



Ollscoil Chathair
Bhaile Átha Cliath
Dublin City University

A Pragmatic Approach to Chronic Pain
Management: Exploring Support, Lived
Experiences, and Intervention Development in
Ireland

Kate Sheridan CAT, MISCP, MSc

Thesis submitted for the award of a DProfElite

School of Health and Human Performance,

Dublin City University

Supervisor: Dr. Siobhán O'Connor, Dr. Enda Whyte

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Declaration

I hereby certify that this material, which I now submit for assessment on the programme of study leading to the award of DProf Elite is entirely my own work, and that I have exercised reasonable care to ensure that the work is original and have conformed to the regulations on the use and declaration of Generative AI, and does not to the best of my knowledge breach any law of copyright, and has not been taken from the work of others save and to the extent that such work has been cited and acknowledged within the text of my work. I hereby certify that no Generative Artificial Intelligence (Gen AI) tools have been used in the creation of the thesis.

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Presented a talk entitled “Know Pain, Know Gain” for Age Friendly DCU, a community initiative focusing on promoting active and healthy aging. Sept 2024

Presented a talk entitled “Empowering Exercise: Strategies for Supporting People Living with Pain’ For Exwell staff across Ireland, delivered as part of their annual national staff day. Dublin.

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List of Abbreviations

AHP	Allied Health Professional
APTA	American Physical Therapy Association
ASMP	Arthritis Self-Management Program
BCT	Behaviour Change Techniques
BPI	Brief Pain Inventory
BPS	Biopsychosocial
CAT	Certified Athletic Therapist
CBT	Cognitive Behavioural Therapy
CDSM	Chronic Disease Self-Management Program
CeHRes	Centre for eHealth and Wellbeing Research
CLBP	Chronic Low Back Pain
COPD	Chronic Obstructive Pulmonary Disorder
CORU	Health and Social Care Professionals Council
DCU	Dublin City University
EBP	Evidence Based Practice
EDI	Equality, Diversity and Inclusion
EDPP	European Diploma in Pain Physiotherapy
EFIC	European Pain Federation
eHEALS	eHealth Literacy Scale
EIP	Evidence Informed Practice
GAD-7	Generalised Anxiety Disorder
GBD	Global Burden of Disease
GDP	Gross Domestic Product
GET	Group Experiential Statements
GP	General Practitioner
GRIPP2-SF	Guidance for Reporting Involvement of Patients and the Public
HCCQ	Healthcare Climate Questionnaire
HCP	Healthcare Professional
HELPP	Healing and Empowering Lives with Pain
HSE	Health Service Executive
IASP	International Association of the Study of Pain

IPA	Interpretive Phenomenological Analysis
ISCP	Irish Society of Chartered Physiotherapists
IVR	Interactive Voice Response
MDT	Multidisciplinary Team
MSc	Master of Science
OT	Occupational Therapist
PCS	Perceived Competence Scale
PET	Personal Experiential Statements
PHQ-9	Patient Health Questionnaire
PMP	Pain Management Program
PPA	Physiotherapy Pain Association
PPI	Public Patient Involvement
PRISMS	Practical Reviews in Self-Management Support
PT	Physiotherapist
RCT	Randomised Controlled Trial
SCT	Social Cognitive Theory
SDT	Self Determination Theory
SUS	Systems Usability Scale
TRSQ	Treatment Self Regulating Questionnaire
UK	United Kingdom
WHO	World Health Organisation

Thesis Abstract:

A Pragmatic Approach to Chronic Pain Management: Exploring Support, Lived Experiences, and Intervention Development in Ireland

Kate Sheridan

Background: The European pain research strategy highlights the importance of self-management strategies in chronic pain care. However, there is limited research on the implementation and efficacy of self-management approaches within Irish pain services.

Aim: This research aimed to (i) examine the components of Self Determination Theory in individuals living with chronic pain in Ireland (ii) explore the lived experience of service users and providers focusing on autonomy support and self-management behaviours and (iii) co-design an eHealth self-management prototype and conduct usability testing of the prototype for adults with chronic pain to enhance self-management support in Irish pain services.

Methods: Chronic pain was defined as pain lasting > 3 months. A cross-sectional study was completed on participants living with chronic pain in Ireland. Participants completed an anonymous survey constructed of outcome measures relating to autonomy support, motivation, competence, pain interference and psychological factors. Semi-structured interviews utilising Interpretative Phenomenological Analysis provided an exploration of both service users and providers personal lived experience of Irish pain services. Insights from these studies, combined with public and patient involvement, informed a three-step co-development plan for the HELP (Healing and Empowering Lives with Pain) online prototype.

Results: Perceived healthcare support varied according to the healthcare professional leading pain care. Higher levels of self-determination were associated with decreased depression and anxiety in individuals with chronic pain. Both service users and providers described regular experiences of invalidation and biomedical approaches to pain management. A lack of educational resources, waitlists and a lack of multidisciplinary services all impacted the development of self-management skills in service users. A working prototype of the HELP-Platform was co-designed, demonstrating excellent usability and readiness for piloting as a scalable, person-centred eHealth support tool.

Conclusion: Practical solutions are needed to strengthen self-management support where existing healthcare infrastructure is limited. Co-designed eHealth tools like the HELP-Platform, developed with PPI, represent scalable, context-sensitive resources that align with the needs of end-users.

Chapter 1. Introduction

1.1 Establishing Context

The Declaration of Montreal (IASP, 2011) states that pain care is a human right and affirms that all people have the right to appropriate assessment and treatment of pain by adequately trained healthcare professionals. Chronic pain affects biological, psychological, and social dimensions making it a complex condition that calls for interdisciplinary approaches to treatment (Kamper et al., 2015). A delay in access to treatment is associated with reduced quality of life and psychological comorbidities (Lynch et al., 2008), opioid dependence (Blake et al., 2015) and increased mortality (Jansson et al., 2012). In contrast, early access to appropriate pain care is associated with improved quality of life and reduced healthcare costs (Gatchel and Okifuji, 2006). A core principle of modern pain care is the early implementation of behaviour change techniques by healthcare providers to support the development of self-management skills by the person in pain (Soderlund et al., 2023). Self-management refers to a person's ability to cope with their symptoms while handling the physical and psychosocial effects of pain on their everyday life (Barlow et al., 2002). Although a promising strategy, supporting self-management through pain care services requires the appropriate resources to do so.

Chronic pain services in Ireland are under resourced (Purcell et al., 2022). Inadequate facilities, lack of specialised training for healthcare professionals and no agreed pathway of care are some of the recognised barriers in this sector (Brennan et al., 2019, Fullen et al., 2006, Purcell et al., 2022). A national audit of pain services in the Republic of Ireland identifies just five clinics nationwide that employ the recommended full interdisciplinary healthcare team (Purcell et al., 2022). A review of pain pathways in Ireland estimates an 8-year delay in patients being referred to specialised chronic pain clinics where appropriate pain related education is disseminated (Faculty of Pain Medicine, 2022). As a result, in many cases, the delivery of pain services in Ireland is conducted by individual clinicians rather than an interdisciplinary team with specialised training. Considering that pain care is often led by individual therapists, it is of notable concern that healthcare professionals in Ireland reportedly lack the confidence and skills to deliver self-management support to individuals in pain (Penlington et al., 2024).

Barriers to optimal pain care in Ireland can be linked to the absence of a national chronic pain strategy, despite a call to action two decades ago (Fullen et al., 2006). While healthcare reforms such as Sláintecare in Ireland promise to deliver care pathways in the community and 'put people at the centre of the health system', concern on the practicalities of such reforms

given the lack of resources and healthcare professionals with appropriate training exist (Faculty of Pain Medicine, 2022). In the absence of an Irish national strategy, the recent publication of the European pain research strategy (Pickering et al., 2024) provides valuable direction for Irish pain researchers and clinicians. A critical aspect of the report identifies the equal importance of non-pharmacological (physical, psychological and social) approaches to care as pharmacological therapies (Pickering et al., 2025). Given the reported lack of interdisciplinary facilities in Ireland, practical solutions to delivering biopsychosocial orientated pain treatment that supports self-management strategies is essential.

The challenges of providing pain care are not confined to one profession, as multiple healthcare professionals in Ireland report significant barriers to providing effective pain care. Pain physicians highlight a lack of interest in the specialty and a shortage of new trainees to meet clinical demand (O’Sullivan & O’Gara, 2021). Nurses report limited time to adequately assess and manage pain (Duignan & Dunn, 2009), while physiotherapists express concern about the continued dominance of a biomedical, secondary-care-led model (Murphy et al., 2013). Across general practitioners, physiotherapists, occupational therapists, and nurses, common challenges include limited and delayed access to multidisciplinary services, unclear care pathways, and inadequate training for healthcare professionals in the management of chronic conditions (Cunningham et al., 2024). While these issues affect all healthcare professions, the following section focuses in detail on the specific role and challenges faced by physiotherapists in pain care, given the relevance to my own clinical practice and professional identity.

1.2 Physiotherapy: Clinical Contexts and Considerations

The title of physiotherapist or physical therapist connotes a strong relationship to physical movement. The Irish Society of Physiotherapy defines physiotherapists as “health professionals who are responsible for developing, maintaining or restoring movement and functional ability throughout the lifespan using evidence-based practice” (ISCP 2022). Furthermore, the American Physical Therapy Association enforces the dependency of physical therapists on movement through their vision statement, the “physical therapy profession will transform society by optimizing movement to improve health and participation in life” (APTA 2009). Although this title provides a clear message to society of

our role and dedication to improving physical activity it could be argued this simplistic directive is reductionist to the behaviour change, motivation and educational role involved in our clinical practice, particularly the professions' role in chronic illness including chronic pain care. There has been a call for physiotherapists' role in health promotion beyond physical activity prescription (Dean 2009).

In Ireland, standards of professionalism of physiotherapists include demonstrating evidence-based clinical reasoning and working within a defined regulatory framework of personal and professional standards (ISCP 2022). However, a progressive framework for physiotherapy led pain management does not exist in Ireland with neither the Irish Pain Society or the Irish Society of Chartered Physiotherapists publishing professional standards or skills necessary to support optimal practice in pain physiotherapy. In 2017, the European Pain Federation published core competencies of pain management and created the European Diploma in Pain Physiotherapy (EDPP) to standardise pain assessment and treatment across Europe. To date just 7 Irish physiotherapists have become EDPP Diplomates (EFIC, 2024).

Historically, the profession of physiotherapy drew on a biomedical paradigm for legitimacy, working closely with medical practitioners in early clinical settings (Nicholls and Holmes 2012). Aligning with the medical community enhanced the professional integrity for the physiotherapy community both politically and culturally, however, as a result the foundations of professional standards and skills were also aligned with the medical community where the concept of 'body as a machine' arose (Nicholls and Gibson 2010). As will be discussed in detail in Chapter 2, there is an undeniable discord between the person-centred approach detailed in research and the deep-rooted biomedical culture that the profession of physiotherapy has grown from. This is important given that therapeutic outcome is negatively affected by ignoring the patient's preferences and previous experiences (O'Keefe et al., 2015).

As healthcare professionals we hold a duty of care and a moral responsibility to provide the highest quality of practice (CORU, 2019). Evidence based practice (EBP) has become a recognised approach to provide high quality care. EBP has been defined 'as the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients' (Sackett, 1996). Although Sackett expands on this definition recognising that EBP should in fact integrate clinical expertise with the best available evidence (Sackett, 1997), EBP has become a source of criticism. Criticism towards an EBP

model includes the barriers of implementing research findings due to resources at a ground level, the potential for empirical findings to be outdated as they are published and its capacity to ignore the unique context of both clinicians and patients (Rubin 2007). EBP supports a hierarchy of evidence with significant value placed on Randomised Controlled Trials (RCT). RCTs focus on singular variables, despite the view that evidence should be contextual and not static (Rycroft-Malone 2008). RCTs often focus on a single variable within a large, homogenous group to identify a causal relationship between specific elements. However, this narrow focus rarely aligns with the complexity and multidimensional nature of chronic pain conditions. RCT's commonly don't acknowledge the whole of the human experience being forced to explore elements of the whole separately resulting in knowledge that does not lend itself to practical application in a clinical context. In contrast pragmatism is a research approach that does not adopt a hierarchical structure to evidence rather it supports considering the most applicable knowledge that serves the community within question and their specific context (Allemang et al., 2022).

In the context of clinical practice, there is a need for the profession to adopt a more interpretive ontology and recognise its professional artistry (Kell and Owen 2008). That is that reality is shaped by how people experience and interpret the world around them and within clinical practice, this means understanding patients' experiences, values, and meanings, not just their symptoms. In fact, clinical practice is now described as an art as much as it is a science with researchers recognising the importance of the unique characteristics of clients and context of practice (Nevo & Slonim-Nevo 2011). It has been suggested that scientific rationality should be met with practical wisdom to deliver a meaningful and effective approach to care for the person in need (Nevo & Slonim-Nevo 2011). Reflective practice has been deemed an imperative element of developing this diversified ontology (Kell & Owen 2008). The ontological complexity of the field of physiotherapy ensures that a single epistemology is inadequate to provide patient centred care (Shaw & DeForge 2012). Engle et al. (2019) note that tension can arise in healthcare settings striving to integrate both evidence-based practice (EBP) and patient-centered care, emphasizing that organizations must cultivate distinct traits to successfully balance both approaches.

It has been suggested that physiotherapists should be considered bricoleurs, 'a person who creates using whatever materials are available' (Shaw & DeForge 2012). As Shaw and DeForge (2012) describe, clinical knowledge is founded in social, cultural and historical

contexts and as such practical research should consider each of these elements within its design. The reference of physiotherapy as a bricoleur encapsulates the benefits of adopting multiple epistemologies to provide a holistic level of care. Considering this, my personal belief is that Evidence Informed Practice (EIP) is a preferable approach than the traditional EBP. EIP places the patient's preferences and values at the core of their care plan while considering the current evidence base and utilising professional judgement and flexibility to create an effective treatment plan that is applicable in each clinical context. EIP epitomises patient centred care where the evidence is integrated into the dynamic needs of a personalised rehabilitation plan (Nevo & Slonim-Nevo., 2011).

Shaw and Connelly (2012) report the importance of integrating phenomenological research into clinical practice so that the lived experience of both patients and clinicians can enhance clinical decisions. Qualitative research emphasising the psychological, social and emotional factors contributing to the lived experience in pain rehabilitation is recognised as playing a key role in EIP (van Rysewyk et al., 2023). Barradell et al., (2021) noted that physiotherapists' knowledge can be developed outside of scientific research and that therapists have discussed the value of being a creator and contributor of knowledge not merely a passive recipient of knowledge. EIP considers clinicians as active beings engaged in a problem-solving process which requires a complex skill set based on multiple epistemologies. The EIP approach aligns closely with that of patient centred care where the clinician's expertise and professional judgement, the clinical context and the best available evidence all align to produce an individualised treatment plan that meets the patient's values. Adoption of an EIP model will support the contextual and dynamic nature of physiotherapy supporting multiple types of knowledge in practice (Shaw & DeForge 2012).

1.3 Personal Narrative

I am one of a small but growing community of allied health professionals specialising in pain management in Ireland. I began my career in 2009 as a Certified Athletic Therapist and subsequently completed a pre-registration MSc in Physiotherapy in 2012. As a new profession in Ireland, barriers to employment as an athletic therapist introduced me to the hierarchy that exists within healthcare organisations (Essex et al., 2023). This experience has nurtured a quality of resilience and an open mind to alternative models of practice that can deliver quality healthcare. Working clinically, I quickly developed a rising curiosity in the

complexities of pain and the available conservative approaches that can be applied in its management. From an early point in my career, I observed firsthand the discrepancy between knowledge founded on current research and clinical practice for those living with chronic pain in Ireland (IASP 2021). Daily, I experienced those living with pain reporting pain invalidation, a loss of identity and a sense of isolation, all experiences which are echoed in current research (Windrim et al., 2024, Nicola et al., 2021). My experience and observations in clinical practice do not align with what I consider an optimal standard of care.

The clinic that I practiced in had a primary focus on self-management and exercise as medicine. The clinic's philosophy was to change community healthcare models and evolve care from traditional biomedical led rehabilitation to support a biopsychosocial approach, an ethic that mirrored my personal approach to pain care. My clinical philosophy has been to harvest self-efficacy in individuals living with pain and support them to regain control in their lives in a way that is meaningful for them. Despite my efforts to deliver a biopsychosocial model of care, and the clinic's philosophy I was disheartened with the challenges associated with the practical implications of doing so effectively. Short-appointment times, the volume of patients expected to be seen per day, the isolation of working outside of an interdisciplinary team are but a few of the barriers I experienced. Despite my best efforts the emotional challenge of working in the area of chronic pain led to an uphill battle against emotional exhaustion and symptoms of burnout, an experience echoed by other clinicians working in a pain context (Ashton-James et al., 2021, Kroll et al., 2016, Riquelme et al., 2018).

To truly embody the application of the biopsychosocial model of care and to overcome the barriers I was encountering I enthusiastically engaged in further education in search of an answer to my clinical practice conundrum 'how to deliver best practice at a ground level'. I completed an advanced manual therapy diploma hosted by Curtin University. Despite a focus on passive therapies, the course enabled interactions with international researchers and practitioners. This proved a rich and rewarding experience and clarified my desire to specialise formally in pain rehabilitation, ironically reducing my application of manual therapies. I quickly followed this with entrance into a master's program in Clinical Pain Management at the University of Edinburgh, a part-time master's that allowed continued clinical practice and hence facilitated an opportunity to translate my new skills directly into practice. Having the humbling experience of working day in and day out with individuals

suffering from varying levels of pain and disability, my drive to improve their experience escalated from the commencement of this master's. During this master's degree, I was diagnosed with chronic pelvic pain, an experience that further deepened my motivation to understand pain more fully and contribute to improving its care.

The appeal of choosing this specific master's degree was the multidisciplinary peer cohort it consisted of. Open to GP's, consultants, nurses and allied health professionals, I expected this element to bring healthcare workers together and explore the commonalities of how each profession can support each other in the uphill climb against chronic pain. The reality for me was that the program emphasised the division between healthcare professionals and the protectiveness associated with healthcare titles. It also highlighted the core continuation of biomedical practice of pain management despite the superficial discussion of biopsychosocial approaches. I completed the master's with merit but was surprised to find myself possessing an even greater level of clinical frustration than before the master's. In 2021 I completed the European Diploma in Pain Physiotherapy (EDPP), affirming confidence in my clinical skills and knowledge base. However, the ability to satisfactorily implement such skills in my healthcare context continued to elude me. As Ng et al., (2021) conclude, the successful integration of biopsychosocial orientated pain care is reliant on 'whole of health' system frameworks, which entails a complex interaction of microlevel, mesolevel and macrolevel healthcare factors. I had built proficiency at a microlevel (healthcare professional knowledge and skills) but my professional development to date had not provided me with an avenue to effectively navigate both mesolevel (clinical practice guidelines, funding models and health service provision) or macrolevel factors (health policy, social factors) (Ng et al., 2021).

In 2020 an invitation to join the lecturing team in DCU led to a part-time position teaching on the Athletic Therapy and Training program. I had begun to recognise the limitations of my impact working solely in clinical practice. My new role co-ordinating modules addressing chronic pain rehabilitation and pain science allowed an opportunity to raise awareness of clinical approaches to pain care, introduce appropriate models of care and to challenge the cultural beliefs about healthcare practice in undergraduate students. Approaching my tenth year in clinical practice and with my new role I conceded that I was approaching a ceiling effect with taught continuous professional development courses relating to pain. The opportunity to engage in the Professional Doctorate program supported my desire to source practical solutions for active clinicians.

Reflecting on my professional status following these experiences, I have concluded that I am committed to delivering enhanced pain rehabilitation to those living with persistent pain. I have witnessed the detrimental effect of therapists without specialist pain training applying inappropriate treatments in this cohort and the long-term negative impacts of the current infrastructure and pain care pathways in Ireland. Reflecting on my clinical interactions with both persons living with pain and with pain clinicians in Ireland, I disagree that our global approach to treating pain is supporting the principles of beneficence, acting in the patient's best interest and non-maleficence, doing no harm (Sokol, 2013). I am committed to exploring the research gaps that I have witnessed in my clinical practice. It is my desire through the professional doctorate to establish myself as a pain therapist specialising in the implementation of a true biopsychosocial approach and engaging in patient orientated research. My goal is to complete research which translates to clinical practice enhancing both the service users and the service providers experience. Furthermore, I hope any research I engage in can enhance clinician education in pain rehabilitation particularly at an undergraduate level and support Ireland's clinicians to deliver effective pain care that puts the person in pain at the centre of the rehabilitation plan. I am committed that each of my study protocols will be finalised following review from service users living with persistent pain as per the recent call for 'patients as partners in research' (Belton et al., 2019). The intended impact of this research is a call to action to enhance pain rehabilitation services in Ireland by exploring alternative, cost-effective strategies of delivering rehabilitation that truly integrates a biopsychosocial approach.

1.4 Research Philosophy

My practice philosophy aligns firmly with that of a patient-centred approach. At the core of my professional values are, respect of the person, consideration of the person in their context and the facilitation of shared decision making (Montori et al., 2022). By adopting a patient-centred approach to care I focus on prioritising patient preferences and demonstrating flexibility in practice to support patient values in their individualised context. The American Physical Therapy Association has identified seven core values associated with physiotherapists, accountability, altruism, compassion, caring, excellence, integrity and professional duty (APTA 2009). These values align with both my research and practice philosophy. I am committed to engaging in a collaborative environment with individuals living with pain and creating a culture where decision making is shared so that each party is

offered an equal voice in decisions. The research I develop will focus on enhancing the individual's journey by enhancing autonomy and a safe collaborative space. Both my practice and research will be dedicated to an interactive model of care where myself, as the therapist and the person seeking care will interact as equals with common goals constructing an egalitarian relationship (Bellner 1999). Being a professional in healthcare demands responsibility for supporting autonomy of the individual, to both relieve suffering and enhance living (Entwistle et al., 2010). My philosophy is to accept that the healthcare profession is dynamic and continually changing and as such there is a need to consistently self-reflect and question my practice (Koshy et al., 2017). The invisible skills, such as critical thinking, creativity, reflection and lateral thinking are highly placed in my professional values. I am dedicated to the reconceptualization of the treatment and rehabilitation of chronic pain from a behavioural perspective. I am focused on achieving this by expanding the limitations of practice culturally and politically placed on healthcare professionals.

