joints can prevent me from making the movements required for swimming. It's good because it's non weight bearing.* *Most of the time it's the only exercise that I really take. I do love the feeling of being in water.* *I can be quite ungainly on land sometimes and so that made me think of seals and the artform I have chosen to express this is poetry.* *The poem is called Hobbling/Flying and hobbling is the technical term for the movement that seals make on land and not just me trying to walk along when I am in pain.* *Hobbling Flying* *Seals shuffle flump on land* *But as they slide of sand into the sea they glide* *As if in flight streamlined to soar through the water* *Instead of walking I limp and stagger* *When I swim I am sleek* *My arms pull smoothly through cool blue* *Feet like fins on scissoring legs* *Propel me fast as marlins* *We haul out to rest* *And bask in the sun*	*Co-researcher 4*
Page 13	On this page opposite Jill's poem there is an image of a penguin and a seal at the top and bottom of the page. They are coloured in with an image of a blue sky with fluffy white clouds. In a box it reads:	Narrator

	'Hobbling' that's like the technical term for the movement that seals make on land - and of course, you know, when you're walking badly, that can be called hobbling as well. *So I was thinking about penguins and seals cause they also are much sleeker in the water than on land [like me]... the water is where the magic happens.* Next page…	*Co-researcher 4* Narrator
Page 14	*God is my number one, I dance with him.* *I am Sunishi and I have created a page, bringing together colourful stickers of parrots, flamingos, cats, smiley faces, and colourful flowers. At the top of the page are letters cut out of a magazine, spelling G O D – God.* *These three golden hearts above the word God, they represent the holy trinity – father, the son and the holy spirit. And these eleven hearts at the bottom of the page, they are showing the twelve tribes of Israel.* *In the middle of the page are the words – Love, be you not them, and joy.* *I used a cut and paste method to create because she wasn't sure what she wanted to say initially, so she let the stickers and collage pieces show me what my message was. I had to think about who am I and what do I really think on and how am I on being.* *This piece is about joy in movement and God – I love to dance with him.*	*Co-researcher 5*

Page 15	Across the page there are dancing figures. Their bodies are round and soft and they are coloured in with tree textures. *My ADHD is my energy, it keeps me going. My OCD brings order When the pain is bad, or something is not feeling right, I ask God for healing and help. God is a place inside where everything is good and right. But some pain just takes time to be removed.* *I love music, dancing, joy. God got me to know and love myself, Ann, Sunishi, and also Anna–* These words appear in colourful boxes which dance across the page alongside the moving figures. *Dancing is something that naturally makes you happy. You can never see anyone dancing and they are miserable. It's something that brings joy to their life.* *Next page....*	Narrator *Co-researcher 5* Narrator *Co-researcher 3*
Page 16	*Well my contribution looks like, um at the top there's a butterfly, and a butterfly to me has two lifes - so you have the caterpillar life where they are crawling until they go into the cocoon, and then they blossom out into this beautiful butterfly.* *And that's a bit like chronic pain where you first have chronic pain, you know you're a caterpillar crawling or trying to crawl, or trying to walk and then you go into this dark place and it takes a while for you to accept that you have chronic pain and once you do accept chronic pain you can come out at the other end by um, trying to get on with your life. Things that you'd stopped doing you can now begin to do again.* *Also my page has a chair in it, that is a safe place for people with chronic pain. This chair is a cosy chair. It looks nice and it actually feels really comfortable for when we need to sit down to rest our achy bodies or our back - if it's your back that's hurting, or your neck. The chair would actually support it.* *I have two people dancing on my zine and dancing is something that is joyful, makes you happy and anyone can do it regardless of*	*Co-researcher 3*