My research philosophy aligns with that of pragmatism (Shaw et al., 2010). I commit to approach research questions both logically and practically. I am dedicated to conducting research that best addresses the research question with an ultimate focus on the practical implications of research and to research that enhances social justice. I value engagement with research that delivers action at a community level. I strive to understand the context of the participant in my research and consequently I am dedicated to conduct studies in the field where participants work and live. I embrace the ontological assumption of multiple realities (Erlingsson & Brysiewicz, 2013). The patient's expertise serves a valuable role in my professional context. I am committed to embracing patients as partners in research (Belton et al., 2019). A pragmatic approach encourages the use of varied methodology including interview, observation, questionnaires and document analysis (Long et al., 2018) and as such I value the importance of a mixed-method approach to answer research questions.

Historically both in research and practice, the therapist has been viewed as the expert and the patient as the recipient of care (Nicholls, 2017). This traditional paternalistic approach to healthcare that prioritises professional integrity over optimal patient centred care continues to play an active role in the healthcare domain (Nicholls, 2017). To evolve from paternalism, I am committed to evolving the definition of expertise in the profession of physiotherapy. I envision an expertise in communication and collaboration and the development of a professional context that can support a true patient centred approach. I am uncomfortable with 'the body as a machine' paradigm which remains a core element of modern healthcare

practice (Bellner 1999, Nicholls 2017). The research I develop will focus on enhancing the individual's journey through a biopsychosocial lens diverging from the limitations imposed by the biomedical model of care.

According to the UK Physiotherapy Pain Association (PPA, 2014) "Expert level practice works within complex, unpredictable and normally specialised contexts that demand innovative work that may involve extending the current limits of practice" (PPA 2014). I will embrace innovation and dissemination of knowledge to contribute to the current limits identified in physiotherapy practice. Applying a philosophy of pragmatism means that knowledge is only meaningful when coupled with action (Grayling et al., 2005). The value of my research will be placed on the extrinsic usefulness in addressing practical questions in daily clinical practice. One of the key applications of pragmatism is to solve societal problems (Grayling et al., 2005). Pragmatism puts an emphasis on the outcome and action that results from research and as such focuses on enhancing societal welfare (Turyahikao 2014, Pansiri 2005). The strong alignment of the pragmatic paradigm and the patient-centred care model both of which I embrace has been documented (Allemang et al., 2022). Both patient centred care and pragmatism strive for social change that is meaningful to the person in pain (Allemang et al., 2022). Furthermore, both paradigms aim to generate knowledge through problem solving that results in action and stimulates change. I am committed to engaging in practical research that can deliver social justice and practical solutions to the chronic pain epidemic.

1.5 Aims and Objectives

Study 1 Aims and Objectives

Aim

To investigate the components of Self-Determination Theory (SDT) (perceived autonomy support, motivation and competence in physical activity) in persons with chronic pain accessing Irish healthcare service providers.

Objectives

- To examine autonomy support, motivation and competence in physical activity of individuals living with chronic pain in Ireland.

- To investigate if there are differences in perceived autonomy support, motivation and competence in physical activity in individuals undergoing treatment with different Irish healthcare professionals.
- To investigate if there is an association between pain interference, psychological wellbeing and the components of self-determination theory (autonomy, motivation and competence in physical activity) in persons living with chronic pain.

Study 2 Aims and Objectives

Aim: To explore the lived experience of service users and service providers participating in Irish healthcare services, specifically focusing on autonomy support and self-management behaviours in the context of chronic pain.

Objectives

- To examine the lived experience of service users accessing Irish pain services
- To examine the lived experience of service providers working within Irish pain services.
- To explore levels of autonomy support and self-management as experienced by service users of Irish pain services.
- To explore experience in providing autonomy support and self-management support by service providers working within Irish pain services.

Study 3 Aims and Objectives

Aim:

To codesign a user-centred eHealth self-management support resource; led by public, patient involvement; the HELP-Platform (**H**ealing and **E**mpowering **L**ives with **P**ain) for persons living with chronic pain.

Objectives

- To co-design a novel eHealth self-management support resource utilising mixed-methods.

- To evaluate a novel eHealth self-management support resource for appropriateness and content clarity

1.6 Structure of the Thesis

The current research was conducted in three main studies, and the thesis is accordingly organised into six chapters. Chapter one opens the thesis by establishing background context that led to my engagement in this doctoral journey. Importantly Chapter 1 provides both a personal narrative and my research philosophy, establishing a foundation for my personal perspectives, my professional views and how they influenced the progression of this research. Chapter 2 provides a narrative review and details the problem of pain in modern society, the available models of care, the concept of self-management for pain and the opportunities of eHealth interventions for pain care.

Study 1, which has been published in PLOS One, is detailed in Chapter 3. The findings present for the first time perceived levels of autonomy support, motivation and competency in persons living with chronic pain in Ireland. It also reports that higher levels of perceived competency in physical activity are associated with lower levels of pain interference, depression and anxiety. Chapter 4 presents Study 2, currently under review in Pain Research and Management. Study 2 explored the lived experience of service users and service providers participating in Irish healthcare services specifically focusing on autonomy support and self-management behaviours. Overall Study 2 identified that both service users and providers desire access to multidisciplinary services that support a biopsychosocial model of care. However, healthcare professionals are prevented from delivering what service users expect due to macro, meso and microlevel factors. Importantly both service users and providers described regular experiences of invalidation and biomedical approaches to pain management in Ireland.

Chapter 5 presents the findings of the final study of the current research, the codesign of a user-centred eHealth self-management support resource, the HELP-Platform. It details the three-step development plan, adopting public and patient involvement to co-develop a novel eHealth resource. In conclusion, Chapter 6 discusses the implications of this research in relation to: (1 the existing literature, (2 its impact on Irish pain services, and (3 its influence on my development as a practitioner.

Chapter 2. Literature Review

2.1 Introduction

Pain is defined as 'an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage' (Raja et al., 2020). Pain is considered chronic if it persists for more than three months (Treede et al., 2015). It is divided into two categories, chronic primary pain and chronic secondary pain. Chronic primary pain is defined as pain of three months or more in one or more anatomical region associated with significant emotional distress and disability such as fibromyalgia and chronic regional pain syndrome (Nicholas et al., 2019) whereas chronic secondary pain is classified as pain as a symptom of another underlying disease such as osteoarthritis (Treede et al., 2019). Both categories of pain contribute to substantial societal and personal costs and lead to the potential for prolonged suffering. The following literature review will consider literature involving both primary and secondary pain classifications. It will explore the burden of pain in modern society, provide an overview of models of healthcare applied in current clinical contexts, explore the role of self-management in pain care and the potential of e-health in chronic pain management.

2.2 The Impact and Burden of Chronic Pain

2.2.1 The Prevalence of Pain

A systematic review across Europe found a point prevalence of chronic pain ranging from 12% to 48%, and a 12-month prevalence ranging from 8.1% to 44.6%, highlighting variation in reporting due to inconsistent diagnostic criteria and differing assessment methodologies (Rometsch et al., 2025). There are limited studies examining the prevalence of chronic pain in Ireland, with only two nationally representative studies published to date (Breivik et al., 2006; Raftery et al., 2011). Raftery et al., (2011) report a prevalence of 35.5% and Breivik et al., (2006) report a prevalence of 13%. The findings of Raftery et al., (2011) are in keeping with the prevalence of chronic pain conditions reported in a large-scale global study reporting a chronic pain prevalence of 37.3% in developed countries (Tsang et al., 2008). The direct comparison of prevalence studies is difficult given methodological differences including heterogeneity of the definition of chronic pain and the evidence that data collected via surveys appears to result in higher prevalence estimates than data collection by interview (Steingrimsdóttir et al., 2017). This finding may explain the disparity between the survey data from Raftery et al, (2011) and the interview findings of Breivik et al (2006). Despite Breivik et al. (2006) reporting that Ireland has one of the lowest prevalences of chronic pain in

Europe (13%), a third of those affected reported experiencing severe pain. However, only 12% had been reviewed by a pain management specialist, and 71% stated that their pain medication was not always adequate. These findings remind us that exploring prevalence alone is not sufficient in assessing the impact of pain. Collectively the findings of these two studies highlight that chronic pain affects a substantial portion of the Irish population, underscoring the need for effective pain management strategies.

Worldwide, females report higher prevalence rates of chronic pain than their male counterparts (Steingrimsdóttir et al., 2017). There is limited evidence examining gender differences in chronic pain, particularly within the Irish context. At a pan European level, a greater proportion of women (62.3%) report pain than men (55.5%) (Bimpong et al., 2022). Interestingly, within this large study exploring 19 European countries, no significant gender pain inequalities were reported for participants from Ireland where the prevalence of pain reported was 31% and 34.6% in males and females respectively (Bimpong et al., 2022). However, despite its recent publication, it is important to note the data utilised for analysis in this study was recorded in 2014 and so an up-to-date review of pain prevalence and an analysis of prevalence across genders is required. The only other available Irish data on gender differences in pain, reported by Raftery et al., (2011) found no statistically significant differences between males and females. From a qualitative perspective a recent study by Windrim et al., (2024) investigating Irish women's experiences seeking healthcare for abdominal pain reported that female participants were often dismissed, invalidated and were required to self-advocate to access appropriate care. Research investigating gender differences in pain prevalence and experience is still in its early stages in Ireland but is critically needed to enhance understanding and promote equitable care for all individuals living with pain.

2.2.2 The Burden of Pain

The burden of pain is widespread, affecting individuals and society alike. Significant reductions in health-related quality of life have been reported in a large variety of pain conditions (Girach et al., 2019; Gormsen et al., 2010; Oliveira et al., 2009). Years lived with disability describes the impact of conditions on individuals, their communities, societies, and the health and social services that they require (GBD 2017). Low back pain is the leading cause of years lived with a disability with migraine, neck pain and musculoskeletal disorders

also recorded in the top seven listed conditions (Rice et al., 2016). Given its significant impact, it is unsurprising that improving chronic pain management is recognized as a global health priority (Goldberg & McGee, 2011).

Chronic pain has been associated with substantial economic burden across Europe. In Ireland, cost analysis studies estimate the economic burden of chronic pain to range between €5,665 (Raftery et al., 2012) and €23,283 per person (Gannon et al., 2013). The wide variation in cost estimates is attributed to differences in methodological approaches where Raftery et al., (2012) explored costs related to those in the community and Gannon et al., (2013) explored costs in those accessing a specialised pain clinic. Nonetheless, the estimated cost of chronic pain at 2.86% of Irish Gross Domestic Product (GDP) is comparable to findings from Portugal (Azevedo et al., 2016), with reported ranges across Europe varying between 2% to 10% of GDP (Gustavsson et al., 2012; Stubhaug et al., 2024). Across the available research it is the indirect costs associated with chronic pain, such as loss of wages and loss of productivity that result in the largest costs. In their review, Patel et al., (2012), present the substantial burden of chronic pain on the European workplace, affecting individuals' ability to return to work, a loss of productivity in work and the need for early retirement (Patel et al., 2012). In Norway and the Netherlands, it is estimated that 80% and 93% of chronic pain costs are related to indirect costs (Stubhaug et al., 2024; van Tulder et al., 1995). Of note, an increase in cost is associated with increasing age (Bernfort et al., 2015), elevated depression scores, pain severity (Raftery et al., 2012), having multiple sites of pain and being female (Mayer et al., 2019). Interestingly the first study of its type to estimate the full economic burden associated with chronic pain linking individual-level administrative data and self-reported survey answers in Norway estimated a cost of €55,000 per individual living with chronic pain, a yearly burden of €12 billion nationally (Stubhaug et al., 2024). An up-to-date study investigating both the direct and indirect costs of chronic pain in Ireland is required to explore the true socioeconomic costs. While precise current figures are lacking, it can reasonably be assumed that chronic pain imposes a substantial financial burden. Therefore, improvements in pain management approaches that not only reduce healthcare utilisation but importantly reduce the indirect costs associated with chronic pain are essential. However, exploring cost analysis of new clinical management strategies is challenging without an up-to-date measure of the economic cost.

While the economic burden of pain is significant, the personal suffering associated with chronic pain is arguably more concerning. Pain related suffering is a multidimensional

phenomenon defined as a '*severely negative, complex, and dynamic experience in response to a perceived threat to an individual's integrity as a self and identity as a person*' (Noe-Steinmüller et al., 2024 p1441). To address pain related suffering, consideration must be given not only to the widely recognised social, psychological, physical factors but also spiritual, existential, cultural, cognitive and affective factors (Noe-Steinmüller et al., 2024). The successful treatment of pain relies on addressing the person's emotional state (Gatchel et al., 2007). In a study based in Northern Ireland, persons living with pain expressed their need for increased emotional and psychological support from their GPs when compared to a cohort without pain (Kirby et al., 2009). Active listening, open communication, access to healthcare with individuals with speciality training in pain, and adequate appointment times are all required to support high quality therapeutic relationships that can support the suffering experienced with chronic pain (Gruß et al., 2020). Establishing credibility with healthcare professionals can be challenging for people living with chronic pain (Werner & Malterud, 2003) as exemplified from an Irish perspective in the Windrim et al., (2024) study mentioned in section 2.2 of Irish women's experience of abdominal pain and invalidation.

The lived experience of pain and the potential for suffering are further compounded by its association with secondary health comorbidities. The association between chronic pain conditions and increased psychological distress has long been recognised (Von Korff et al., 1988). Regarding psychological comorbidities, the prevalence of clinical symptoms for depression is 39% and for anxiety 40%, with considerable variability observed between different types of pain and methodological differences in data collection (Aaron et al., 2025). The lifetime prevalence of suicide attempts ranges between 5-14% in individuals with chronic pain, with 1 in every 5 people living with chronic pain reporting suicidal ideation (Tang & Crane, 2006). Sleep disturbance is another common complication in persons living with chronic pain, reported in 70% of people, ranging between 65-95% prevalence depending on the specific pain condition considered (Sun et al., 2021). Furthermore, musculoskeletal diseases have been associated with a 17% increase in chronic diseases, with a particular link between arthritis and cardiovascular disease (Williams et al., 2018).

While the personal burden of chronic pain is paramount, it is equally crucial to consider its strain on healthcare systems, especially the clinicians responsible for managing it. It is reported that 81% of GPs believed that most patients received suboptimal treatment of chronic pain (Stannard & Johnson, 2003). In the United States 84% of primary care providers find the management of chronic pain stressful (Jamison et al., 2014). One in five Australian

clinician's working within a multidisciplinary pain team experience high levels of emotional exhaustion and report feeling low personal accomplishment (Ashton-James et al., 2021). Similarly, almost two thirds of pain physicians report high emotional exhaustion and one in five report low personal accomplishment (Kroll et al., 2016). The work-related determinants of burnout include collective workload, professional relationships, role, autonomy, and access to supervision (O'Connor et al., 2018). Concern has been expressed regarding the sustainability of European healthcare systems and their ability to support the high burden placed on them by chronic pain (Pickering et al., 2024).

2.2.3 Pain Management as a Human Right: Access and Service Challenges in Ireland

Ireland operates a two-tiered healthcare system comprising both public and private services (Heavey, 2019; Murphy et al., 2020). The system is further complicated by the overlap between sectors, as private healthcare is often delivered within public hospitals using public infrastructure and resources (Heavey, 2019), while public care is sometimes outsourced to private providers through the National Treatment Purchase Fund (NTPF) (Burke et al., 2019). This integration makes it difficult to study either sector in isolation; therefore, this thesis includes both public and private healthcare settings. Access to pain services also reflects this division. Public pain services are primarily delivered through multidisciplinary teams (MDTs), yet there are only five fully staffed MDTs nationwide (Purcell et al., 2022). In contrast, private pain services typically offer faster access but are individualised in nature, requiring patients to consult multiple professionals across different locations without integrated MDT support.

In Ireland, both physiotherapists and doctors play key roles in chronic pain care, though their clinical pathways and specialisation qualifications differ. Pain education curricula for both professions across Europe show considerable variability in content, duration, and integration, with a lack of interdisciplinary training (Skidmore et al., 2025). Postgraduate physiotherapists can undertake the Expert Diploma in Pain Practice (EDPP) to demonstrate advanced knowledge in pain, while doctors can pursue the Expert Diploma in Pain Medicine (*EDMP*) to certify expertise in chronic pain management. However, uptake of both qualifications in Ireland remains low.

In Ireland, Chronic Pain Ireland's Charter of Rights (2009) advocates for the recognition of pain management as a fundamental human right, emphasizing the need for accessible and effective pain relief for all individuals. This document aligns with the Declaration of Montreal (2010), urging governments and healthcare providers to prioritize pain management within their obligations (IASP 2011). When considering pain care in Ireland it is important to note the three specific articles of the Declaration of Montreal (2011).

Article 1. The right of all people to have access to pain management without discrimination

Article 2. The right of people in pain to acknowledgment of their pain and to be informed about how it can be assessed and managed

Article 3. The right of all people with pain to have access to appropriate assessment and treatment of the pain by adequately trained health care professionals'

The Pain Steering Committee has identified inconsistencies in the availability of pain services across Europe and advocates for a minimum standard of pain care accessible to all individuals living with pain (Baker et al., 2010). In 2020 a national audit of public pain services was completed in Ireland (Purcell et al., 2022). This audit highlighted three key points; firstly, there is unequal access to pain services with services in rural areas significantly limited. Secondly, the audit highlights a delay in access to services due to long wait times. A review of the National Public Hospital waiting lists for Outpatients, Inpatients, Day cases and Planned Procedures further echo the findings of Purcell et al., (2022) regarding long wait times (NTPF 2025). Thirdly, the majority of pain services offer limited treatment options with a primary focus on medication and interventional medical procedures. Purcell et al., (2022) identify that Ireland has 17 hospital led chronic pain services. Of these 17 services, 6 services have a full-time physiotherapist, 3 report part-time physiotherapy hours and 8 services reported no physiotherapy services at all. Similarly, poor records of psychology roles are reported with only five services reporting full- time psychology services and three reporting part-time psychology hours to support their pain service. This lack of multidisciplinary care by allied health professionals is in direct contradiction to guidelines as published by the International Association of Pain (Lynch et al., 2008, IASP 2021) emphasising the requirement of multidisciplinary conservative management.

In February 2025, a total of 13,940 people were waiting for a new patient appointment in pain clinics. The number of patients waiting between 6-12 months for their first appointment was 4244 (30.4%), 12-18 months was 1765 (12.6%) and over 18 months for a first appointment

was 967 (6.9%). A total of 6816 patients were waiting for their first treatment. The number of patients waiting between 6-12 months was 1964 (28.8%), 12-18 months was 432 (6.3%) and over 18 months was 390 (5.7%). Unacceptable adverse impacts are associated with waiting six months or more for pain treatment, such as decreased psychological wellbeing and lower quality of life (Lynch et al., 2008). Interestingly the Sláintecare Implementation and Action Plan 2021-2023, an Irish government initiative aimed at transforming the healthcare system in Ireland, details wait time targets of 10 days for a diagnostic test, 10 weeks for an outpatient appointment and 12 weeks for an inpatient procedure (Sláintecare Report, 2017). Although its aim of community led care seems practical in theory and could decrease the burden on hospital-based services, its success relies on the presence of correct resources including adequately trained professionals. Reports show that across Europe only 53% of primary care physicians report being confident in managing chronic pain (Baker et al., 2010). When asked to indicate how confident they feel understanding and using existing guidelines for the management of chronic pain on a scale of 0-10, Irish doctors' mean score was 5.6, significantly lower than other European countries (Baker et al., 2010). Given the issues of access to care, waitlist times, and healthcare professional training, it cannot be said that Ireland is meeting the three articles on human rights outlined in the Declaration of Montréal (IASP 2011).

2.3 Models of Care in Chronic Pain Management

2.3.1 Models of Care

The knowledge-practice gap in chronic pain care becomes particularly evident when comparing the biomedical and biopsychosocial models of care. The biomedical model attributes structural abnormalities as the fault contributing to all disease (Melzack & Wall, 1965). The complex nature of chronic pain is overlooked when simple, mechanistic rationales for its treatment are employed (Harris et al., 2020). As Gatchel et al. (2007) note, the amount of pain experienced by a person would be directly proportional to the extent of tissue pathology if the biomedical model was exhaustive. The limitations of the pathoanatomical relationship to pain is evident in multiple imaging studies that demonstrate the regular discrepancy between structural changes and the experience of pain (Barreto et al., 2019; Blankenstein et al., 2020; Horga et al., 2020; Nakashima et al., 2015). Pain cannot be measured solely through diagnostic tests; it is a subjective experience and as such the person's narrative should direct care plans regardless of diagnostic tests or structural findings.

Decades of research now support the multidimensional nature of pain and the need for a model of care that encompasses all aspects of the human experience to effectively treat it (Kovačević et al., 2024). Psychological factors, fear avoidance, poor support networks, low socioeconomic status and high levels of pain are all implicated in the transition from acute to chronic pain (Dunn et al., 2024; Pincus et al., 2002) as well as in the maintenance of chronic pain (Booher, 2019; Zale & Ditre, 2015). Furthermore, it is well recognised that conceptual inputs to the central nervous system, including expectations, beliefs, past experiences, emotional state, and the meaning attributed to pain, modulate pain in a variety of ways (Moseley & Butler, 2015). While a pathoanatomical diagnosis may remain constant throughout life, a person's function, pain interference, and psychological status are dynamic and can be modified by addressing their context (Rosignoli et al., 2022). This adaptability makes the biopsychosocial model a more suitable approach for pain management.

George Engel proposed the Biopsychosocial (BPS) model, a holistic approach to healthcare that integrates a person's biological, psychological, and social health (Engel, 1977). In its simplest term the BPS model can be defined as encompassing multidimensional, integrated care utilising a range of differing treatment modalities (Thomas et al., 2018). The core elements of the BPS were published by the World Health Organisation in their definition of health in 1948; '*Health is a state of complete physical, mental and social well-being and not merely the absence of disease*' (WHO 2019). Clinical guidelines and systematic reviews support the implementation of the BPS model in the treatment of chronic pain (NICE 2021, van Erp et al., 2019). There is moderate quality evidence that a BPS approach delivered by physiotherapists is more effective at improving disability and pain than education at short, medium and long term follow up (van Erp et al., 2019). Kamper et al., (2014) report moderate strength evidence that multidisciplinary biopsychosocial rehabilitation programs result in larger improvements in pain and function than usual care or care focusing on physical health alone. However, these programs are often limited in community contexts due to the substantial time and resource investment they require.

One criticism of the BPS model is that it can be viewed as a framework or approach to care rather than a scientific model (Bolton, 2023; Dong & Bäckryd, 2023). Other criticisms highlight its vagueness, which theoretically could impact its practical application (Farre & Rapley, 2017). However, viewed from another outlook the lack of strict guidelines surrounding the implementation of the BPS model can also provide opportunity for its adaption into varying health contexts with differing resources and infrastructure. As Meints

and Edwards (2018) comment, the flexibility in applying the biopsychosocial model is perhaps its biggest strength (Meints & Edwards, 2018). Part of the criticism of the BPS model arises from its illustration using a 3 circle Venn diagram (Figure 1). Visually appearing as three entities there is a tendency to view the BPS as three individual elements that can be treated separately. This visual is accused of misrepresenting the complex interaction and overlap between each entity and the impossibility of separating each section (Waddell, 1992). Evidence of applying the BPS model in a fragmented approach can be observed in research on low back pain. A systematic review demonstrates that the biological and cognitive aspects of the model are more often applied in care while the social, cultural and interpersonal dynamics are commonly neglected affecting the delivery of the model in its entirety (Mescouto et al., 2022). To truly implement a biopsychosocial approach, a deliberate and skilled approach to exploring the social impacts of chronic pain is essential. A focus on social factors could reduce the isolation and exclusion so regularly reported by those living with chronic pain (Koesling & Bozzaro, 2021). The fragmented application of the BPS model risks creating a reductionist approach, which contrasts George Engel's original proposal and is likely inefficient to support the successful management of chronic pain.

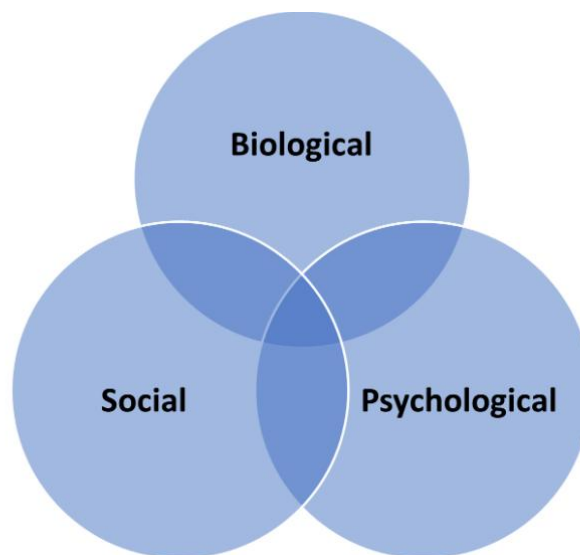


Figure 2.1 The Biopsychosocial Model (Engel, 1977)

Suls and Rothman (2004) note the encouraging increase in the term 'biopsychosocial' in published research across a 27-year period, however they simultaneously note the 9:1 ratio

use of the terminology of ‘biomedical’ to ‘biopsychosocial’ concluding that despite progress being made, the biomedical model remains dominant in research publication. While this analysis provided valuable insight at the time, it is important to acknowledge that the study is now two decades old, and the landscape of pain research may have evolved further since then. Importantly they note that simply using the term biopsychosocial in published research does not confirm its implementation (Suls & Rothman, 2004). Kamper et al., 2020 report the under use of evidence-based advice and education and overuse of imaging and opioid prescription in the treatment of low back pain demonstrating the considerable difference between clinical guidelines and the delivery of care in a clinical context (Kamper et al., 2020). Furthermore, in their systematic review, Ng et al. (2021) observed that structural approaches to chronic pain management are predominantly employed by healthcare professionals (Ng et al., 2021). Undoubtedly there is a need for a paradigm shift in healthcare management strategies from a biomedical approach to a true biopsychosocial approach. Healthcare workers need to develop the skills, attitudes, and beliefs to deliver a true biopsychosocial model of care; however, this must occur in parallel with broader system-level changes that support and sustain such an approach.

There are challenges in truly delivering a BPS model in a clinical environment. These challenges include organisational barriers, role confusion, and patient expectations (Johnson, 2007; van der Roer et al., 2008). Furthermore, limited clinician education and incomplete training have also been identified as barriers to implementing the BPS model (Zangoni & Thomson, 2017). A review by Holopainen et al. (2020) found that gaining knowledge and skills in the biopsychosocial approach did not automatically lead to its successful application in practice. Instead, clinicians adapted their knowledge of the BPS model to their specific clinical context, influenced by factors such as organizational constraints, patient expectations, and their professional roles, all of which likely affected the delivery of the approach (Holopainen et al., 2020). Similarly, the pragmatic use of the BPS in GPs clinics has been described as more rhetoric than practical (Dowrick et al., 1996). Although healthcare professionals recognise the importance of the BPS model, they report the limited support they have to implement it effectively (Cowell et al., 2018). A study with Spanish physiotherapists reports that just 40% of physiotherapists frequently apply a BPS approach when treating chronic pain and only 10% apply it in all cases (Díaz-Fernández et al., 2024). Investigating private physiotherapy practice websites that provide information on low back and neck pain, a recent study further highlights the continued reliance on the biomedical model (van der

Noord et al., 2025). The findings show that online information from physiotherapists is inconsistent with the BPS model and supports the biomedical model, providing information that has the potential to negatively impact patients' knowledge, attitudes, and beliefs regarding their pain. Ultimately, it appears that the biomedical model continues to lead as the default approach to pain management and the BPS model has not been widely implemented (Wade & Halligan, 2017).

Despite its criticisms and challenging implementation, there is broad consensus that the BPS model effectively bridges science and humanism (Papadimitriou, 2017). The BPS model is considered a compromise between medical and social models of care which can be applied at a clinical level (Bolton, 2023). There continues, however, to be a lack of consensus on how to best implement the BPS model (Almeida et al., 2024). We need to train healthcare professionals not only to be aware of it but also to implement it. However, it's not just about the right model of care being provided; early access to interventions is required to prevent suffering and psychological distress (Keefe et al., 2004). The complexity of addressing chronic illness with short appointment times has been reported (Østbye et al., 2005). Where healthcare professionals face increasing pressures to provide comprehensive BPS approaches to care while simultaneously managing extensive waitlists, short appointment times and reduced staffing levels, pragmatic approaches that support the delivery of a BPS model to the public are required (Dong & Bäckryd, 2023). It is reasonable to hypothesize that until a BPS approach is implemented and supported at a macro level, its full potential to improve clinical outcomes will remain unknown.

There is an argument that no one model, including the BPS model, will meet the needs of all healthcare environments (Kontos, 2011). A more practical solution may be for clinicians to adopt an approach that is adaptable to context. It is proposed that a patient-centred approach to care can serve as a catalyst for the successful implementation of the BPS model (Farre & Rapley, 2017; Smith et al., 2013). By focusing on the patient's personal context, preferences, and circumstances, patient-centred care helps ensure that the BPS factors influencing health are fully considered in the clinical decision-making process. Patient centred care calls for therapists to empower patients into taking an active role within their care and considers the biological, psychological and social needs of everyone (Pelzang, 2010). It involves consideration of the person in their context and the facilitation of shared decision making (Montori et al., 2023). Shared decision making is defined as an interactive, dynamic process of treatment planning that extends beyond informed decision making (Frantsve & Kerns,

2007). In research-based clinical environments it has been shown that behavioural techniques to promote behavioural change in chronic pain are essential. However, in practice, musculoskeletal therapists have neglected the use of theory based behavioural interventions to date and a biomedical driven strategy to rehabilitation continues to dominate clinical practice (Mansell et al., 2016). There is limited evidence of therapists using a patient centred care approach in Ireland and across the globe (Dukhu et al., 2018).

The historical application of a biomedical framework in healthcare environments appears to have led to a cultural dependency on paternalism in current practice. A study by Cooper et al., (2008) investigating patient centred care through the patient's perspective, demonstrated the desire of participants to have their healthcare professional make treatment decisions for them (Cooper et al., 2008). This cultural dependency based on historical care models is a certain barrier to progressing current healthcare models to an enhanced patient-centred care model with shared decision making at the centre of its delivery. Despite the barriers, research has shown that enhanced perceived levels of caring were reported by patients when they were treated as an individual and not a disease entity (Gillespie et al., 2004). This is encouraging with respect to the patient centred care model. Caring is a core value of health professional practice. For patients to experience caring however requires correctly resourced services with appropriately trained professionals. The current thirty-minute appointment model based on the biomedical paradigm may not align with the value of care. Research has shown that physiotherapists perceive their practical work as ethically complex, requiring consideration of the therapeutic relationship, institutional contexts, and societal factors (Delaney, 2018). Practicing in alignment with scientific evidence, clinical guidelines, and patient-centred care within the constraints of the current healthcare infrastructure is a formidable challenge. Grover et al. (2022), in their umbrella review, underscore the critical need to empower clinicians to deliver patient-centred care, emphasizing that meaningful change can only occur through comprehensive systems-level reform (Grover et al., 2022). Given the barriers within the current system, self-management strategies may present a viable solution, empowering individuals to take an active role in managing their pain and improving their overall well-being

2.3.2 Self-Management

In the context of chronic pain management, self-management represents a shift from individuals being passive recipients of care to actively engaging as partners in managing their

own health. This approach empowers people to take responsibility for monitoring and managing their symptoms, treatments, and lifestyle changes on a daily basis. Barlow et al. (2002) define self-management as “*an individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent in living with a chronic condition*”(Barlow et al., 2002). The self-management of chronic illness involves three core tasks undertaken by the person living with pain: managing medical or behavioural aspects of the condition, fulfilling daily responsibilities and roles, and addressing emotional and identity-related challenges (Lorig & Holman, 2003). Lorig and Holman (2003) outline five essential self-management skills needed for effective pain management: problem solving, decision making, resource utilization, forming partnerships with healthcare providers, and taking action. These frameworks and skill sets highlight the diverse and multicomponent factors affecting the development of self-management skills. Self-management plans that are flexible, pragmatic, and capable of addressing the diverse needs of individuals living with chronic pain are required.

Importantly self-management strategies have the potential to enhance a person’s life by bridging the gap between the needs of the person in pain and the capacity and availability of pain services (Barlow et al., 2002). Self-management is gaining increasing prominence, with the European Pain Federation's recent research strategy highlighting the need for person-centred behavioural treatments that support this approach (Pickering et al., 2025). Clinical guidelines also emphasize its importance in chronic pain care (BPS 2013, NICE 2021 Qaseem et al., 2017). However, despite growing recognition in policy and research strategies, self-management often remains a second-line treatment in clinical practice, typically introduced only when pharmacological or medical interventions have failed (Gordon et al., 2017).

2.3.3 Supported Self-Management of Pain

Reflecting on the Barlow et al., (2002) definition of self-management, it could be incorrectly construed that the role of self-management should be placed solely on the shoulders of the person living with chronic pain. Supported self-management involves a collaboration between the healthcare professional and the person in pain where the healthcare professional’s role is to empower the person to take an active role in managing their condition and develop health behaviours that meet their personal needs and context (de Silva,

2011; Penlington et al., 2024). Any activities that support people in their self-management are referred to as self-management support (Pearce et al., 2016). One role of the healthcare professional in supporting self-management is reassuring the person in pain. As identified by Linton et al., (2008) reassurance is a complex process involving the integration of the lived experience, thoughts, beliefs and emotions of the person in pain and their social context (Linton et al., 2008). Pain explanations and education, also termed cognitive reassurance, is associated with improved outcomes in patients in primary care (Pincus et al., 2013). Specific improvements related to reassurance include decreased isolation and anxiety and increased confidence and sense of control (Braeuninger-Weimer et al., 2021; Cheung & Soundy, 2021).

Jonkman et al., (2016) define supported self-management as “*Interventions that aim to equip patients with skills to actively participate and take responsibility in the management of their chronic condition. This includes knowledge acquisition, and a combination of at least two of the following: (1) stimulation of independent sign and/or symptom monitoring; (2) medication management; (3) enhancing problem-solving and decision-making skills for treatment or disease management; (4) or changing physical activity, dietary and/or smoking behaviour*” (Jonkman et al., 2016). This definition was adopted by Dineen-Griffin et al., (2019) in their review of self-management support strategies in primary healthcare practice. Reviewing 58 articles that applied self-management interventions for chronic disease conditions, they discovered that in-person programs delivered by healthcare professionals that are multicomponent and in primary care can lead to enhancements in both clinical and humanistic outcomes (Dineen-Griffin et al., 2019).

Gaining the confidence and ability to self-manage after a pain diagnosis is a gradual process and a strong therapeutic relationship is considered one of the key requirements to providing support for self-management (Holopainen et al., 2018). An effective therapeutic relationship is associated with a meaningful connection built between the healthcare professional and the person in pain (McCabe et al., 2022). It can result in improved clinical outcomes including reduced pain (Kinney et al., 2020). Being present, supportive, empathetic, non-judgemental and knowledgeable are some of the key characteristics required by healthcare professionals to support a therapeutic relationship and consequently to deliver patient centred care (Thomas et al., 2018).

Penlington et al. (2024) report that 66% of healthcare professionals had completed further training in self-management strategies; however, despite this additional knowledge, training

did not improve clinicians' confidence in delivering self-management strategies in clinical practice compared to those without further training (Penlington et al., 2024). The authors concluded that what is needed is not just additional training, but ongoing support to help clinicians implement self-management strategies effectively in real-world settings. Elsewhere physiotherapists have highlighted the challenge of supporting self-management in those with chronic pain and delivering clinical guidelines (Cowell et al., 2018). Supporting an individual to live well with pain has been associated with promoting resilience and providing emotional support (Clauw et al., 2019). There is an urgent need to not only upskill healthcare professionals but also to provide ongoing support to ensure the consistent delivery of supported self-management strategies, particularly for clinicians based in the community, who will provide first line care for chronic pain patients. Currently, there is no data on the number of Irish clinicians engaging with self-management strategies, nor on their perceived ability to effectively implement these approaches in chronic pain care.

2.3.4 Effectiveness of Self-Management Interventions

Self-management interventions are not a new concept. One of the first fundamental programs was the Arthritis Self-Management Program (ASMP), which has stood the test of time, evolved to reach a broader audience, and continues to inform self-management programs today. Utilising self-efficacy theory and taught in 2-hour sessions across 6 weeks the ASMP reports clinical reductions in pain and reduced healthcare utilisation up to 4 years post intervention (Lorig et al., 1993). The same 6-week program has been implemented in the community in both Australia and the Netherlands. In Australia, the intervention group showed significant improvements in knowledge, self-reported health behaviours, and reduced disability scores at 12 months (Lindroth et al., 1989). Similarly in the Netherlands, Taal et al., (1993) found significant positive improvements in function, physical exercise practices, self-efficacy, and knowledge at 14-month follow up (Taal et al., 1993). These findings suggest that health education programs like the ASMP can provide significant and sustained benefits for individuals with chronic arthritis, including pain reduction and decreased health care utilization, leading to overall cost savings.

Encouraged from the positive clinical effects of the AMSP on chronic arthritic pain, the self-management program was modified by LeFort et al., (1998) to provide a program suitable for idiopathic chronic pain (LeFort et al., 1998). Following its implementation, attendees

reported greater self-efficacy, engagement in valued activities and improved life satisfaction (LaFort et al., 1998). Furthermore, the program was deemed effective in promoting health behaviours and enhanced perceptions of control. More recently, the same program has again been modified and termed the Chronic Disease Self-Management program (CDSM) and implemented in an Irish public hospital (Campbell et al., 2022). This study was associated with a decrease in depression scores where the proportion of the sample meeting criteria for depression at baseline testing decreased from 55% to 36% at 6 month follow up. However, only 31% of participants responded at 6 month follow up, thus affecting the long-term outcomes of this program in an Irish context (Campbell et al., 2022). Nonetheless, collectively these studies completed over 30 years imply an ongoing research interest in the core elements of the ASMP program and its clinical effectiveness in chronic pain cohorts.

More recently a large variety of self-management programs have been created and tested in various chronic pain cohorts. In their systematic review and meta-analysis, Elbers et al., (2018), aimed to assess both the short term and long-term (more than six months) effectiveness of generic self-management interventions for patients with chronic musculoskeletal pain (Elbers et al., 2018). Adopting strict inclusion criteria including utilising the five self-management skills as defined by Lorig and Holman (2003), 20 studies published from 1994-2015, were included for analysis. Moderate-quality evidence was reported that self-management programs lead to statistically significant improvements in physical function and pain intensity in the short term and a small, but clinically insignificant, improvement in self-efficacy at long-term follow-up. Importantly Elbers et al., (2018) consider the generic element of self-manage programs as the root cause for the limited results. They advocate for a personalised approach to self-management noting that personalized approaches differ from generic self-management interventions that only provide one set of skills expected to benefit all patients. In contrast, Geraghty et al. (2021) reviewed 39 RCTs, conducted between 1994 and 2020, and found that self-management interventions can be effective in improving physical function and reducing pain in both the short and long term for chronic widespread pain, including fibromyalgia. However, these conclusions are considered preliminary due to the overall low quality of the evidence (Geraghty et al., 2021). Both systematic reviews considered six months as a satisfactory definition for long-term follow up which arguably does not provide satisfactory long-term assessment of clinical effectiveness in the context of chronic pain, a potential lifelong condition.

2.3.5 Challenges associated with self-management interventions

Despite growing evidence supporting the benefits of self-management in chronic pain, it remains one of the most challenging components of chronic disease management to be implemented in clinical practice. While Lorig et al. (1993) provide evidence of sustained benefits over four years using a self-efficacy framework, as alluded to in section 2.8, most interventions report outcomes up to six months only and often lack a clearly defined theoretical foundation (Dineen-Griffin et al., 2019; Elbers et al., 2018; Geraghty et al., 2021). In primary care, just 28% of self-management programs report any theoretical underpinning, with cognitive behavioural therapy being the most common (Dineen-Griffin et al., 2019). Elbers et al. (2018) also note that generic self-management interventions tend to produce minimal clinical improvements, reinforcing the need for personalisation. However, personalised programs require healthcare professionals to have the autonomy, skills and systemic support to tailor delivery to everyone, an approach that complicates the standardisation necessary for evaluating clinical effectiveness across studies. These findings reinforce that self-management extends beyond healthcare delivery alone and is deeply shaped by the broader social environment. Coleman and Newton (2005) argue that systemic changes in healthcare delivery are necessary to realise the full potential of self-management strategies in clinical practice.

As well as the complexity of delivering self-management programs in clinical practice there are also barriers that affect an individual's ability to engage with self-management strategies. A qualitative systematic review by Devan et al. (2018) identified several barriers that hinder individuals from engaging in self-management, including difficulties in sustaining motivation and coping with the emotional burden of chronic pain (Devan et al., 2018). To address this, researchers highlight the importance of follow-up strategies such as peer support and booster healthcare sessions (Devan et al., 2018). On the other hand, key enablers include supportive relationships, a sense of empowerment, and the ability to separate one's identity from the experience of pain (Devan et al., 2018). These findings align with Gallant (2003), who emphasise the significant influence of social support, both positive and negative, on self-management engagement (Gallant, 2003). DiMatteo (2004) further highlights the importance of social support, finding that strong family relationships are associated with better adherence to treatment (DiMatteo, 2004). A key challenge for healthcare systems is determining how primary care professionals can deliver flexible, evidence-based self-management support that balances individualisation with scalability, while also fostering long-term motivation for

people living with pain. As healthcare systems increasingly turn to technology to meet these demands, the next section explores the role of eHealth self-management programs and their potential in supporting people with chronic pain (Renzi et al., 2022).

2.4 The Role of eHealth in Self-Management

2.4.1 eHealth

The WHO defines eHealth as “*the cost-effective and secure use of information and communications technologies in support of health and health-related fields, including health care services, health surveillance, health literature, and health education, knowledge and research*” (WHO, 2021). Digital health technologies, such as eHealth, are healthcare practices supported by information technologies that can be used to support the prevention and treatment of disease as well as promote health status and quality of life (Borrelli & Ritterband, 2015). Internet-based interventions, telehealth interventions, virtual reality, videoconferencing and mobile phone apps that deliver health related services are all considered eHealth modalities (Slattery et al., 2019). The use of eHealth technologies is growing exponentially with da Fonseca et al., (2021) noting an increase from 39 published articles in 2018 to 250 in 2019 (da Fonseca et al., 2021). The COVID 19 epidemic and the need to adapt healthcare practices to digital formats has further fuelled the upward trend of eHealth interventions (Tian & Chen, 2022). Interventions delivered through eHealth platforms have been identified as valuable tools in promoting self-management among individuals with chronic diseases such as cardiovascular disease, type 2 diabetes, and COPD (Renzi et al., 2022). Self-management resources delivered via eHealth may offer a cost-effective and efficient means of providing support to individuals with persistent pain, such as chronic musculoskeletal conditions (Slater et al., 2016). The Department of Health’s Digital Health Framework for Ireland (2024–2030) underlines the pivotal role of eHealth in transforming healthcare delivery and enhancing how people experience and interact with health services.

2.4.2 Effectiveness Of eHealth Self-management Interventions

In their systematic review, Heapy et al. (2015) found that psychological informed interventions delivered by telephone, the web, or by interactive voice response (IVR) were all efficacious in supporting self-management strategies among adults with chronic pain. However, as they included just three of the available eHealth modalities and reported

substantial methodological heterogeneity between studies, it was not possible to determine the most effective eHealth modality. A more recent systematic review and meta-analysis by Slattery et al. (2019) evaluated six eHealth modalities, web-based platforms, mobile apps, virtual reality, telephone, video conferencing, and IVR (Slattery et al., 2019). Although mobile apps were associated with a 43% probability of being the most effective eHealth modality, definitive conclusions were constrained by study imbalance given that 23 of the 30 studies were web-based, with only 1–2 studies representing each other modality. Similarly, Scholz et al. (2024), through a meta-analysis of nine studies, found that digital self-management interventions in the form of web or mobile apps can positively influence pain intensity and disability in people with chronic low back pain (CLBP), while De Lucia (2024) reported comparable benefits for older adults using multimodal eHealth interventions (De Lucia et al., 2024; Scholz et al., 2024). These findings reinforce the broad conclusion that technology-assisted psychological interventions, across diverse eHealth modalities, can support chronic pain self-management. However, substantial heterogeneity across studies and methods limits meaningful comparisons between modalities or clear guidance on best practices.