	age or regardless of whether you are able to stand on your feet or if you are in a wheelchair. *And it says that it's more than a dance class, it's a lifeline. And I believe that because um when you are in that dark place of sort of, and in chronic pain, when you dance to your favourite music it brings you back to life again. It brings you back to life.* *The top of my page actually begins with the word Hope and I've always said to myself and to others, we must never give up on hope. It's something that you must always think that you can do. Never give up on that.*	
Page 17	There are cut out circles on this next page, each with some words in them which have been drawn with bright pens and coloured in. *Kind – yourself, others,* *Safe Space,* *Grattitude,* *and Keep on carry on.* Between these images there are wiggly lines made up of dots, ending in arrow heads. Scribbles like handwriting sit beneath each circle and read; *Kind, kind, kind to yourself - because sometimes you are not kind and maybe you then feel pain.* And yes maybe to have a safe space to cry, be loud, be silly, or..... *You have to talk to people. There are people, like when you meet there is someone there who is suffering the same problem and you can mix ideas. So I think this helps.* *So I think group work can really help. It helps you know.* *Gratitude...because sometimes you have to be thankful,* *sometimes it is easier... life is going on and you have to as well, the line is going on, you have to carry on.* *Beneath this is a bold, coloured in red arrow pointing you towards the right hand side of the page, inviting you to turn over.*	Narrator *V4* Narrator *V2* V3 *V2* V4 *V3* Narrator

Page 18	*Happy birthday to you, happy birthday to you, happy birthday dear Angela, happy birthday to you!* Music notes float around the song in a speech bubble. In a pink box below it reads: *It is how you keep yourself, because it is how you take yourself, like age, if you think "because you are old you don't do this-that, that is impossible" that follows you. I say, "no, me I am old I know but I am fairly active. Thank god for that."* If you are enjoying it then you forget the pain. *There is a drawing across the page under these words. It starts with a butterfly pupa, leading with a dotted line to a catterpiller, then another dotted line leads to a crysalise and finally a dotted line ends with a butterfly. This visualises the life cycle of a butterfly – a theme in this zine.* Anybody who's looking at this zine, I'd like them to see it's a process that you're going, to go through - but you can come out at the other end, even if you're living with chronic pain. If you have the right support networks around you and people who are encouraging you. And people who's been through it, telling you their own testimony. This really makes so much of a difference	*GROUP singing* Narrator *V4* V3 *Narrator* Co-researcher 3
Page 19	*We come to the last page...* *It's blue throughout the whole page – it stands out well.* Well, this one I put up, it's like they're having a party, they're having a good time. It looks like they are having a good time, so they are moving around a lot. Then I made two of these beautiful butterflies and then I don't know - this, what is this? He's holding something… Holding something precious - or she's holding that when they're in pain, and showing people that there's something there that can be used.	*Narrator* V2
Page 20 (back cover)	*Thank you to: the PEACE & JOY Peer Support Group - led by Angela Row-Price, an Expert by Experience*	*Narrator*

	Thriving Stockwell - supporting since 2022 *Funding from Project Smith (2024)* *Hosts, Art4Space* *Massey University*	

Appendix H

Flyers to share the zine in dissemination



Appendix I

Instructions: How to fold a one-page zine



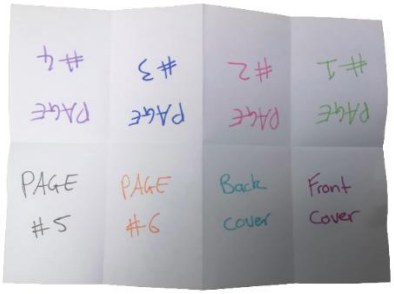
1.Fold page in half, like a book, unfold



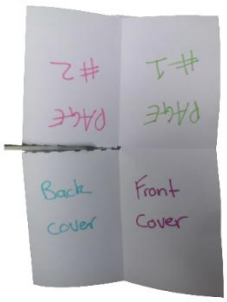
2.Fold edges into centre / into 4 even panels, unfold



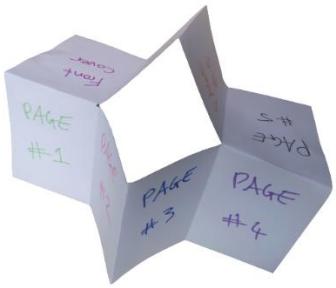
3.Fold in half lengthways, unfold



4. You will now have 8 even sections of your page
Numbers for illustration only



5. Refold and cut on the fold between Page 2 & back cover / Page 3&6.
Make sure you don't cut all the way through !



6. Folding time! Push the outside pages towards each other and the middle ones away.



7. Fold in order and you have a mini-zine to fill the pages of!

Note. Images made in Adobe Express by Emily Martin-Ball