Beyond delivery format, intervention quality is also linked to theoretical foundations. Similar to in-person self-management interventions, many eHealth programs have been criticised for lacking a strong theoretical foundation, particularly in behavioural theory (Borrelli & Ritterband, 2015). Health interventions that apply behavioural theory are considered more effective at changing behaviours than those that do not (Noar & Zimmerman, 2005), and theory-informed design can also help clarify mechanisms of change and promote long-term behaviour maintenance (Borrelli & Ritterband, 2015). In terms of outcomes, Du et al. (2020) conducted a systematic review of eHealth self-management interventions for LBP and found moderate quality evidence supporting short-term improvements in pain and disability (Du et al., 2020). However, only two of the eight included studies reported a theoretical underpinning, raising questions about the rigour and replicability of these interventions. Furthermore, the emphasis on pain intensity as a primary outcome for this review may not fully capture the complexity of chronic LBP and the clinical aims associated with a self-management program. A commonly reported obstacle in conducting self-management intervention research is the difficulty of measuring the extent to which individuals implement self-management strategies (Nicholas et al., 2012).

Evenepoel et al., (2023) conducted a systematic review that included only RCTs where pain intensity was the primary outcome in eHealth self-management programs. Notably, the authors defined self-management as “the patient’s ability to manage their pain individually, without the active support of a healthcare professional”, a definition that arguably contradicts the concept of supported self-management (Evenepoel et al., 2023). The review included 11 studies, all of which were assessed as having a high risk of bias. Of the eleven studies reviewed, only one demonstrated superior outcomes for the eHealth group compared to the control over time. Three additional studies showed improvements within the intervention groups, but these were not significantly better than outcomes in the comparison groups. Qualitative insights from Strain et al. (2024) suggest that users of digital interventions want more than just access to information. Participants valued tailored content, goal-setting tools, and emotional support, preferably from healthcare professionals, highlighting the importance of human connection in digital care (Strain et al., 2024).

Valentijn et al. (2022) conducted a meta-analysis on 56 studies, focusing on the effectiveness of digital health interventions for musculoskeletal pain. Their findings support a small positive effect across outcomes such as pain, disability, emotional functioning, and quality of life. However, risks of bias, poor intervention descriptions, and inconsistent outcome measures are noted (Valentijn et al., 2022). Nicholl et al. (2017) further emphasised the issue of heterogeneity, identifying just six RCTs on eHealth self-management for LBP and highlighting the difficulty in evaluating efficacy due to vague descriptions and inconsistent methodologies (Nicholl et al., 2017). While the findings of these studies suggest that digital health interventions can have a positive effect on managing musculoskeletal pain, limitations such as risk of bias, unclear intervention content, heterogeneity of outcome measures highlight the need for more rigorous and detailed research to strengthen the evidence base. Bartels et al. (2025) advocate for more research on long-term effects, cost-effectiveness, and real-world implementation, with a focus on quality, safety, and stakeholder involvement in order to advance the area of eHealth and chronic pain (Bartels et al., 2025).

Comparisons between eHealth and in-person self-management programs remain sparse making it challenging to identify the optimal delivery of self-management support. Lara-Palomo et al. (2022) concluded that eHealth interventions can be as effective as in person physical therapy in improving pain and function in individuals with chronic low back pain. However, their meta-analysis included highly heterogeneous physical therapy interventions, ranging from McKenzie extension therapy to wearable sensors, with a notable absence of

psychologically informed approaches (Lara-Palomo et al., 2022). This variation in design and delivery limits the ability to draw definitive conclusions and meaningful comparisons between in person and eHealth self-management interventions.

Although research has largely focused on in-person or eHealth self-management programs separately, a third option that is gaining popularity is a blended approach, using eHealth as an adjunct to in-person care. Blended care models, which integrate digital tools with in-person support, show promise in providing the support that individuals in pain require while also offering scalable and enhanced service options. In their scoping review Kelly et al. (2022) report more than half of internet-based interventions used a blended approach. The term “blended care” itself encompasses a wide range of practices, and its lack of standardisation presents challenges for evaluation. To better understand this approach, it is helpful to examine specific examples of blended care interventions currently in use. The “Back2Action” intervention, combining online modules with face-to-face sessions, reportedly helped both patients and clinicians embrace a BPS approach to care (Bijker et al., 2022; Poolman et al., 2024). The “Back2Action” blended intervention allowed clinicians to reinforce key educational topics and provide additional support to implement behaviour changes in a personalised context (Poolman et al., 2024). Interestingly the online modules acted as a catalyst for clinicians to move from a biomedical to a BPS approach to care and served as a reminder of their bias towards favouring the biomedical approach. (Bijker et al., 2024). Although this particular intervention is not specific to chronic LBP (including individuals with subacute low back pain) it nonetheless summarises the potential of a blended eHealth approach both from the person in pain and the clinician’s viewpoint. However, full publication on its clinical effectiveness is not yet available.

The EPIO intervention for chronic pain, developed in Norway, demonstrates the flexibility of blended care delivery. This nine-module self-management programme has been implemented using two distinct blended formats. One study observes its use alongside physiotherapy where participants complete the 9-modules in combination with 7-13 in-person physiotherapy consultations (Eiken et al., 2022). The same eHealth intervention is then reported in another blended care model involving a single introduction face to face session, access to the 9-modules and one follow up call 2-3 weeks into the online program (Bostrøm et al., 2023). Bostrøm et al., (2023) report no statistically significant changes for the primary outcome of pain interference but significant reductions in depression and self-regulatory fatigue for the intervention group at three months. Eiken et al. (2022) have only published qualitative data to

date, and efficacy outcomes for the program have not yet been reported, making direct comparison at this time impossible however the qualitative data reports that blended care is valued by persons living with chronic pain and supports feelings of hope and acceptance. Recently, two blended eHealth models have been developed specifically for the Irish context. These interventions, designed with input from end-users, demonstrate good usability. Although still in early stages with no long-term data available, they appear to hold practical value for supporting clinical practice and assisting people living with fibromyalgia (O'Brien-Kelly et al., 2024) and chronic musculoskeletal pain (Kelly et al., 2024). While these blended care models show promise and highlight innovative approaches to integrating eHealth with traditional care, it remains essential to evaluate their efficacy systematically alongside purely digital or in-person interventions to identify best practices and inform clinical implementation.

While eHealth interventions offer promising avenues for scalable and personalised self-management support, their effectiveness is often undermined by limited user engagement, theoretical inconsistencies, and heterogeneity in delivery and evaluation. Digital interventions should offer tailored information that meets the individual's personalised context, focus on altering pain perceptions, incorporate structured goal-setting mechanisms, and potentially include support from healthcare professionals (Strain et al., 2024). Blended care may offer a middle ground, but its optimal design, delivery, and impact remain insufficiently examined and unclear. Ongoing research must prioritise rigorous methodology, theory-informed development, and co-design to ensure that digital self-management truly meets the needs of people living with chronic pain

2.4.3 Challenges in implementing eHealth

eHealth has the potential to reduce access and care disparities by providing care in low resource settings (Slater et al., 2016). Nearly 80% of American adults have searched the internet to look for health information for themselves and 60% have searched the internet to look for health information for someone else, indicating a value to having health information online (Finney Rutten et al., 2019) and demonstrating the popularity of using the internet to gain health knowledge. In Ireland, 94% of households have internet access (CSO 2024). Due to the high prevalence of pain in Ireland and the lack of geographical equity of healthcare services nationwide, accessible services are warranted (Purcell et al., 2022) and eHealth provides an opportunity to reduce this barrier to care. However, age does appear to be an access barrier when considering eHealth. It is reported that adults aged 18-34 years and 35-49 years were 3.5 and 2.5 times as likely to seek online information than adults aged 65 or older (Kontos et al., 2014). In the United States 96% of people aged 50-64 and 75% of people over the age of 65 use the internet (Faverio, 2022). In Europe, 55% of individuals aged 65–74 reportedly use the internet daily, compared to 96% of those aged 16–29 (Eurostat 2023). While in Ireland just over half of people (54%) over the age of 75 have used the internet in the past three months (CSO 2024). These statistics indicate that while internet usage among older adults is increasing, a significant digital divide remains between age groups and eHealth may not be accessible to all.

Although eHealth has the potential to overcome geographical barriers, concerns remain regarding the impact of socioeconomic status on access and engagement. For example, Deegan et al., (2023) reported that nearly 9% of potential participants in their eHealth chronic pain intervention study either lacked access to a device or the internet or expressed no interest in online interventions. Beyond physical access, an individual's ability to effectively engage with digital health tools is influenced by their level of eHealth literacy. Norman & Skinner, (2006) define eHealth literacy as "the ability to seek, find, understand and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem." A recent meta-analysis by Kim et al., (2023) found a positive correlation between eHealth literacy and health-related behaviours, suggesting that eHealth literacy can mediate the relationship between access to health information and behaviour change. If eHealth is to be successfully integrated into clinical practice, it is essential that healthcare professionals assess and consider patients' levels of eHealth literacy to ensure that

recommended interventions align with their needs and capabilities (Karnoe Knudsen & Kayser, 2015).

Considering both access to digital resources and eHealth literacy eHealth has the capacity to reduce or exacerbate healthcare inequality and so a careful balance of optimising its implementation while still providing patient-centred in-person high quality resources for those who require it is imperative. When integrated with in-person clinical settings, eHealth should serve as an adjunct to high-quality patient care. In order to meet the needs of large cohorts it is recommended that eHealth interventions should be interactive, interoperable, personally engaging and contextually tailored (Kreps & Neuhauser, 2010).

Important to the success of eHealth is the support of healthcare professionals to promote digital interventions within their clinical context. Investigation via interview found that healthcare professionals show concern that the risks and limits of online information may outweigh any potential benefits (Areli et al., 2021). Healthcare professionals favour a 'blended' model where they can implement online resources as a supportive adjunct in the development of self-management skills (Areli et al., 2021). Specific to the area of anxiety and depression, healthcare workers report being unaware of evidence-based eHealth resources and this affected their confidence in recommending online resources (Sinclair et al., 2013; Whitfield, 2004). A lack of knowledge on credible resources appears to be an active barrier to healthcare professionals recommending current eHealth technologies and given the steep increase in eHealth production this caution appears warranted.

In their review of self-management pain mobile apps, Lalloo et al., (2015), report that of 279 apps, 59% included a single self-management function and only 8% included a health care professional in their development. No mobile apps provided a theoretical rationale, and only a single app reportedly underwent scientific evaluation (Lalloo et al., 2015). Although this publication is now a decade old, statistics such as this make it understandable as to why healthcare professionals may lack confidence in recommending eHealth resources. A more recent and smaller study evaluating 19 pain self-management apps found that none of the apps assessed had been validated by individuals living with chronic pain (Devan et al., 2019a). Three studies evaluated the quality of online information available to people living with chronic pain. Washington et al., (2008) evaluated 240 websites, Corcoran et al., (2009), 27 websites and Bailey et al., (2013) 50 websites. All three studies concluded that the majority of available pain related websites were of low quality. Each review highlighted the

potential harm of patients accessing inaccurate non-evidence-based information. While the above three studies emphasise the quality of content on eHealth resources, they do not investigate the success of the content in supporting the development of self-management tools. As Devan et al. (2019b) identify, there is a need to investigate which patients are most likely to benefit from eHealth resources and at what stage of their management journey are resources likely to be most effective. In understanding these factors healthcare professionals may be able to feel confident in recommending eHealth resources to the more appropriate cohort.

Despite growing evidence that eHealth interventions can support chronic pain management, significant gaps remain in the literature. Systematic reviews consistently highlight the lack of long-term follow-up (Kelly et al., 2022; Moman et al., 2019), which is particularly concerning given the enduring and often fluctuating nature of chronic pain. Additionally, there is limited evidence demonstrating reductions in healthcare utilisation following engagement with eHealth self-management interventions (Kelly et al., 2022). While some studies report short-term improvements and scalability, the long-term impact and sustainability of eHealth programs remain uncertain. A key barrier appears to be the discontinuation of eHealth resources post clinical trials due to lack of ongoing funding, as noted by Suman et al. (2019) making long-term follow up impossible. The literature continues to reflect Michie's comment that we are "*in the age of promise rather than delivery*" regarding the field of digital health (Michie et al., 2017).

Encouragingly, the safety profile of eHealth is strong. Nicholl et al. (2017) found no evidence of harm in their systematic review, while Kelly et al. (2022) reported that only 1% of measured outcomes worsened following an eHealth intervention. However, the small number of high-quality RCTs and the heterogeneity in intervention content, delivery methods, and outcome measures continue to limit comparability and generalisability (Bartels et al., 2025).

2.4.4 Cost-Utility of eHealth Interventions for Chronic Pain

A recent meta-analysis examined the cost-effectiveness of digital health interventions for chronic musculoskeletal conditions such as low back pain, osteoarthritis, and fibromyalgia (Fatoye et al., 2023). Nine out of ten studies reported that digital interventions were cost-effective compared to control groups, with an average cost reduction of USD \$417.52 per patient in favour of the digital intervention. However, the nature of the control groups varied

widely, ranging from usual care to in-person delivery of the same eHealth content, or in some cases, no care at all. While these findings offer promising early evidence for the cost-effectiveness of eHealth in managing musculoskeletal disorders, only two studies were eligible for inclusion in the cost-reduction meta-analysis. This underscores the need for further research to evaluate the long-term cost-effectiveness of digital health interventions across a broader and more diverse chronic pain population.

In a cluster randomised trial, Suman et al. (2019) evaluated the cost-utility of a multifaceted eHealth intervention designed to improve beliefs about back pain among individuals with non-specific low back pain (Suman et al., 2019). The intervention included a tailored website and automated email prompts aimed at encouraging behaviour change. Results suggested that the intervention was low-cost and produced modest improvements in health outcomes, supporting its potential cost-effectiveness, particularly by reducing the need for more expensive healthcare services. However, the study also faced limitations: 40% of participants reported their back pain had resolved before the intervention began, and engagement with the digital materials was poor, 31% did not use the materials at all, and 43% accessed them only once. Future research should prioritise cost analyses of eHealth interventions that demonstrate high levels of engagement, adherence, and long-term follow-up among individuals with chronic pain.

2.5 Behaviours Change Theories and Models

Larger effects on behaviour change are seen when eHealth resources incorporate behavioural theories, with some studies reporting that a larger number of behavioural change techniques correlate with enhanced intervention effectiveness (Webb et al., 2010). Early systematic reviews report that between just 22% and 36% of health interventions apply a theoretical framework or theory to guide intervention development (Davies et al., 2010; Painter et al., 2008). In the absence of theory, the mechanisms underlying an intervention's effectiveness may remain unclear (Michie et al., 2009). The Medical Research Council (MRC) guidelines recommend including theory in the design and implementation of complex interventions (Craig et al., 2013), where the use of theory is seen to a) clarify the key factors driving behaviour change b) guide the selection of effective techniques and c) allows for testing and refining theories through practical application (Davies et al., 2010). Specific to chronic pain, a systematic review of behaviour change theories and techniques used in group based self-

management programmes for chronic low back pain and arthritis found that only 12% of studies based their intervention on theory (Keogh et al., 2015). A more recent review indicates that 76% of eHealth interventions designed to support self-management in musculoskeletal pain now report the application of a theory or framework, reflecting an increased uptake in theory-informed design (Kelly et al., 2022). A wide range of behaviour change theories have been applied in the context of chronic pain and chronic illness, including the Health Belief Model (Kasl, 1974), the Transtheoretical Model of Change (Prochaska & Velicer, 1997), the Fear Avoidance Model (Vlaeyn & Linton, 2000), Social Cognitive Theory (SCT) (Bandura 1986), and Self-Determination Theory (SDT) (Deci & Ryan, 1985). However, a small number of theories account for the most commonly identified frameworks in intervention design (Davies et al., 2010). For the purpose of this thesis, SCT and SDT were selected due to their strong empirical application in chronic pain and chronic disease self-management interventions, and their relevance to both individual motivation and interpersonal support as detailed in section 2.5.1-2.5.3.

2.5.1 Social Cognitive Theory

Bandura's early work on self-efficacy theory (1977) emphasised how an individual's belief in their ability to perform specific tasks influences their behaviour (Bandura, 1977). He later expanded these concepts into the broader framework of Social Cognitive Theory (SCT), which incorporates self-efficacy as a central component alongside other cognitive, behavioural, and environmental factors (Bandura, 1986). One of the core concepts of SCT is the concept of reciprocal determinism in which a person's behaviour, personal factors, and environment all interact and dynamically shape one another (Bandura, 1978). According to Social Cognitive Theory, it is an individual's beliefs about the potential outcomes of a behaviour, rather than the actual outcomes, that influence their behaviour (Bandura, 1986). A cornerstone of SCT is the importance of self-regulation in supporting behaviour change where self-regulation involves self-monitoring, self-judgement and self-evaluation (Bandura, 1986). Early difficulties highlighted with this theory relate to the challenge of measuring the difference between self-efficacy and actual performance ability, resulting in a lack of clarity relating to cause or effect (Eastman & Marzillier, 1984). While self-efficacy predicts whether an individual will initiate a behaviour, Social Cognitive Theory (SCT) offers a broader explanation of how people learn and change behaviour through the dynamic interaction of

personal factors, behaviour, and environmental influences (Bandura, 1986). In this way, self-efficacy represents just one component of the wider theoretical framework

2.5.2 Self Determination Theory

According to SDT, motivation is presented as a continuum from externally regulated to intrinsically regulated (Deci & Ryan, 1985). Enhanced and sustained behaviour change is related to intrinsically regulated autonomous motivation (Deci & Ryan, 2008). According to the theory, self-determined behaviour arises from the fulfilment of three basic psychological needs: competence (feeling capable and able to demonstrate that capability), autonomy (feeling a sense of choice and control), and relatedness (feeling connected to and valued by others) (Deci & Ryan, 1985). Much of the research on SDT and health interventions to date has focused on chronic disease rather than chronic pain specifically. One meta-analysis found that SDT based interventions have a modest effect in supporting behaviour change in physical activity, diet behaviours and smoking cessation (Ntoumanis et al., 2021). Elsewhere, individuals with chronic conditions who perceived greater autonomy support from their healthcare professionals demonstrated significantly better self-management skills, highlighting the connection between autonomy and effective self-management in chronic disease (Raaijmakers et al., 2014, Williams et al., 1998). Furthermore, higher levels of perceived autonomy promotion have been associated with lower pain-related disability in older adults living with chronic pain (Matos et al., 2016).

2.5.3 Comparing Self-Determination Theory and Social Cognitive Theory

Social cognitive theory is the most frequently reported behaviour change theory in self-management interventions (Du et al., 2017; Keogh et al., 2015; Richardson et al., 2014). One limitation of intervention-based studies is that even when underpinned by a behaviour change model, they often only utilise select elements relevant to their aims rather than a full theoretical framework. In their systematic review, Painter et al., (2008) discuss this, categorising articles as theory informed, theory applied or theory tested based on the extent to which interventions adopt all theoretical constructs of a model. They highlight that although SCT is the most commonly adopted theory, self-efficacy is often the only construct applied across studies, with other key SCT elements frequently neglected (Painter et al., 2008). Echoing this problem, another systematic review examined SCT-based interventions for

chronic health conditions and found that of 202 full-text articles, 105 were excluded for lacking self-monitoring, a key SCT component (Tougas et al., 2015). Ultimately only 21 studies addressed all three SCT components despite the large amount of literature reportedly informed by SCT.

While SCT views motivation primarily in terms of its quantity, with more motivation in theory resulting in more behaviour change, SDT distinguishes between types of motivation, autonomous and controlled motivation, emphasising that the quality of motivation is more predictive of meaningful outcomes than its amount (Deci & Ryan, 2000). While perceived competence, a construct from SDT is conceptually similar to self-efficacy from SCT, it is distinct in that it emphasises feeling capable in the pursuit of self-endorsed goals, rather than simply believing in one's ability to perform a behaviour (Rodgers et al., 2014). These qualities are particularly important in chronic pain contexts, where long-term engagement and inner motivation are crucial.

SCT acknowledges the social environment, through concepts like modelling, observational learning and social persuasion (Bandura, 1986). However, SCT views the added value of social influence primarily in terms of its functional role in behaviour change, rather than as a basic psychological need whereas in contrast, SDT conceptualises relatedness as a fundamental human need (Deci & Ryan, 1985). As reported by Ryan et al., (2008) '*A sense of being respected, understood, and cared for is essential to forming the experiences of connection and trust that allow for internalization to occur*' (p.3). This emphasis on respect and relatedness aligns with the concept of a patient-centred, supportive clinical environment that fosters shared decision-making and embraces a BPS model of care.

In clinical practice, this sense of being genuinely supported can enhance patient engagement and improve self-management outcomes (Cunningham, 2016). Patient empowerment also aligns closely with SDT, as it fosters intrinsic motivation by supporting individuals' sense of autonomy, competence, and relatedness, helping them feel cared for, connected, and actively involved in their own care (Castro et al., 2016). Considering both models, from a practical perspective SDT may offer a more person-centred and empowering framework for self-management, as it prioritizes individuals' intrinsic motivation and psychological needs within supportive caring relationships. However, one significant limitation of the theory is its lack of consideration for external environmental and systemic factors that impact behaviour change, which is especially important in health behaviour contexts and must be taken into

consideration in real-world practice (Ng et al., 2021). Considering this, there may be value in integrating both SDT and SCT within intervention design, combining the strengths of each to address both internal motivation and external behavioural influences.

2.5.4 A Framework to Support eHealth Intervention Design

Building on the emerging evidence supporting the efficacy of eHealth self-management interventions for chronic pain, the application of established development frameworks and taxonomies offers a structured approach to enhance their theoretical rigour, usability, and alignment with patient-centred care principles. A holistic framework for developing eHealth technologies was proposed by van Gemert-Pijnen et al. (2011) through the CeHRes (Centre for eHealth and Wellbeing Research) Roadmap (van Gemert-Pijnen et al., 2011). This framework is designed to guide developers in creating effective and sustainable eHealth interventions (Figure 2.2). It promotes a multidisciplinary and iterative approach that integrates technological innovation with human-centred design and organizational considerations to enhance the impact of eHealth technologies. In a narrative scoping review, Kip et al. (2022) recommend a range of human-centred design methods to support eHealth development, including focus groups, interviews, questionnaires, usability testing, literature reviews, desk research, and Delphi studies (Kip et al., 2022). They also highlight the importance of generating development outputs such as prototypes, behaviour change strategies, and business models to inform the design process. The updated CeHRes Roadmap 2.0 further emphasizes the importance of integrating evidence-based behaviour change techniques and the consideration of domain-specific theories when developing eHealth interventions (Kip et al., 2025). Notably, the framework encourages a flexible, non-linear implementation rather than a rigid step-by-step process, which mirrors the adaptable nature of the BPS model of care. While this flexibility allows for tailoring in diverse contexts and user needs, it may also contribute to heterogeneity in eHealth design, making comparison across studies more challenging.



Figure 2.2. The CeHRes Roadmap 2.0 (Centre for eHealth and Wellbeing Research) (Kip et al., 2025)

2.5.5 Behaviour Change Taxonomies

Despite the recognised benefits of theory-based intervention design, the use of vague terms such as ‘education’, ‘support’, and ‘resources’ in past interventions has hindered both the replication and the practical implementation in clinical settings. Behaviour change taxonomies offer a potential solution by providing a more structured and transparent way to describe intervention components (Michie et al., 2009). Table 2.1 provides an overview of the three taxonomies discussed in this section. The PRISMS taxonomy comprises 14 components that can be used to structure and describe self-management support interventions (Pearce et al., 2016). A recent review found that adherence support and lifestyle interventions are the most included PRISMS components in eHealth modalities targeting chronic musculoskeletal pain (Kelly et al., 2022).

Table 2.1 A summary of Behaviour Change Taxonomies

	Behaviour Change Taxonomy (v1) Taxonomy (Michie et al., 2013)	PRISMS Taxonomy (Pearce et al., 2016)	SDT Taxonomy (Gillison et al., 2019)
Focus	Comprehensive list of Behaviour Change Techniques used in interventions	Supportive self-management components for long-term conditions	Motivation and psychological needs supporting behaviour change based on SDT
Number of Items	93 individual items, grouped into 16 clusters	14 components	19 individual items grouped into 3 constructs (autonomy, competence, relatedness)
Theoretical Underpinning	Theory neutral	Self-management support, chronic condition management	SDT
Application	Intervention design, coding behaviour change content	Designing and evaluating self-management interventions	Understanding motivation and autonomy support in behaviour change
Strengths	Widely used, standardized taxonomy enabling precise intervention coding	Emphasizes pragmatic support components in self-management	Focuses on motivational quality, autonomy, and psychological needs

SDT, Self-Determination Theory

Another widely used framework is Michie et al.'s (2013) 93-item taxonomy, which provides a structured guide to report and implement evidence-based strategies within behaviour change interventions (Michie et al., 2013). While Michie's taxonomy is commonly used in health psychology and digital health, Pearce et al., (2016) argue that their 14-item PRISMS taxonomy is more practical and better reflects the concept of self-management support. It offers a more accessible framework for clinicians and health service researchers, whereas

Michie's taxonomy potentially holds enhanced value for intervention coders and behaviour scientists (Pearce et al., 2016).

While Michie's taxonomy is comprehensive, it is theory-neutral and does not explicitly link techniques to theoretical constructs. In contrast, Gillison's taxonomy builds on this by incorporating a theoretical framework grounded in SDT, offering a more targeted lens for understanding behaviour change (Gillison et al., 2019). The SDT taxonomy has been created listing 18 strategies that contribute to autonomous motivation (Gillison et al., 2019). Findings suggest that behaviour change techniques based on SDT have strong positive effects on perceived autonomy support and autonomy satisfaction, and moderate effects on competence satisfaction and overall motivation (Gillison et al., 2019). By mapping behaviour change taxonomies onto theory this taxonomy helps to bridge the gap between practical clinical techniques and theoretical mechanisms. The Gillison et al., (2019) SDT-informed taxonomy of behaviour change techniques was developed in relation to, and partially mapped against, Michie et al.'s (2013) taxonomy v1 and as such techniques in the SDT taxonomy correspond to entries in Michie's taxonomy but are reframed and reorganized to reflect their grounding in SDT. According to Gillison et al., (2019) there does not appear to be a correlation between increased behaviour change strategies and larger clinical outcomes within interventions, rather the quality and delivery of the chosen strategies over the number appears important (Gillison et al., 2019). This finding is in contrast to other studies that report a correlation between higher performing eHealth resources and number of behaviour change strategies implemented (Devan et al., 2019a, Devan et al., 2019b). These contrasting findings further highlight the complexities involved in using theory and taxonomies effectively, raising important questions about how best to employ them in practice, an issue explored in the following section.

2.5.6 Challenges in applying theory and taxonomies in practice

The number of available theories, the significant overlap between theories and lack of guidance on selecting an appropriate theory for a specific intervention complicate the selection of theories in intervention design (Michie, 2008). Given the difficulty in identifying a single superior theory, some intervention design studies have opted to integrate multiple theoretical frameworks. For example, one study drew on Social Cognitive Theory, the Theory of Planned Behaviour, Cognitive Learning Theory, and the Fear Avoidance Model in developing a theory-informed self-management programme for chronic pain (Taylor et al.,

2016). A further challenge in applying behaviour change theories and strategies lies in their assessment. The effectiveness of a self-management intervention underpinned by behaviour change theory can be evaluated using clinical outcomes (e.g., pain, depression) or behaviour-specific outcomes (e.g., problem-solving, skill acquisition). Most studies focus on clinical outcomes while the measurement of self-management skills or knowledge of behaviour is not common practice (Mansell et al., 2016). As a result, it is difficult to determine whether improvements in clinical outcomes are directly attributable to behaviour change.

Consequently, although behaviour change theories and taxonomies are increasingly used in the design of eHealth interventions, their overall impact remains unclear.

A further complicating factor in measuring the success of behaviour change strategies in relation to chronic pain is that individuals living with pain are expected to change multiple types of behaviours at once. This may include physical activity behaviours, the implementation of psychological strategies, sleep, diet behaviours to name but a few. This presents challenges both for clinicians in measuring outcomes and for individuals in sustaining motivation and adherence over the long term (Jensen et al., 2003). To effectively translate theory into practice, Jensen et al. (2003) recommend that clinicians enhance patients' self-efficacy by encouraging the active practice of skills, modelling self-management strategies, use supportive dialogue to challenge unhelpful beliefs, and help individuals develop plans to overcome potential barriers. Despite guidelines such as this, Hagger and Hardcastle (2014) importantly highlight that although taxonomies have provided a detailed breakdown of what to include in order to support behaviour change, the 'how' relating to its delivery is often neglected. From a practical perspective and for clinical success in behaviour change implementation the clinician's approach to delivery, their interpersonal style and how much this contributes to successful behaviours change needs to be explored.

Despite these theoretical advances, real-world implementation of theory-informed digital interventions continues to encounter significant practical barriers. Marier-Deschênes et al. (2024), for example, developed a web-based self-management program using an interdisciplinary team as recommended by the CeHRes Roadmap, that included healthcare professionals and individuals with lived experience of pain. The program also incorporated 26 behaviour change techniques from Michie's taxonomy, demonstrating a theoretically sound and co-designed intervention. Despite its impressive design features, participant engagement was a significant challenge, with response rates of just 15% at study commencement with further attrition rates noted at three months follow up with the sample

reducing to 56% (Marier-Deschenes et al., 2024). Similarly, Thiblin et al., (2022) report an 11% response rate following recruitment invitations sent to over 500 potential participants to a CBT-based eHealth intervention. These response rates indicate the difficulties with participant recruitment and retention in digital formats which exist regardless of the quality of the health intervention in question. This is a concern, while digital tools can deliver evidence-based content, they may struggle to replicate the therapeutic alliance formed through in-person care, a key component of self-management interventions. This could limit both adherence and the potential for long-term impact. Despite providing innovative care opportunities, a challenge remains in delivering online interventions that support the essence of patient-centred care (Fritz & Kongsted, 2023).

Ultimately, intervention design should be grounded in behaviour change theory while clearly specifying the behaviour change strategies employed, to enhance both the rigour and reproducibility of the intervention. Combining a taxonomy that is firmly rooted in theory with pragmatic application strengthens intervention design and should be a priority in developing new programmes. From the practical perspective of this thesis, we highlight the value of applying theory in real-world clinical practice. In particular, the three core principles of SDT, autonomy, competence, and relatedness, offer a clear and actionable framework for addressing psychological needs, which may be more accessible and feasible for clinicians to implement compared to the broader, more complex components of Social Cognitive Theory.

2.6 Literature Review Conclusion

Chronic pain is highly prevalent in Ireland and contributes to significant economic and societal costs. It compromises health, wellbeing, and productivity, often leading to social exclusion and emotional distress. Despite the clear need, gold-standard multidisciplinary pain treatment services are not widely accessible, leaving many without appropriate care. In response, innovative and equitable health interventions are urgently needed to support those living with pain, including tools that help individuals navigate resources and support systems. Evidence-based research consistently advocates for the adoption of the BPS model over the traditional biomedical approach. However, its implementation in clinical practice remains limited. As Sharma et al., (2020) argue, treatment that focuses solely on disease rather than illness conflicts with the World Health Organization's definition of health, which emphasises the integration of social and psychological wellbeing.

Self-management as an intervention for chronic pain requires support through flexible and personalised approaches. While some individuals may benefit from fully digital self-management tools, others may need blended care or additional face-to-face support. These varying needs call for adaptable, patient-centred solutions embedded across the healthcare system. To guide clinical practice and system-level planning, future research must prioritise long-term evaluations, cost-effectiveness assessments, and meaningful engagement with patients and stakeholders in the design and evaluation of interventions.

Although clinicians recognise the importance of self-management, consistent integration into practice remains a challenge. Current healthcare infrastructures often hinder the application of a BPS approach, creating tension between clinical guidelines and the realities of service delivery. This disconnect can foster ethical and professional conflict for clinicians striving to provide patient-centred care. It is therefore essential to build a supportive clinical environment that acknowledges these challenges and empowers practitioners to deliver whole-person care. A resilient and well-supported health workforce is vital to address the growing complexity of healthcare. Future research should explore the needs of clinicians across community and hospital settings to identify the supports necessary for effective implementation of clinical guidelines.

Chapter 3.

Autonomy supportive healthcare environments and chronic pain: A Cross-Sectional Study

Sheridan K, O'Connor S, Whyte E. An investigation into perceived autonomy support, motivation and competence in chronic pain patients in Ireland: A cross-sectional study. (2024) PLoS One. May 6;19(5):e0301861. Doi: 10.1371/journal.pone.0301861. PMID: 38709725; PMCID: PMC11073679.

3.1 Abstract

Autonomy supportive healthcare settings are associated with enhanced behaviour change and self-management strategies in individuals living with chronic disease. The level of autonomy support provided by healthcare professionals to individuals living with chronic pain in Ireland is unknown. A cross-sectional study was completed on participants living with chronic pain (>3 months) in Ireland. Participants (n=389) completed an anonymous survey constructed of patient reported outcome measures relating to autonomy support (HCCQ), motivation (TSRQ), competence in physical activity (PCS), pain interference (BPI) and psychological factors (PHQ-9, GAD-7). Results showed the median HCCQ ($H=39.287$, $p<0.001$), Autonomous Motivation ($H=13.568$, $p=0.019$) and PCS ($H=30.701$, $p<0.001$) scores were significantly different when patients received care from different healthcare professionals. There was a negative correlation between PCS and pain severity ($r=-0.32$, $p<0.01$), pain interference ($r=-0.44$, $p<0.01$), PHQ-9 ($r=-0.50$, $p<0.01$) and GAD-7 ($r=-0.34$, $p<0.01$).

This study has identified that healthcare supportive environments in Ireland vary according to the healthcare professional leading pain care. Furthermore, higher levels of self-determination were associated with enhanced psychological wellbeing in individuals with chronic pain. Given the limited number of MDT clinics to provide pain management programs, an alternative cost-effective community led solution is required. The results of this study indicate that allied health professionals may be well placed to fill this void. Future research to explore the barriers to providing healthcare supportive environments from both clinicians and person's living with chronic pain perspectives are required.

Keywords: autonomy support, self-management, self-determination theory, persistent pain

3.2 Introduction

Pain and pain-related diseases are the leading cause of disability and disease burden globally (GBD, 2017). Pain requires the integrated consideration of biological, psychological and social factors in order to support meaningful treatment strategies (Breivik et al., 2008; Turk et al., 2008). The prevalence of chronic pain in Irish adults is 35% (Rafferty et al., 2011). Despite the high prevalence of chronic pain, Ireland's pain services remain under-resourced (Fullen et al., 2006). Multidisciplinary Team (MDT) clinics are advocated as best practice to support optimal treatment of chronic pain (Gatchel et al., 2014; Kamper et al., 2015). Despite sixteen public pain management clinics offering interventional pain therapies in Ireland, only five clinics offer MDT pain management programs (Purcell et al., 2022). Consequently, in many cases, the delivery of pain management services in Ireland is conducted by individual clinicians.

Clinical guidelines recommend that clinicians provide patient centred care and optimise self-management skills (Bernstein et al., 2017; Qaseem et al., 2017). Self-management has been defined as an “individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition” (Barlow et al., 2002). Self-management in chronic pain requires altering lifestyle behaviours and hence behaviour change interventions should be employed by healthcare professionals (Keogh et al., 2015). Self-Determination Theory (SDT) supports both patient-centred care and enhanced self-management skills (Brooks et al., 2018; Rahman et al., 2011; Williams et al., 2004). According to SDT, behaviour change can be enhanced if a person's autonomy (feeling free to engage in a behaviour), competence (feeling effective to engage in a behaviour) and relatedness (feeling cared for and valued) are optimised in healthcare settings (Ryan et al., 2008; Williams et al., 1998). One of the elements contributing to a patient's self-determined behaviour is the presence of an autonomy supportive healthcare setting (Ntoumanis et al., 2021; Williams et al., 1998). Autonomy supportive healthcare settings have been associated with enhanced biological and psychosocial outcomes in individuals living with chronic disease (Ntoumanis et al., 2021). Specific to chronic pain, enhanced levels of autonomy and competence have been associated with decreased disability levels (Podlog et al., 2021). Hence, autonomy supportive healthcare settings that support health behaviours are beneficial and desirable in relation to chronic pain conditions.

The level of autonomy support provided by individual healthcare professionals is currently unknown in Ireland. As healthcare professionals in Ireland generally do not have the support

of MDT clinics in providing patient centred care, they are required to support autonomy and competence in self-management skills (such as physical activity) independently. In order to optimise patient experience, a review of existing levels of autonomy support in Irish healthcare settings is required. Therefore, this study aimed to examine the components of SDT (autonomy support, motivation and competence in physical activity) of individuals living with chronic pain in Ireland. Secondly, this study aimed to explore differences in autonomy support, motivation and competence in physical activity in individuals undergoing treatment with different Irish healthcare professionals. Finally, the association between pain interference, psychological wellbeing and the components of self-determination theory (autonomy, motivation and competence in physical activity) were explored.

3.3. Materials and methods

3.3.1 Participants and Procedures

Adult participants living with chronic pain (pain > 3 months) in Ireland were eligible for study inclusion. To achieve a confidence level of 95%, the required sample size was determined as 384 participants (online software www.raosoft.com). Ethical approval was granted by Dublin City University research ethics committee (DCUREC/2022/082). The studies plain language statement and informed consent form were completed electronically at the beginning of the online survey (Appendix A.1,A.2). Participants could not complete the anonymised survey if they did not first complete the compulsory consent form.

Participants were recruited from 1st August 2022 to 30th of October 2022 with survey reminders sent at 2-week intervals. The study was promoted a) on social media (Twitter, Facebook, Instagram) by two chronic pain advocate groups, b) by poster in Pain Management, Orthopaedic and Neurosurgical Clinic waiting rooms and c) in one medical exercise clinic. Participants completed an anonymous and confidential online survey (13 ± 1.8 minutes) on survey website Qualtrics (*Qualtrics.*, 2022)(Appendix A.3).

3.3.2 Outcome Measures

Section one of the survey recorded demographic information including gender, age, county, diagnosis and years lived with pain. Section two of the data collection protocol included reliable and validated questionnaires in the following order, Health Care Climate Questionnaire (HCCQ) (Williams et al., 1996), Brief Pain Interference (BPI) (Cleeland & Ryan, 1994), Treatment Self Regulating Questionnaire (TSRQ) (Williams et al., 1996),

Perceived Competence Scale (PCS) (Williams et al., 1996), Patient Health Questionnaire-9 (PHQ-9) (Kroenke et al., 2001) and the General Anxiety Disorder-7 (GAD-7) (Spitzer et al., 2006).

3.3.3 Health Care Climate Questionnaire

Perceived autonomy support was assessed using the 15-item Health Care Climate Questionnaire (HCCQ) (Williams et al., 1996). The HCCQ identifies the participant's perceptions to which their primary healthcare professional is autonomy supportive. For the purpose of this survey, the primary healthcare professional was defined as the person the participant considered to have the most influence on their treatment and pain management. Responses were given on a 7-point Likert scale (1 strongly disagree to 7 strongly agree). Participant's scores were averaged, with higher mean scores demonstrating higher perceived autonomy support. The scale had a high level of internal consistency (Cronbach's $\alpha=0.97$).

3.3.4 Treatment Self Regulating Questionnaire

Motivation towards regular physical activity was assessed using the 15-item Treatment Self Regulating Questionnaire (TSRQ) (Williams et al., 1996). Responses are given using a seven-point Likert scale (1 not at all true to 7 very true). The TRSQ consists of three subscales, autonomous motivation (the patient is internally motivated), controlled motivation (the patient is externally motivated) and amotivation scale (the patient is not motivated). Participant's scores for each subscale were averaged individually, with higher scores demonstrating higher levels of motivation or amotivation. The combined scale (Cronbach's $\alpha=0.76$) along with the subscales autonomous motivation (Cronbach's $\alpha=0.91$) and controlled motivation (Cronbach's $\alpha=0.76$) demonstrated high internal consistency. The subscale amotivation was considered optimal (inter-item correlation=0.26) (Briggs & Cheek, 1986).

3.3.5 Perceived Competence Scale

Perceived competence towards regular physical activity was assessed using the 4-item Perceived Competence Scale (PCS) (Williams et al., 1996). Responses are given using a seven-point Likert scale (1 not at all true to 7 very true). An individual's score was calculated by averaging the total score of the 4-items. The scale had a high level of internal consistency (Cronbach's $\alpha=0.96$).

3.3.6 Brief Pain Inventory

Pain intensity and pain interference scores were assessed using the Brief Pain Inventory (BPI) (Cleeland & Ryan, 1994). Pain intensity was measured with four items (worst, least, average and current pain intensity). Pain interference was measured with seven items, including general activity, mood, walking, work, relations with others, sleep and enjoyment of life. For both pain intensity and pain interference responses were gathered on a 0-10 scale with 10 indicating the worst imaginable pain and complete pain interference. An individual's pain intensity score was calculated by averaging the total score of the 4-items. The pain interference score was calculated by averaging the total score of the 7-items. Both pain severity (Cronbach's alpha=0.86) and pain interference (Cronbach's alpha=0.91) scales had a high level of internal consistency.

3.3.7 Patient Health Questionnaire

The presence and severity of depression was assessed using the Patient Health Questionnaire-9 (PHQ-9) (Kroenke et al., 2001). The PHQ-9 consists of 9-items relating to depression that correspond to the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2006). Responses are scored from 0 (not at all) to 3 (nearly every day) with a total score of 27 possible. In chronic physical health conditions, a cut off score ≥ 10 has been utilised for depression identification (McManus et al., 2005). The scale demonstrated a high level of internal consistency reporting a Cronbach's alpha of 0.87.

3.3.8 Generalised Anxiety Disorder

The presence of anxiety was assessed using the Generalised Anxiety Disorder (Gad-7) (Spitzer et al., 2006). Responses are scored 0 (not at all) to 3 (nearly every day) with a total score of 21 possible. When screening for an anxiety disorder a recommended cut-off point of ≥ 10 has been utilised for anxiety identification (Sapra et al., 2020). The scale had a high level of internal consistency (Cronbach's alpha=0.92).

3.3.9 Statistical Analysis

Statistical Analysis was performed with IBM SPSS statistics version 27 (*IBM SPSS Statistics for Windows*, 2020). Descriptive and analytical statistics were analysed to evaluate mean and the standard deviation of the HCCQ, BPI, TSRQ and PCS scores. A Kruskal-Wallis H test was used to determine if there were differences in HCCQ, TSRQ and PCS between six groups of healthcare workers, "General Practitioner" (GP) (n=160), "Rheumatologist" (n=49), "Pain Management Consultant" (n=50), "Neurologist" (n=39), "Allied Healthcare Professionals" (AHP) (n=53) and "Other Medical Professionals" (n=31). Complementary

therapists were excluded from group analysis due to insufficient data collection in this group (n=4). Pairwise comparisons were performed with a Bonferroni correction for multiple comparisons (Dunn, 1964). Effect size was classified by Cohen (1988) criteria (.1=small effect, .3=medium effect, .5=large effect). Spearman correlations coefficients were completed to explore the association between BPI, GAD-7, PHQ-9 and HCCQ, TSRQ and PCS scores. Correlation coefficients were classified as low (0.1 and 0.29) moderate (0.3 and 0.49) and high (>0.5) high (Pallant, 2011). Statistical significance was set at $p < .05$.

3 Results

3.4.1 Descriptive Statistics

A total of 681 participants opened the online survey. Insufficient responses (completing demographic information only) were removed (n=292). Participants (n=389) had a mean age of 48.7 ± 13.6 (range 18-83) years and reported 11.69 ± 10.4 (range 0.3-58) years of pain. Participant demographics are summarised in table 1. Participants identified a total of 17 healthcare professionals as their primary healthcare professionals (table 2). Participants reported a mean pain severity of 4.5 ± 1.9 (range 0-10) and mean pain interference of 5.4 ± 2.5 (range 0-10). Current treatment strategies reportedly relieved pain by a mean of $41\% \pm 27.0$ (0-100). Mean PHQ-9 scores were 10.6 ± 6.4 (Range 0-27) and mean GAD-7 scores were 6.9 ± 5.7 (Range 0-21).

Table 3.1 Population Demographics

Characteristic	Number (n)	Percentage (%)
Gender	Female (321)	82.5
	Male (16.7)	16.7
	Non-Binary (2)	0.5
	Transgender (1)	0.3
Chronic pain pathologies	Single pathology (192)	49
	Two pathologies (89)	23
	Three or more pathologies (102)	26
Current Treatments	Pharmacology	65
	Conservative Therapy	6
	Pharmacology and Conservative Therapy	12
	None	17

Table 3.2 Primary Healthcare Professionals of persons living with chronic pain

Healthcare Professional Groups		N	%
General Practitioner		160	41.1%
Pain Management Consultant		50	12.9%
Rheumatologist		49	12.6%
Neurologist		39	10%
Allied Health Professionals	Physiotherapist	48	12.3%
	Athletic Therapist	3	.8%
	Occupational Therapist	2	.5%
Other Medical Health Professionals	Orthopaedic Consultant	12	3.1%
	Neurosurgeon	4	1%
	Gynaecologist	3	.8%
	Nurse	3	.8%
	Oncologist	2	.5%
	Infectious Disease Consultant	2	.5%
	Endocrinologist	2	.5%
	Respiratory Consultant	2	.5%
	General Medicine Consultant	1	.3%
Complimentary Therapists	Massage Therapist	4	1%

3.4.2 Autonomy support, motivation and competence levels

The levels of perceived autonomy support, motivation and competence of individuals living with chronic pain in Ireland are detailed in table 3.

Table 3.3 Autonomy support, motivation and competence levels

Outcome Measure (n)	Subscales (n)	Mean \pm SD (Range)
HCCQ (389)		4.6 \pm 1.7 (0.8-7)
TSRQ	Autonomous Motivation (352)	5.2 \pm 1.5 (0-7)
	Controlled Motivation (353)	2.8 \pm 1.2 (0-7)
	Amotivation (353)	2.2 \pm 1.2 (0-7)
PCS (351)		3.6 \pm 1.9 (0-7)

HCCQ (Healthcare Climate Questionnaire), TSRQ (Treatment Self-Regulation Questionnaire), PCS (Perceived Competence Scale), SD (Standard Deviation)

3.4.3 Individual healthcare professional groups

Healthcare Climate Questionnaire

A statistically significant difference between healthcare professional groups was observed for HCCQ scores ($H(5)=39.287, p<0.001$) (table 4). Post hoc analysis revealed statistically significant differences with a medium effect size between AHPs (Md=6.2) and GPs (Md =4.3), ($p<0.001, r=0.4$), AHPs and Neurologists (Md = 4.3) ($p=0.002, r=0.41$), AHPs and Other Medical Health Professionals (Md = 5.3) ($p=0.022, r=0.4$) and a small effect size between AHPs and Rheumatologists (Md = 5.2) ($p=0.04, r=0.28$). No statistical differences were observed between any other group combinations.

Table 3.4 Median outcomes of healthcare professional groups

Healthcare Professional	HCCQ	TSRQ			PCS
		Autonomous Motivation	Controlled Motivation	Amotivation	
GP	4.3	5.2	2.5	2	3.3
Pain Management Consultant	5.5	5.2	3	2	3.5
Rheumatologist	5.2	5.2	2.5	2	3.3
Neurologist	4.3	4.8	2.8	2	2
AHP	6.2	6	2.8	2	5
Other Medical Professionals	5.2	5.5	2.5	1.8	4.6
P-Value	<0.01*	0.01*	0.21	0.87	<0.01*

P<0.05* HCCQ (Health Climate Questionnaire), TSRQ (Treatment Self Regulation Questionnaire), PCS (Perceived Competence Score)

Treatment Self-Regulation Questionnaire

For autonomous motivation scores, a statistically significant difference between healthcare professional groups was observed ($H(5)=13.568, p=0.019$). Post hoc analysis revealed statistically significant medium effect size in median autonomous motivation scores between AHPs (Md = 6) and Neurologists (Md = 4.8) ($p=.011, r=0.36$). No statistically significant differences were observed between groups for controlled motivation scores ($H(5) = 7048, p = .217$) or amotivation scores ($H(5) = 1.844, p = .87$).

Perceived Competence Scale

A statistically significant difference between healthcare professional groups was observed for PCS scores ($H(5)=30.701, p<0.001$). Post hoc analysis revealed a large effect size between AHPs (Md = 5) and Neurologists (Md = 2) ($p=.000, r=0.51$) and a medium effect size between AHPs and GPs (Md = 3.3) ($p=0.000, r=0.32$), AHPs and Rheumatologists (Md = 3.3) ($p=.005, r=0.36$), AHPs and Pain Management Consultants (Md = 3.5) ($p=0.01, r=0.31$) and Other Health Professionals (Md = 4.6) and Neurologists (Md = 2) ($p=.05, r=0.4$).

3.4.4 Correlations

There was negative correlation between HCCQ and both PHQ ($r=-0.18$, $p<0.01$) and GAD-7 ($r=-0.11$, $p=0.02$) (table 5). There was a negative correlation between autonomous motivation and PHQ ($r=-0.18$, $p=0.01$) and a positive correlation between controlled motivation and PHQ ($r=0.14$, $p=0.01$) and GAD-7 ($r=0.24$, $p<0.01$). Amotivation was positively correlated to both pain interference ($r=0.10$, $p=0.04$) and GAD-7 ($r=0.11$, $p=0.02$). There was a negative correlation between PCS and pain severity ($r=-0.32$, $p<0.01$), pain interference ($r=-0.44$, $p<0.01$), PHQ-9 ($r=-0.50$, $p<0.01$) and GAD-7 ($r=-0.34$, $p<0.01$).

Table 3.5 Correlation Coefficient between autonomy support, motivation, competence, pain interference and psychological well-being.

	Pain Severity		Pain Interference		PHQ-9		GAD-7	
	<i>r</i>	<i>p</i>	<i>r</i>	<i>P</i>	<i>r</i>	<i>p</i>	<i>r</i>	<i>P</i>
HCCQ	-0.07	0.13	-0.09	0.06	-0.18	<0.01**	-0.11	0.02*
Autonomous Motivation	-0.03	0.51	-0.09	0.06	-0.18	0.01**	-0.09	0.09
Controlled Motivation	-0.02	0.67	0.06	0.21	0.14	0.01**	0.24	<0.01**
Amotivation	0.10	0.05	0.10	0.04*	0.05	0.31	0.11	0.02*
PCS	-0.32	<0.01**	-0.44	<0.01**	-0.50	<0.01**	-0.34	<0.01**

* $p<0.05$ ** $p<0.01$

HCCQ (Healthcare Climate Questionnaire), PCS (Perceived Competence Scale), PHQ-9 (Patient Health Questionnaire), GAD-7 (General Anxiety Disorder)

4. Discussion

This is the first study of its kind investigating autonomy supportive healthcare environments in a chronic pain population accessing pain services. In this study, the collective level of

autonomy support is reported as 4.6 (SD \pm 1.7), indicating that it is ‘somewhat true’ that persons living with pain in Ireland experience an autonomy supportive healthcare environment. These results are lower than autonomy support values for other chronic conditions including obesity (Schmidt et al., 2012; Williams et al., 1996), bipolar disease (Ludman et al., 2002) and melanoma (Czajkowska et al., 2017). Higher levels of autonomous motivation (5.2 SD \pm 1.5) were observed compared to controlled motivation (2.8 SD \pm 1.2) and amotivation (2.2 SD \pm 1.2). In the context of healthcare, autonomous motivation has been related to enhanced self-management behaviour, while controlled motivation and amotivation has been negatively correlated to self-management behaviour (Podlog et al., 2021; Williams et al., 1996, 1998). This indicates that persons living with chronic pain in Ireland are autonomously motivated to engage in behaviours that enhance self-management of their pain condition. Finally, competence to engage in physical activity (3.6 SD \pm 1.9) was notably lower than competence to engage in physical activity in primary care patients (5.9 SD \pm 1.2) (Fortier et al., 2007). This is despite the importance and multiple benefits of physical activity in preventing comorbidities and enhancing quality of life in chronic pain populations (Ambrose & Golightly, 2015).

Secondly, this study explored differences in autonomy support from different healthcare professionals as perceived by individuals with chronic pain. Significantly higher levels of autonomy support were reported when the main healthcare provider was an AHP in comparison to GPs, neurologists, other medical health professionals and rheumatologists. In contrast to our high HCCQ scores for AHPs, lower HCCQ scores in AHPs (2.7 SD \pm 0.7 to 4.5 SD \pm 0.8) were previously recorded after a single AHP patient interaction in a public outpatient physiotherapy department (Murray et al., 2015). The difference observed in autonomy support between AHPs in these studies is potentially associated with a difference in number of clinical interactions. With no limitations to healthcare appointments in the current study, increased clinician patient interactions may have provided a greater opportunity to develop an autonomy supportive healthcare environment.

The current study found that participants living with chronic pain reported the lowest levels of autonomy support from both GPs and neurologists. Although no comparison scores for neurologists are available, similar HCCQ scores have been reported for GPs treating chronic diseases (4.2 SD \pm 0.8) (Raaijmakers et al., 2014). Although the importance of supporting autonomy in populations living with chronic pain has been established (Cummings et al., 2017), both the environmental context and organisational barriers (time and workload) may

negatively affect the implementation of an autonomy supportive environment (Matthews et al., 2015). Specific to Ireland, GPs and consultants working with patients in chronic pain services are heavily affected by both policy systems and patient factors (Fullen et al., 2008). The standard GP consultation time is 15 minutes (Blumenthal et al., 1999), at least half the time available to an AHP. Thus, time and workload could vary widely between different healthcare professionals influencing the results observed in this study.

Similar to autonomy support, people with chronic pain treated by AHPs demonstrated the highest scores of autonomous motivation and competence in physical activity, compared to the other groups of healthcare professionals. Although no comparative research specific to chronic pain is available, previous research in both post-surgical rehabilitation (5.4 SD \pm 1.0) (Chan et al., 2009) and cardiac rehabilitation (5.9 SD \pm 1.0) (Russell & Bray, 2010) show similar autonomous motivation scores in healthcare environments led by AHPs. As AHPs are well placed to educate and support physical activity behaviour, it is unsurprising this group demonstrates the highest competence score of all healthcare professionals.

Participants treated by neurologists, GPs and rheumatologists reported the lowest autonomous motivation and competence in physical activity scores. Physical activity is indicated in chronic pain rehabilitation and should be recommended to all persons attending chronic pain services (Borisovskaya et al., 2020). However, the individual nature of pain means that there is no specific recommended exercise dose and intensity, complicating its prescription for healthcare professionals (Ambrose & Golightly, 2015). Although healthcare professionals may advise patients of the importance of physical activity, healthcare workers require the skill set to encourage behaviour change as well as simply imparting knowledge (Morrow et al., 2004). Future research should explore the barriers and facilitators to healthcare professionals supporting patients to achieve higher levels of competency in self-management behaviours such as physical activity.

The final aim of this study was to explore the association between pain interference, psychological wellbeing and the components of self-determination theory (autonomy, motivation and competence). Similar to previous research (Ntoumanis et al., 2021), it was observed that higher levels of autonomy support, autonomous motivation and competence were associated with improved psychological wellbeing. As chronic pain patients record high levels of both depression (Raftery et al., 2011) and anxiety (Lerman et al., 2015), it is imperative that any future interventions using self-determination theory report not only

improvements in self-management behaviours but also improvements in psychological outcomes. Unexpectedly, in contrast to previous chronic pain research (Matos et al., 2016), the current study observed no relationship between autonomy support or motivation and pain severity and pain interference. As this study is the first to investigate autonomy, motivation and competence in a diverse chronic pain population, further research is required to explore this relationship further.

3.6 Implications to Practice

The results of this study indicate that the level of autonomy support and competence in physical activity is suboptimal across chronic pain services in Ireland and more specifically in individual healthcare professionals groups. This is despite the fact that persons living with pain have identified a desire for healthcare professionals who approach treatment holistically and with empathy (Mose et al., 2022). The results of this study indicate that some healthcare professionals currently do not provide optimal levels of self-determination which may affect motivation and competence in behaviour change strategies in the chronic pain population.

A new approach to pain rehabilitation in Ireland is warranted. Firstly, an investigation into the specific barriers to autonomy support, motivation and competence in clinical groups with the lowest outcomes scores in chronic pain services should be completed. Future research investigating the individual elements of the self-determination theory taxonomy may assist healthcare professionals working in varying infrastructures to identify the strategies that they can adopt to implement an autonomy supportive environment in their clinical context (Gillison et al., 2019). Secondly, as well as supporting clinician's to develop autonomy supportive environments, a further solution to promoting self-determined behaviour is to improve service pathways to AHPs. The results of this study indicate that AHPs are well placed to deliver autonomy supportive healthcare environments that optimise self-management behaviours.

3.7 Limitations

Causal relationships among the study variables were not possible. This study recruited diverse participants with a variety of chronic pain conditions and as such did not capture the nuances of a specific chronic pain conditions. However, the participant demographics and related variables (e.g., psychological wellbeing and co-morbidities) were similar to those reported in previous Irish pain research (Raftery et al., 2011), suggesting some comparability with the broader chronic pain population. Nonetheless, as participants self-selected to complete the survey, selection bias may limit the representativeness of the findings.

Furthermore, this study did not record the number of treatment sessions that patients completed with healthcare professionals. It is possible that increased treatment sessions will have related to an increased therapeutic alliance and influence on autonomous support. Lastly, the limitations of self-reported data in relation to healthcare research are acknowledged. We acknowledge the tendency for participants to provide what they believe are socially acceptable answers, however, it is hoped the anonymous nature of this study minimised this limitation.

3.8 Conclusion

Autonomy support and competence to engage in physical activity were recorded as suboptimal in people living with chronic pain in Ireland. Secondly, this study has identified that healthcare supportive environments in Ireland vary according to the healthcare professional leading pain care. Given the shortfall of MDT clinics to provide pain management programs an alternative cost-effective community led solution is required. The results of this study indicate that AHPs may be well placed to fill this void. Future research to explore the barriers to providing healthcare supportive environments from both clinicians and person's living with chronic pain are required.

3.9 Link to Chapter 4

The results of Study 1, Chapter 3 have a number of important implications including demonstrating variability in perceived autonomy support by persons living with chronic pain across healthcare professionals, with AHPs rated highest and GPs and neurologists rated lowest. In Ireland, GPs are the most frequently accessed community healthcare provider and play a pivotal role in managing chronic conditions, including chronic pain (ICGP, 2022). They are the first point of contact for people living with pain, act as gatekeepers to specialist services, and coordinate long-term care (ICGP, 2022). As such, the low levels of perceived autonomy support from GPs in the context of chronic pain management are particularly concerning. This in addition to the current strain on services, marked by long waiting lists and limited access to specialist pain clinics or physiotherapy, may negatively influence individuals' experiences of autonomy support and their ability to engage in self-management. Importantly, this study does not include perspectives from clinicians working in chronic pain services; therefore, further research exploring their experiences of service provision is warranted.

Secondly our results indicate that autonomy support and competence are associated with decreased anxiety and depression, reinforcing findings from similar research in rheumatoid arthritis, where psychological well-being was linked to the extent to which individuals' psychological needs (autonomy, competence, relatedness) were met (Ryan & McGuire, 2016). While our study assessed autonomy support and competence in line with SDT, the component of relatedness was not investigated. This research gap reflects a limitation noted by Painter et al. (2008), who observed that many studies fail to fully embed all theoretical constructs. In the case of SDT, all three components, autonomy, competence, and relatedness, should be explored to fully understand self-determined behaviour. These will be addressed in Study 2 (Chapter 4) where all three components will be explored qualitatively.

Considering these findings, Study 2 will explore the lived experiences of both individuals living with chronic pain and clinicians working in Irish healthcare services, across both community and hospital settings. The aim of this qualitative study is to deepen our understanding of how autonomy support and self-management behaviours are experienced by service users and service providers within the Irish healthcare context.

Chapter 4:

The lived experience of pain services: A comparison of service users' and service providers' experience of Irish health services.

Sheridan, K. Whyte, D., McNamara, A., O'Connor, S. (Under Review). The lived experience of pain services: A comparison of service users' and service providers' experience of Irish health services. Submitted to Pain Research and Management

4.1 Abstract

Background: A supportive healthcare experience that implements a biopsychosocial model of care can empower a person with chronic pain to make informed decisions and engage in self-management behaviours. Despite the positive influence of supportive healthcare, little is known about the presence of healthcare support in under-resourced chronic pain services. This idiographic study explores the lived experience of service users and providers participating in chronic pain services with a specific focus on autonomy support and self-management skills.

Methods: Semi-structured interviews were conducted on service users (n=7) self-reporting a diagnosis of chronic pain (pain >3 months) and service providers (n=5), defined as healthcare professionals with >3 years of experience in clinical healthcare settings managing pain conditions. Interview transcripts were analysed using interpretative phenomenological analysis.

Results: Analyses generated four themes: 'Biomedical model leads care'; 'lost in a system'; 'I need support' and 'the essentials of self-management'. Both service users and providers described regular experiences of invalidation and biomedical approaches to pain management. Long waitlists, a lack of multidisciplinary services, short appointment times and a lack of educational resources all impacted the development of self-management skills in service users.

Conclusion: Service users and providers desire access to multidisciplinary services that support a biopsychosocial model of care. Healthcare professionals cannot deliver what service users expect due to macro, meso and micro level factors. Future research is needed to explore practical solutions to deliver pain services that optimise the development of self-management skills where existing infrastructure and resources negatively impact service delivery.

Keywords: lived experience, chronic pain, healthcare support, self-management

4.2 Introduction

Chronic pain is a life changing experience for those who live with it (Fisher et al., 2007). Affecting one in every five persons (et al., 2018), chronic pain affects multiple aspects of a person's life including their psychological health, occupational performance, personal relationships and life satisfaction (Dueñas et al., 2016; Fisher et al., 2007). Chronic pain requires multidimensional treatments to reduce burden and optimise quality of life (Breivik et al., 2013; Hylands-White et al., 2017). Therefore, a biopsychosocial model of care addressing the dynamic interaction of physiological, psychological and social factors associated with chronic pain is warranted (Bever et al., 2016; Kusnanto et al., 2018). A biopsychosocial approach can be delivered clinically through the implementation of patient-centred care (Tramonti et al., 2021). Patient-centred care ensures patients are informed, empowered, share in the decision-making process, and develop self-management skills in a partnership with their healthcare professional (Hoffmann et al., 2022; Delaney, 2018; Stewart, 2001).

An interdisciplinary pain management program (PMP) is recognised as the gold standard intervention to provide patient-centred care and introduce self-management skills (BPS, 2013). In the absence of PMPs, often due to limited resources, individual clinicians are tasked with providing patient-centred care and self-management strategies for living with pain. Autonomy supportive healthcare is a core pillar of providing patient-centred care (Williams et al., 2000). According to Self-Determination Theory (SDT), autonomous behaviour is dependent on three basic psychological needs; autonomy, competence, and relatedness (Ryan & Deci, 2000). Autonomy supportive healthcare environments are settings where healthcare professionals fulfil the three basic psychological needs of SDT, thereby supporting patients to engage in autonomous health related behaviours and self-management practices (Kayser et al., 2014). Autonomy supportive healthcare results in positive changes to both psychological and physical health (Ntoumanis et al., 2021; Williams et al., 2000).

Despite the benefits of autonomy supportive healthcare in supporting self-management skill development, an acknowledged gap between current evidence and clinical practice in pain management may affect its implementation (IASP 2018). Furthermore, the limited availability of PMPs in healthcare services is a potential limitation to the delivery of patient-centred care for chronic pain sufferers. Therefore, this study aimed to explore the lived experience of service users and service providers participating in Irish healthcare services specifically focusing on autonomy support and self-management behaviours.

4.3 Methods

4.3.1 Design

Interpretative Phenomenological Analysis (IPA) was chosen due to its idiographic nature, providing a detailed exploration of the participants' personal lived experience (Smith & Fieldsend, 2021). IPA is a valuable methodology in chronic pain and healthcare research as it explores complex biopsychosocial phenomena (Biggerstaff & Thompson, 2008; Smith & Osborn, 2015).

4.3.2 Participants

Persons living with chronic pain (service users) (n=7) were purposefully recruited from a medical exercise clinic in Ireland. A sample of participants, 18-65 years of age, reporting ≥ 3 years of chronic pain and experiences of chronic pain treatment from ≥ 3 healthcare professionals were recruited. This inclusion criteria ensured multiple clinical experiences across the sample. Healthcare professionals (service providers) (n=5) with ≥ 3 years working with persons living with chronic pain were recruited via a targeted email invitation and snowball sampling. A sample size of twelve participants was considered satisfactory in line with guidance for Interpretative Phenomenological Analysis (IPA), which prioritises depth of exploration over breadth. IPA aims to provide detailed, idiographic insights into participants' lived experiences rather than produce generalisable findings (Reid et al., 2005). While smaller, homogeneous samples (typically 6–10 participants) are often recommended, studies have shown that slightly larger samples can be appropriate when the group shares key characteristics and when the analysis remains focused and interpretative (Pietkiewicz & Smith, 2014). Given the diversity of experiences within chronic pain care, twelve participants allowed for sufficient variability to capture nuanced perspectives while maintaining analytic depth and coherence. Participants read the plain language statement and provided informed written consent prior to data collection (Appendix B.1, B.2). To ensure anonymity, service users were not direct patients of service providers accepted for the study. Ethical approval was granted by DCU Research Ethics Committee (DCUREC/2023/039).

4.3.3 Procedure

Individual, semi-structured interviews were completed on the online Zoom platform (Zoom Video Communications Inc., San Jose, California) offering logistical benefits to both researchers and participants (Archibald et al., 2019). All interviews were conducted by the first author who has a 12-year history of working as a Certified Athletic Therapist and

Chartered Physiotherapist specialising in pain management and an experienced clinical interviewer. Each interview commenced with the question “Tell me about your experience with chronic pain services in Ireland?”. Next, exploratory prompts and questions, informed by SDT (Deci & Ryan, 1985), were used to encourage elaboration and provide participants with the opportunity to discuss topics pertinent to them. As such the interview guide for Service Users (Appendix B.3a) and the interview guide for Service Providers (Appendix B.3b) were used in a way that allowed participants to lead the interview and for new topics to be explored as they arose. As well as audio recordings, the interviewer made written notes during the interviews to include non-verbal communication, new topics introduced by the participant and personal reflections on the interview process. Interviews ceased when participants confirmed they had exhausted their personal accounts. Interviews ranged from 32 to 63 minutes (mean 47 ± 11 minutes). A pilot interview was conducted prior to recruitment to review interview technique and clarity of questions. No changes were made to the interview guide following the pilot.

4.3.4 Data Analysis

Data analysis was completed as per the framework of analysis detailed by Smith and Fieldsend (2021) described in Table 1.

Table 4.1 IPA Data Analysis_(Smith & Fieldsend, 2021)

IPA Data Analysis	Action
Step 1 Familiarise with transcript	Transcribe interviews verbatim. Read and reread transcribed interview while listening to audio recording
Step 2 Exploratory noting in right-hand margin	Adopt a phenomenological focus by exploring semantic content and language
Step 3 Experiential statements in left-hand margin	A synergistic process of combining the analyst’s interpretation and the participant’s lived experience

Step 4 Development of Personal Experiential Statements (PETs)	Conceptual ordering of experiential statements to form Personal Experiential Statements
Step 5	Repeat Step 1-4 for each participant
Step 6 Development of Group Experiential Themes	Explore convergence and divergence across all participants PETs to create Group Experiential Themes (GETs)

4.3.5 Reflexivity and Trustworthiness

Throughout data collection the first author was aware of the importance of considering her own pre-cognitions and influence on participants and data interpretations. Bracketing was employed to allow reflection on the data and consideration of how any subjectivity interacted with the data analysis (Tufford & Newman, 2010). One of the co-authors acted as a critical friend, challenging the meaning units developed by the first author (Costa & Kallick, 1993) through conversations focused on ‘How might my background be influencing how I interpret this experience’ and ‘Am I over-interpreting based on my own preconceptions’. The resulting themes were discussed and agreed upon with an interdisciplinary team of Chartered Physiotherapists, Certified Athletic Therapists and qualitative researchers. Finally, given the importance of presenting the lived experience of the participants, thick description is used through significant direct quotations to preserve the richness of the participants’ accounts. Given the importance of credibility and trust, the steps taken to develop a level of rapport with participants were important (McGrath et al., 2019). Credibility and rapport were also enhanced by the first author’s positioning in a professional role and her clinical experience in the area, which may have increased the likelihood of participant openness.

4.4 Results

Table 2 and 3 summarise participant demographics. None of the service users had been referred to a multidisciplinary PMP to engage in a self-management program by their healthcare professionals. Six participants were unaware that self-management programs existed, with one participant being advised their knowledge exceeded what a self-

management program could offer. Only one of the five healthcare professionals had access to refer patients to a PMP. This PMP had a two-year waiting list. Final analysis of the data highlighted four group experiential themes summarised in Table 4. All themes have sub-themes which we exemplify with verbatim quotes.

Table 4.2. Service Users Demographics

Service User	Gender	Age (years)	Years of Pain	Pathology	HCP
1	Male	45	3	Neuropathic Pain post Cauda Equina	GP, PT, OT, Rehabilitation Consultant,
2	Male	65	30	Chronic Low Back Pain	GP, PT, Pain Consultant, Consultant Neurosurgeon
3	Female	57	40	Degenerative Spine Disease & Ankylosing Spondylitis	GP, PT, Orthopaedic Consultant, Consultant Neurosurgeon, Pain Consultants, Rheumatologist,
4	Female	36	8	Chronic Migraine	GP, Neurologist, Consultant in Internal Medicine
5	Female	59	30	Chronic Low Back Pain, Rheumatoid Arthritis,	GP, PT, Rheumatologist,
6	Male	45	11	Chronic Neuropathic pain	GP, PT, Consultant Neurosurgeon, Pain Consultant

7	Female	63	40	Rheumatoid Arthritis, Psoriatic Arthritis & Chronic Low Back Pain	GP, PT, Orthopaedic Consultant, Pain management Consultant, Rheumatologist
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HCP (Healthcare Professionals engaged with since chronic pain diagnosis) GP (General Practitioner) OT (Occupational Therapist) PT (Physiotherapist)

Table 4.3. Service Providers Demographics

Service Provider	Gender	Age	Years in practice	Public/Private	Access to refer to PMP	Wait list for PMP
GP	Female		30 years	Both	No	NA
Neurologist	Female	38	8 years	Both	Yes	2 years
Pain Consultant	Male	51	12 years	Private	No	NA
Rheumatologist	Female	46	15	Private	No	NA
Physiotherapist	Female	36	11	Private	No	NA

MDT (Multidisciplinary Team) PMP (Pain Management Program) NA(Not Available)

Table 4.4. Group Experiential Themes

Group Experiential Themes	Sub-themes
1. Biomedical model leads care	<ul style="list-style-type: none"> i. Medication led management ii. A desire for a biopsychosocial model of care
2. Lost in a system	<ul style="list-style-type: none"> i. No clear pathway ii. Accessibility
3. I need support	<ul style="list-style-type: none"> i. I can't do it alone ii. Pain invalidation

4. The essentials of self-management	<ul style="list-style-type: none"> i. Exercising autonomy ii. Expanding knowledge iii. Supported behaviour change techniques

4.4.1 Biomedical model leads care

This theme referred to participants’ accounts of how the biomedical model of care dominated their experience and comprised of two subthemes: ‘Medication led management’, and ‘A desire for biopsychosocial model of care’.

Medication Led Management

All service users and three of the five healthcare professionals reported pharmacology as a first line treatment for chronic pain. Despite the limitations of pharmacology in treating chronic pain, some healthcare professionals felt pressure to employ a medication-led approach with one GP acknowledging “*it’s probably the easiest thing to do but probably the least effective method of dealing with chronic pain*”. All healthcare professionals and service users reported a negative experience when pharmacology was not effective in treating chronic pain, often experienced at the individual level. For the service user this was described as “*I was made to feel guilty that I was failing the medication rather than the medication wasn’t working for me*” (Service User 4). While for the healthcare professionals there was a sense that “*you’ll reach the end of the road (prescribing) with those patients, and you feel that there’s nothing left for them*” (Neurologist). Although all healthcare professionals vocalised the importance of also adopting non-pharmacological therapies in pain treatment, service users universally reported a resistance by healthcare professionals to believe that non-pharmacological therapies such as modifications to lifestyle behaviours could have a positive impact on pain.

“When I started seeing an improvement and I was suggesting that it was me moving to a holistic approach, he didn’t believe me and thought it might have been the medication that I was on, but I had been on that medication for like 3 years at the time and nothing had happened until I started the different holistic things” (Service User 4)

A desire for a biopsychosocial model of care

All service users expressed a desire for care that was individualised and addressed all aspects of their health. This desire for a biopsychosocial model of care was exemplified by one service user who expressed their frustration at not having their values, experiences or personal context considered in their care plan suggesting a homogenous approach to care with the premise that *“I'm not sure if I was 20 years older if the treatment would be much different”* (Service User 6). Service users unanimously agreed there was a lack of attention given by healthcare professionals to individual psychological and social needs, leading to experiences of distress and frustration. In particular, service users described the suffering associated with receiving a diagnosis without any follow up care; *“I was told by my neurologist that I probably wouldn't walk or work again and was then sent off to deal with that information without any support.”* (Service User 4).

In spite of a predominantly medication-led management approach, healthcare professionals all acknowledged the importance of psychological and social support in pain management. A gap in psychological implementation was evident with four healthcare professionals highlighting the limited availability of psychologically trained professionals in their service and three healthcare professionals expressing concern relating to their professional capacity to support psychological wellbeing with the physiotherapist noting; *“you just don't know where the line is crossed within the threshold of my professional scope of practice”*. In this regard, all service users and healthcare professionals noted the need for a multidisciplinary team with expertise in pain management to support the implementation of a biopsychosocial model of care. The lack of provision was highlighted as a significant factor with MDT care not available in the private sector unless service users self-referred and individually paid for each service. Despite a reported presence of MDTs in the public sector there was agreement by healthcare professionals that they do not *‘exist in a meaningful way’* due to limited staffing and long waitlists.

4.4.2 Lost in a system

This theme ‘Lost in a system’ refers to the ambiguous experiences reported in navigating pain services and comprises two subthemes: ‘No clear pathway’ and ‘Accessibility’.

No clear pathway

All service users and four healthcare professionals described an unclear treatment pathway for chronic pain. For example, one service user described that *“I just didn't know where to go, what to do, who to believe”* (Service User 5). Interestingly, the metaphor of fog was utilised by both a service user and a service provider when speaking about treatment pathways, illustrating the confusion, uncertainty and unknowns present in relation to pain services. The physiotherapist described how she associated the lack of clarity of pain pathways to a treatment *“merry-go-round that the patients are constantly on”*.

Although one service user viewed their GP as the gatekeeper to coordinate their pain care, all other service users expressed a desire for an individual healthcare professional who showed leadership and direction in their pain care. One service user described how *“there's no overall sort of helicopter view of your problem”* (Service User 2). There was agreement between healthcare professionals that the available treatment pathways do not provide optimal standards of pain care, and that there was motivation for change despite ongoing resource limitations with the recognition that services had improved significantly in the last ten years *“We are not really there . . . but we are moving in the right direction for sure.”* (Pain Consultant)

Accessibility

Delayed access to MDT services due to waitlists and under-staffed services was noted by all healthcare professionals as a blockade to essential pain care. The GP expressed their frustration with access to services noting that *“we have no access to psychology and physio is similarly bad. Allied health professionals are much better at chronic pain than we are, but it's unfortunately left to us to deal with”*. Speed of access was reported as highly important by all healthcare professionals in the challenge of treating chronic pain. The neurologist, rheumatologist and pain consultant all described their services as being overwhelmed by the demands placed upon them and this impacted their ability to review patients in a timely manner. These accessibility issues, with participants reporting wait times of between 1-4 years, had significant impacts on the service user.

Increased support staff and new pain treatment algorithms were all proposed as solutions to more timely access to pain care. However, despite the best efforts of healthcare professionals, delays in recruitment and available funding affected their efforts to enhance service provision. This failure to expand services was illustrated by the pain consultant who spent

five years applying for funding for an advanced nurse practitioner to support their pain service before approval. Furthermore, all service users and healthcare professionals noted that access to pain treatment was only available in hospital settings reflecting a frustration with the lack of community-based resources, *“The HSE (Health Service Executive) has a responsibility to provide better access to resources within the community and trying to get these things out of the hospital” (GP)*.

All service users and four healthcare professionals expressed how the length of current appointment times *“10 minutes is not going to get you through an explanation” (GP)* affected the therapeutic relationship and was insufficient for meaningful conversations to support long-term engagement in self-management strategies. Simultaneously, service users sympathised with the pressures on healthcare professionals to ‘churn through’ a high number of appointments daily; *“For a consultant you probably have a 15-minute window to try and explain what has been going on for potentially 6-months and dancing all that into 15-minute slot it's just, it's not doable” (Service User 4)*. In contrast, enhanced satisfaction was reported where service users spent thirty minutes or more in appointments.

4.4.3 I need support

This theme highlights the fundamental requirement of support, the need for encouragement, empathy and assistance, desired by both service users and providers in navigating pain care. It is comprised of two subthemes ‘I can’t do it alone’ and ‘pain invalidation’.

I can’t do it alone

Reflecting a perception that they felt isolated, both service users and healthcare professionals reported a need for support to successfully navigate and implement pain services. The level of support desired by service users varied and was influenced by the frequency, severity and nature of pain. For example, there was agreement across service users that they could largely support themselves when pain levels were low but during flares of pain, they desired increased support from healthcare professionals.

“You need someone to take a look and say, okay, hang on here now you're struggling too much because you don't realise how far down that rabbit hole you're going” (Service User 7)

Support was seen by service users as a balance between being encouraged and pushed outside of their comfort zone. When service users felt well supported, they described that experience as ‘life changing’. Feeling supported was associated with being given hope for the future and feeling cared for but was not associated with resolution of pain symptoms. Despite the desire for support, most service users noted that their support needs were not met; *“You're on your own. Definitely. I would love to be in a room when someone said, that's not the case. I would challenge that heavily”* (Service User 1). Interestingly, three service users expressed a desire for pain support services to have the same visibility and access as cancer support services. They described a desire to have their hand held, to be provided with high levels of information, and to feel supported like other long-term conditions.

“With the cancer support services, it's there, where it really isn't there for pain you're given all this information and your hand held and you know, you're very well looked after, really supported environment, very supportive environment.” (Service User 7)

Healthcare professionals also expressed a feeling of isolation and a need for enhanced support for themselves to continue to provide pain care. Healthcare professionals described the experience of working in pain care as stressful, challenging and mentally exhausting. A number of healthcare professionals noted their distress at feeling inadequate in the service they provide, the physiotherapist described; *“I don't know if we are doing anything really well to be honest. I definitely think support for health professionals is needed”*.

Pain invalidation

All service users and three healthcare professionals reported experiencing invalidation of pain within health services. Service users described being told the pain was ‘in their head’ and ‘feeling like hypochondriacs’. One service user reported his disappointment at feeling dismissed and misunderstood; *‘half of them don't want to know and half of them don't seem to understand’* (Service User 6). Both the physiotherapist and rheumatologist also expressed concern at ongoing invalidation of chronic pain by their colleagues; *“there are always going to be people (clinicians) that don't believe it, won't accept it, won't acknowledge it”* (Rheumatologist). Both healthcare professionals recalled the negative impact on their clients when they interacted with healthcare professionals who invalidated the complexities and challenges associated with living with an invisible illness. Both healthcare professionals expressed hopelessness that these colleagues would move from a biomedical model of care to

considering the biopsychosocial needs of the person in pain noting *'it's probably a waste of resources trying to make them'*.

Service users reported that validation from healthcare professionals was heavily reliant on visible pain behaviours and expressions of low psychological wellbeing. One service user recalls the need to perform *'an act'* in order to receive adequate validation of their pain; *"You want to go in there and really look like you're in a very, very poor state, and they might do something. But if you walk in there, dressed, showered and upright, you're ticking the boxes."* Two healthcare professionals expressed surprise at the positive impact that resulted from talking with service users. The neurologist noted *"sometimes you spend an hour with them in clinic not doing anything just listening to them"*. These communication skills such as active listening were perceived as an important step for service users to *'feel believed'*. In contrast, many service users described how they were not listened to, or consulted, as exemplified by service user 4: *"he doesn't listen. He'll just fire questions until he gets some sort of an answer that he wants."* This experience of not feeling heard had a negative influence on service user experience.

4.4.4 The essentials to self-management

This theme highlighted the value that both service users and providers placed on self-management strategies in managing chronic pain. Developing self-management skills was associated with three subthemes *'Exercising autonomy'*, *'Expanding knowledge'* and *'Supported behaviour change techniques'*.

Exercising autonomy

Service users all agreed that their experience in health services improved when they developed the confidence to express their opinions and contribute to the decision-making process of their pain management. One service user described autonomy as *"trying to work out what would be the right solution for me as opposed to the clinician saying this is the right thing for you"*. Although four healthcare professionals described supporting service user autonomy, all service users had experienced paternalistic interactions where they did not feel supported to exercise autonomy by healthcare professionals with one service user recalling *"it was very difficult to kind of shift that relationship so that you are taking more control"*. Service users expressed distress, regret and frustration at the lost time where they perceived they had no control or input to their treatment plan with one service user expressing; *"Maybe*

I should have pushed a little bit more maybe gone somewhere else, you know I just took what he said was wrong with me and did what he said. (Service User 5). While the physiotherapist acknowledged the healthcare system can make it “*difficult for them to find their voice*” all other healthcare professionals noted the need for service users to take the lead, be proactive and demonstrate internal motivation in order to self-manage their care. Despite the desire for service user proactivity, one service user noted the significant challenge of exercising autonomy while consumed with high levels of pain, “*basically the legs had been kicked out from under me. So, I was just kind of going on along with whatever treatment plan.*” (Service User 4).

Service users associated autonomy support with feeling cared for by their healthcare professionals. Feeling cared for was dependent on the time taken to explain a diagnosis, the empathetic nature of the professional, their relatability, kindness, and honesty. Interestingly, service users did not report that feeling cared for was associated with the healthcare professional’s level of experience or ability to resolve the pain.

“He just cared about my quality of life, and he really wanted to in so far as possible, to have me back out there. And yeah, he showed that he cared, and he put himself out there to try and do anything that he could within his capacity.” (Service User 1)

Service users reported feeling a lack of care and understanding where the chronic pain condition was the focus of the clinical interactions. One service user identifies the dehumanising experience of being considered by their diagnosis and not as a whole person; “*I think they could read the lines on paper, but they just they didn't get what does that mean?*” (Service User 1).

Expanding knowledge

All participants expressed a desire for additional educational resources and pathways of care to enhance knowledge. All healthcare professionals reported the importance of pain education in clinical appointments and their priority in increasing service user’s knowledge. Only the physiotherapist and GP reported that time constraints may affect the success of education in current clinical practice describing their ability to deliver “*a snippet of education*” which by their reflection did not meet the needs of the person in pain. Despite healthcare professionals acknowledging the importance of knowledge, all service users had independently accessed

patient advocacy support groups online to enhance their knowledge of pain management and were frustrated at not being guided to these free resources by service providers. Service users attributed a lack of knowledge upon receiving a pain diagnosis as the primary reason that delayed them in exercising autonomy and developing self-management skills. One service user described the problem of ‘*unknown unknowns*’ expressing the significant challenge of advocating for oneself when there are significant gaps in your knowledge while another service user noted “*it takes a lot to try and find those resources when you're so low on energy*”.

Supported behaviour change techniques

Three healthcare professionals reported frustration at not having the ability ‘*to fix*’ chronic pain and therefore recognised the need to engage the service user in health behaviours that support self-management. All healthcare professionals admitted that despite initial guidance and early-stage education they could not provide long-term assistance nor were community resources available to support behaviour change techniques that would assist living with pain. Service users expressed a desire to be able to self-manage their symptoms and improve their quality of life and also highlighted the lack of available supports in the community to develop the required skills. Despite the joint agreement on the need for self-management a number of service users felt dismissed by their healthcare professionals and their efforts to engage in what they considered to be health behaviour changes such as lifestyle adaptations, conservative and holistic therapies. Service users described the process of developing self-management skills as an isolating experience that was primarily self-guided and involved a series of trial and errors. Despite the frustration at navigating the behaviour change techniques without the support of healthcare services, for many service users the eventual act of developing self-management skills was empowering, confidence building and provided a significant sense of achievement.

“I feel more capable of managing it now than I ever have and the improvements that I've seen since coming off medication and taking charge of the ownership of managing it has been huge.” (Service User 4)

4.5 Discussion

This study aimed to explore the lived experience of service users and providers participating in Irish healthcare services specifically focusing on autonomy support and self-management behaviours. Participants in this study described their experiences of pain services centred strongly on a biomedical care model where the primary focus is pain severity reduction using pharmacology and interventional pain medicine. This is despite evidence that improvements in pain and disability are recorded where pharmacological and interventional treatments are delivered in combination with physical, psychological, and behavioural therapies (Kamper et al., 2015). Although healthcare professionals acknowledged the need for non-pharmacological therapies, long waitlists, staff resources and a lack of multidisciplinary referral pathways obstructed a biopsychosocial model of care. Significantly, none of the service users in this study were referred to a PMP and only one service provider had access to refer to a PMP, demonstrating the limited access to PMPs in Ireland.

It is of concern that both service users and providers experienced invalidation of pain particularly where symptoms were not visible. The pain invalidation observed in this study corresponds with evidence that an absence of visible pain results in service users feeling stigmatised and receiving less empathy from healthcare professionals (Paul-Savoie et al., 2018; Walker et al., 1999). This finding of pain invalidation is surprising given the widespread knowledge that pain is a subjective experience and that a person's report of pain should be respected (Love-Jones, 2019). Interestingly, the desire for chronic pain to be approached with the same support as cancer services has been recorded previously and highlights the desire for increased visibility and acceptance of chronic pain as a diagnosis (Lavie-Ajayi et al., 2012).

Importantly, service users in this study expressed a desire for autonomy, competence in self-managing pain, and a preference for feeling cared for as a whole person, aligning with the three basic psychological needs of SDT (autonomy, competence, relatedness) (Ryan et al., 2008). Despite their reported desire to be autonomous when making decisions about their pain care, service users found that high pain levels, a lack of confidence and vulnerability while living with pain affected their ability to act autonomously, particularly early in their diagnosis. Service users expressed a need for significant support in achieving autonomy and competence in their pain care. The barriers to autonomy supportive healthcare that service users reported included controlling language, judgement of choices and limited appointment times all which have been reported previously (Kors et al., 2020). In comparison, service

providers agreed that appointment times affected service provision but also reported accessibility to allied health professionals and a lack of referral pathways in the community as further barriers. Importantly, insufficient time in appointments has been reported as a direct barrier to implementing the biopsychosocial approach (Ng et al., 2021).

Neither an early introduction to self-management skills nor direction to evidence informed resources were reported by service users despite service providers acknowledging the importance of education and resources. Service users described learning to advocate for themselves over time by self-educating and conducting their own research (Hopkins et al., 2022). Self-management development was therefore driven by service user's dissatisfaction with pain services rather than a treatment practice encouraged by healthcare professionals. Service users require support and shared decision-making practices to develop health behaviours, learn problem solving skills and engage in activities led by their individual values and goals (Gauntlett-Gilbert & Brook, 2018). Prior research advises that healthcare professionals have admitted their need for additional skills in supporting self-management to address the challenge of chronic pain (Hutting et al., 2020). The need for enhanced healthcare professionals support is reflected in our findings that service providers reported concern for their own wellbeing as well as concern of extending outside of their professional scope of practice in supporting service user's psychological health.

Ultimately the results of this study echo the pain management evidence-practice gap highlighted internationally (IASP, 2018). This study's results align with research that highlights the continued dominance of the biomedical model in pain care settings (Henning & Smith, 2023; Hopkins et al., 2022; Karstens et al., 2015; Macneela et al., 2010). The dominance of the biomedical model for chronic pain management is in direct contrast to clinical guidelines calling for a biopsychosocial model of care (Lin et al., 2020; Qaseem et al., 2017; *RACGP.*, 2024). The findings of this study echo previous research that a review of processes at macro (healthcare policy), meso (funding, resources) and microlevels (healthcare professionals factors) of health services is essential in order to deliver the desired biopsychosocial model (Ng et al., 2021).

There are a number of strengths and limitations to the above study. As a physiotherapist with experience in chronic pain services and personal experience of pain, I occupied a dual insider position that enhanced rapport and insight but also required reflexivity to manage potential bias. Service users who had long histories of chronic pain treatment and service providers

with experience in numerous healthcare settings were chosen for this study in an attempt to explore a rich variety of lived experiences of pain in Ireland, however service users were not direct patients of healthcare professionals accepted for the study impacting the comparison of experiences. Furthermore, healthcare professionals taking part in this study primarily worked in private health care services at the time of data collection, however it is noted that all healthcare professionals had completed medical training in public health settings and could detail experiences in both environments.

4.6 Conclusion:

The lived experience of pain by both service users and providers highlights a conflict between a desire for autonomy supportive environments that support self-management skills and the available resources to provide such experiences. An individual healthcare professional alone cannot resolve the concerns highlighted in this study; rather to support healthcare professionals a review of performance is needed at macro, meso and microlevels. At a microlevel service providers can improve the pain experience of service users by active listening, enforcing pain validation, supporting autonomy and providing educational resources promoting self-management early in clinical interactions. Further research is required to identify where pragmatic changes to services can be applied to enhance both service users and healthcare professionals experiences in Irish pain services

4.7 Link to Chapter 5

In Study 2 (Chapter 4), participants consistently described feeling disempowered within Irish healthcare services and highlighted a lack of choice and collaboration in treatment decisions, clear barriers to autonomy. Similarly, many participants stressed the importance of access to evidence-based resources and guidance from healthcare professionals, which could support them to feel more confident and capable in managing their condition. These results align with those of a systematic review of qualitative research applying SDT in chronic illness, which identified disempowerment and lack of control as barriers to autonomy and highlighted the role of information provision in supporting competence (Eassey et al., 2020). The convergence of these findings reinforces the relevance of SDT's core psychological needs, in chronic pain care, and suggests that these principles are especially important in the Irish context, where systemic and relational challenges may complicate patients' experiences of self-management. Moreover, our findings in Study 2 (Chapter 4) indicate that Irish healthcare professionals require additional support, both emotional and infrastructural, to effectively assist individuals living with chronic pain.

In the context of chronic pain, eHealth resources have been shown to support improvements in pain, disability, emotional wellbeing, and quality of life (Valentijn et al., 2022). Their potential lies in improving access to care and addressing gaps in service provision, particularly in low-resource settings (Slater et al., 2016). Consistent with the findings of Study 2 (Chapter 4), difficulty accessing self-management resources has also been identified among individuals living with fibromyalgia in Ireland. In that context, access to an eHealth resource designed to meet end users' needs demonstrated a statistically significant medium positive effect on pain self-efficacy, further highlighting the potential for eHealth to help fill service gaps in chronic pain care (O'Brien-Kelly, 2024). The development of context-specific eHealth resources may offer a valuable means of bridging the gap between clinical guidelines and everyday clinical practice. Such tools have the potential to empower individuals in pain to engage with self-management strategies, while also providing clinicians with trusted, evidence-based resources, particularly important in settings constrained by time and limited resources. Study 3 (Chapter 5) will describe the co-design of a novel eHealth self-management support resource, developed using mixed methods and guided by Public and Patient Involvement (PPI).

Chapter 5:

Healing and Empowering Lives with Pain (HELPP): A PPI-Driven, Theory-Based Digital Intervention Supporting Self-Management in Chronic Pain

Sheridan, K., O'Connor, S., O'Keeffe, S., Fildes F., Whyte, E. (Under Review) Healing and Empowering Lives in Pain (HELP): A PPI-Driven, Theory-Based Digital Intervention Supporting Self-Management in Chronic Pain. Submitted to PLOS Digital Health

5.1 Abstract:

Background; Digital health resources present an opportunity to expand chronic pain services in resource-limited contexts. This study involved the co-design of the HELP-Platform (Healing and Empowering Lives with Pain), a PPI-driven, theory-based digital resource to support self-management for adults living with chronic non-cancer pain.

Methods: A three-step approach was implemented with continuous public and patient input, including individuals living with chronic pain and healthcare professionals working in pain services. The Centre for eHealth and Wellbeing Research Roadmap 2.0 framework was implemented. Step 1 involved content design; Step 2, heuristic testing; and Step 3, usability testing.

Results: Eight key determinants of well-being in the context of chronic pain were identified and mapped onto a matrix of objectives, aligned with Self-Determination Theory and a behaviour change taxonomy. A prototype website was developed, with usability testing indicating excellent usability.

Conclusion: A user-centred, theory-based eHealth prototype has been developed to support self-management in individuals with chronic non-cancer pain. Further research is now needed to evaluate its feasibility, preliminary efficacy, and acceptability among both people living with pain and clinicians in pain services.

Patient and Public Contribution: The HELPP Public and Patient Involvement (PPI) group comprised of 14 people living with chronic pain. They all contributed to step 1, the content design, three contributed to step 2, heuristic evaluations while three contributed to step 3, usability testing.

Keywords: chronic pain, public patient involvement, eHealth, self-management

5.2 Introduction

Chronic pain occurs in approximately one in five European adults and one in three Irish adults (Breivik et al., 2006; Raftery et al., 2011). It affects a person's functional ability, mental health, and their capacity to engage in social activities and employment (Rometsch et al., 2025). As chronic pain impacts all aspects of a person's life, it requires a whole-person approach to care, one that integrates management strategies targeting the biological, psychological, and social dimensions of health (Gatchel et al., 2007; Ojala et al., 2015). Self-management is widely recognised as a fundamental component of effective chronic pain management (IASP, 2021; NHS, 2020). Barlow et al. (2002) define self-management as “*an individual's ability to manage the symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent in living with a chronic condition*” (Barlow et al., 2002, p178). For self-management to be impactful and sustainable, particularly in the context of chronic pain, it must be supported (Kerns et al., 2022). Supported self-management describes the collaborative approach formed between individuals living with pain and their healthcare providers whereby the person in pain is empowered to actively engage in coping strategies and lifestyle behaviours that meet the needs of their personal context, thereby enhancing quality of life (Rijken et al., 2008).

Self-management interventions have been shown to be impactful by improving pain and disability in conditions such as low back pain (Oliveira et al., 2012), arthritis (Du et al., 2011), and chronic widespread pain (Geraghty et al., 2021). Self-management interventions promote positive health behaviours by increasing self-efficacy, an individual's belief in their ability to successfully accomplish specific tasks (Damush et al., 2016). Despite these benefits, the long-term sustainability and clinical impact of self-management programs for chronic pain remains uncertain, largely due to the wide variation in intervention content, delivery methods and longitudinal evaluation (Elbers et al., 2018). Delayed introduction to self-management strategies by healthcare professionals, short appointment times and long waiting lists all hinder self-managements effective implementation in primary care settings (Gordon et al., 2017). Additionally, individuals living with pain often struggle to sustain motivation to engage in self-management techniques over time suggesting a need for booster sessions to provide ongoing support (Devan et al., 2018). Considering these barriers, innovative approaches to sustainably support evidence-based self-management strategies are required with eHealth interventions recently emerging as a promising and scalable alternative (Sivakumar et al., 2023).

The term eHealth refers to health services and information delivered or enhanced through the internet and related technologies (Eysenbach, 2001). Interventions delivered through eHealth platforms have been recognised as effective tools for promoting self-management in chronic conditions such as cardiovascular disease, type 2 diabetes, and chronic obstructive pulmonary disease (Renzi et al., 2022). The benefits of eHealth include its potential for scalability, accessibility for service users at home, cost-effectiveness, and its capacity to support healthcare services in low-resource settings (Rakers et al., 2023., Shaw et al., 2017). Both healthcare professionals and individuals living with chronic pain have indicated that eHealth has the potential to facilitate self-management support (Kelly et al., 2024a). Web-based programs designed to support individuals with chronic pain have been well received by both younger and older adult populations (De Lucia et al., 2024; Stinson et al., 2013). In order for eHealth interventions to be effective they must be trustworthy and evidence-based; and clinicians need to be aware of them (Sinclair et al., 2013; Whitfield, 2004) and confident in their safety (Devan et al., 2019c). From the patient's perspective there is a desire for eHealth resources that are credible, freely accessible, and easy to use (Wilson et al., 2025). For digital solutions to be truly effective and pragmatically delivered, they must be developed in ways that reflect the needs, values, and real-world contexts of those who will use them and recommend them (Melles et al., 2021).

One of the goals of the recent European pain research strategy is to reduce research waste, with PPI recognised as a key approach to achieving this within health and social care (Pickering et al., 2024; Minogue et al., 2018). Co-design is a participatory method that operationalises the principles of PPI by actively engaging service users in the creation of health interventions, ensuring that solutions are grounded in lived experience and aligned with user needs (Zogas et al., 2024). Co-design is considered a fundamental requirement in order to deliver patient-centred care, however, PPI is rarely involved in the early design stages of digital health innovations (Baines et al., 2022). Despite the promise of eHealth, just 22% of eHealth chronic pain interventions employ meaningful patient involvement in their design (Kelly et al., 2022) The development of the HELP-Platform (Healing and Empowering Lives in Pain), a PPI-driven, theory-based digital resource to support self-management for adults living with chronic pain, plans to address these limitations by integrating behaviour change theory, clinician input, and the lived experience through a participatory co-design process. This paper presents the systematic development and usability testing of the HELP-Platform. We hypothesise that this collaborative, user-centred design

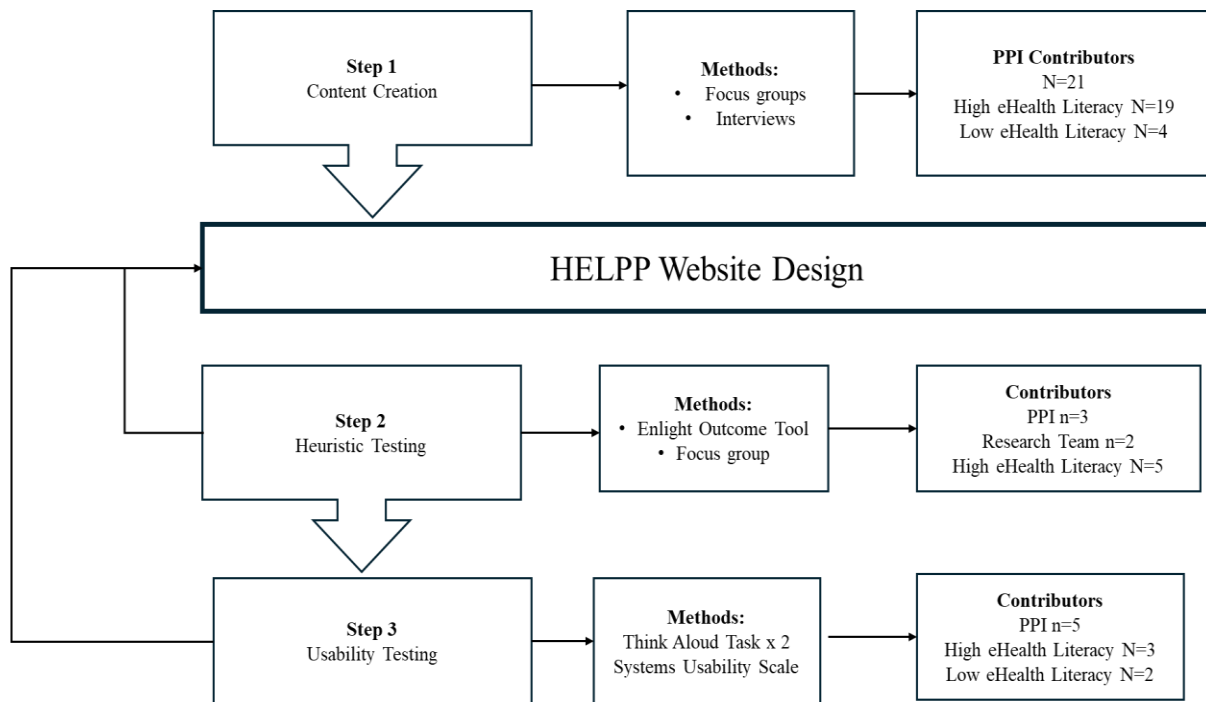
will enhance the acceptability, usability, and clarity of the intervention for both patients and healthcare providers.

5.3 Methods:

5.3.1 Design

This study adopted a multi-method approach to design an eHealth resource involving three steps (Figure 1). The CeHRes (Centre for eHealth and Wellbeing Research) Roadmap 2.0 framework was implemented to ensure the eHealth resource was user-centred and aligned with the contextual needs of its end users (Kip et al., 2025). This study focused specifically on the first three phases of the roadmap, which pertain explicitly to the development of an eHealth resource. The three steps were informed by 1) an iterative co-design approach applied to chronic musculoskeletal conditions (Kelly et al., 2023) and 2) preliminary research (Sheridan et al., 2024; Sheridan et al., under review). PPI, a fundamental element of this project, was integrated at each of the three steps ensuring that the research remained aligned with the genuine needs and experiences of those it aimed to serve. The Guidance for Reporting Involvement of Patients and the Public (GRIPP2-SF)(Appendix C.1) a reporting tool to improve reporting of patient and public involvement in research has been implemented to ensure the clear reporting of PPI throughout the study (Staniszewska et al., 2017). Ethical approval was granted by Dublin City University research ethics committee (DCUREC/2024/152).

Figure 5.1. Summary of the HELPP Intervention development



PPI (Public, Patient Involvement)

5.3.2 PPI Recruitment

This study employed strategic PPI recruitment to include individuals with chronic pain from diverse groups based on gender and digital literacy. PPI were recruited by advertising in three areas a) hospital pain management department in North Dublin - posters were hung in the pain department and clinical psychology staff provided individuals with the patient information sheet on request, b) the community - an email advertisement was sent through one higher education institution's Age Friendly University mail list in the catchment area of the North Dublin Hospital, c) PPI Ignite network - advertisements were listed on the opportunities network board, an online platform hosted by the PPI Ignite Network to connect Irish researchers with members of the public and patients who are interested in participating in research.

Recruited PPI participants were required to be over 18 years, English speaking, able to provide electronic or written consent and experiencing self-reported chronic non-cancer pain

of any diagnosis (pain > 3 months in duration). Recognising the importance of Equality, Diversity, and Inclusion (EDI) in recruitment, the research team screened all prospective PPI members to ensure representation across gender and varying levels of eHealth literacy. Prospective PPI members completed an online survey asking 1) demographic details, and 2) the eHealth Literacy Scale (eHEALS) (Norman & Skinner 2006a) (Appendix C.2). As a greater proportion of women (62%) report experiencing chronic pain compared to men (Bimpong et al., 2022), a recruitment strategy aiming for a minimum of 60% female participation in each stage of the codesign process was applied. Each design step was also made up of a combination of individuals with low (eHEALS score <26) and high eHealth literacy (eHEALS score >26) (Richtering et al., 2017). Following this approach, PPI contributors living with chronic pain were recruited from both the community (n=12) and local hospital pain services (n=2). Clinician contributors (n=7) included, 2 clinical psychologists, 2 nurses, 1 physiotherapist, 1 consultant and 1 fellow in pain medicine, all of whom worked as part of a single Multidisciplinary Team (MDT) pain service. Plain language statements and online consent forms provided to all potential PPI contributors prior to the commencement of data collection (Appendix C.3, C.4).

5.3.3 Theoretical Underpinning

This study utilised an a priori theoretical framework, drawing on SDT to guide the development of the intervention content. SDT is considered a useful framework for theory-informed research and evaluation in primary care and its potential impact in the development and evaluation of complex interventions has been noted (Huang et al., 2022). To translate theoretical principles into practical design elements, we drew on two established taxonomies aligned with SDT and self-management to guide behaviour change strategies; the SDT taxonomy (Gillison et al., 2019) and the Practical reviews in self-management support taxonomy (Pearce et al., 2016).

5.3.4 Stepwise Development of the HELPP Intervention

Step 1: Content Creation and Value Specification

Focus groups were facilitated by the primary author and attended by both PPI contributors (n=14) and healthcare professionals working in secondary pain services (n=7). A pre-established question guide was used to flexibly guide focus group discussions on the benefits and challenges of online resources, current use of online resources and desired content for a new pain resource (Appendix C.5). Focus groups were chosen to encourage sharing of information and group brainstorming (Then et al., 2014) and involved a maximum of four participants per group (Dilorio et al., 1994). Separate focus groups were purposely held for healthcare professionals and PPI contributors, which enabled the researchers to gather in-depth insights specific to each group's experiences and preferences (Wilson et al., 2025). Focus groups were conducted online (Zoom Video Communications Inc., San Jose, California) offering logistical benefits, such as avoiding the challenge of travelling with chronic pain for focus group attendees (Archibald et al., 2019). When attendance at a focus group was not possible due to scheduling conflicts, individual interviews were offered to support the inclusion of all contributors. Focus groups and interviews averaged 52 ± 14 minutes (range 37-86 minutes). Audio recordings were transcribed and analysed.

A descriptive synthesis was conducted using NVivo to identify the key determinants of effective self-management. The topics identified in the focus groups and interviews were translated into determinants for the HELP-Platform. Determinants were defined as what stakeholders reported as important regarding the eHealth resource from their personal or professional perspective (Kip et al., 2025). PPI contributors living with chronic pain next completed a post-interview ranking task via an online questionnaire, selecting the determinants they believed would best support their ability to self-manage chronic pain from a scale of 1-8 (with 1 meaning most valued and 8 least valued). The resulting ranking data were analysed by calculating the total score for each item, derived from the sum of individual participant rankings, with lower total scores indicating higher perceived importance. Next a matrix of objectives was developed to inform the creation of the online resource. The intervention content was mapped onto this matrix, which guided the overall design.

Step 2: Heuristic Testing

Enlight Tool

A panel of five reviewers, including two researchers and three PPI who contributed in stage 1, utilised the Enlight tool (Baumel et al., 2017) to complete heuristic testing of the HELP-Platform prototype (Appendix C.6). The tool has demonstrated excellent interrater reliability, good internal consistency and preliminary concurrent validity (Baumel et al., 2017). Enlight is used to evaluate the quality of eHealth interventions and is made up of three sections, 1. Classification (classifying the program based on acknowledged categories), 2. Quality assessment (usability, visual design, user engagement, content, therapeutic persuasiveness, therapeutic alliance and general program potential) and 3. Checklists (credibility, privacy explanation, basic security, and evidence-based program ranking). Given the HELP-Platform digital intervention was at development stage, section 3 (the checklist) was not completed as it was not applicable to this study. Of the seven domains in Section 2, Quality Assessment (usability, visual design, user engagement, content, therapeutic persuasiveness, therapeutic alliance, and general subjective evaluation) each comprises 5–6 items rated on a 5-point Likert scale (1 = very poor to 5 = very good), with higher scores indicating superior quality. A total score between 3 and 5 for an eHealth resource indicates a ‘fair to good’ potential benefit for its target audience (Mindtools.io, 2023). Following completion of the Enlight tool, a reviewers panel meeting was held on Zoom (37 minutes duration), where the outcomes were discussed and areas of revision were identified prior to progression to step 3.

Step 3: Usability Testing

Think Aloud Assessment

The goal of this stage was to identify any usability problems by end-users and gather detailed information on recommended points of improvement. Assessment of the prototype was completed using mixed-method usability testing. A panel of five (3 PPI contributors and 2 Clinical Psychologists - all previously involved in step 1 - content creation but not step 2 - heuristic testing) completed this final step. This sample was chosen as a sample of five test subjects has been shown to identify up to 85% of usability issues (Nielsen, 1994). Upon arrival, the primary author provided individuals with an instruction leaflet (Appendix C.7), after which she assumed the role of a non-participant observer, systematically recording field notes to capture the perspectives and experiences of the PPI contributors. PPI contributors

were asked to complete two set tasks on the online resource and to verbalise their thoughts, feelings and opinions while completing the task, thus providing insights into the cognitive process of users (Güss, 2018). The tasks included a) seeking text or video information on how someone living with chronic pain could improve their physical activity levels and b) finding a web link to extra resources that support physical health. After completing the specified task, contributors were invited to explore the website at their own pace while thinking aloud. All think-aloud sessions were completed in-person and averaged 53 ± 3 minutes (range 48-67 minutes). Audio recordings of the think-aloud sessions were also captured via Zoom to allow the primary author to review their field notes in conjunction with the participants' verbal feedback and interactions during the sessions.

The Systems Usability Scale

The Systems Usability Scale (SUS) was completed by each reviewer immediately following the think-aloud session. The SUS is a 10-item questionnaire, presenting statements such as 'I found the system unnecessarily complex' and 'I thought the system was easy to use', where each question is scored on a five-point Likert scale of "Strongly Disagree" to "Strongly Agree" (Brooke, 1996) (Appendix C.8). The SUS is scored on a scale of 0 to 100, with 100 representing a perfect usability score. Throughout the iterative process, the HELP-Platform was updated (following steps 2 and 3) based on evaluations by PPI contributors, clinicians, and the research team.

5.4 Results

Step 1: Content Creation and Value Specification

PPI contributors (n=14) were recruited (62.0 ± 5.9 years of age with 28.0 ± 16.8 years' experience of pain). Table 1 details the PPI attendees of each workshop.

Table 5.1 PPI Demographics

Focus Group/ Interview	Gender	Age	Years of Pain	Attendees	Health Literacy*
1.	Male	75	1	Chronic Back Pain	High
	Male	59	30	Crohn's Disease & Arthritis	High
	Male	61	44	Crohn's Disease	High
2.	Female	63	30	Chronic Back Pain	High
	Female	65	51	Chronic Back Pain	High
	Female	70	35	Pelvic Pain	Low
3.	Female	67	20	Rheumatoid Arthritis & Fibromyalgia	Low
	Female	60	20	Fibromyalgia	Low
	Female	63	5	Psoriatic arthritis and Fibromyalgia	High
	Female	66	20	Fibromyalgia	High
4.	Female	56	10	Arthritis, Migraine, Fibromyalgia	High
5.	Female	59	42	Ankylosing spondylitis, spondyloarthritis and psoriatic arthritis	High
6.	Female	57	57	Scoliosis, Spina Bifida, Pancreatitis	Low
7.	Male	53	23	Ankylosing Spondylitis	High

*Scored according to the eHEALS Health Literacy Scale (Richtering et al., 2017) (high = >26 low = <26)

Table 5.2 Multidisciplinary Team Demographics

Focus Group/ Interview	Gender	Years of Experience	Attendees
1.	Female Female Female	13 23 24	Clinical Psychologist Physiotherapist Advanced Nurse Practitioner
2.	Female Male Male	12 NK 12	Clinical Psychologist Consultant in Pain Management Senior Staff Nurse
3.	Male	15	Pain Fellow

NK (Not Known)

Eight determinants of wellbeing in the context of chronic pain (Table 3) were identified (full details from focus groups and interviews are available in Appendix C.9. All 14 PPI contributors participated in the post-interview ranking task, selecting the factors they believed would most effectively support them in self-managing their pain. Ten of the PPI contributors ranked 'The Challenge of Living with Pain' as their number one determinant, indicating a strong desire for validation and information that acknowledges the suffering associated with living with an invisible illness. Table 4 reports each determinant in the order of ranking by PPI. Table 5 presents the matrix of objectives guiding the intervention design, including the mapping of both SDT components and the PRISMS taxonomy, while Table 6 provides further detail on the behaviour change taxonomies relative to the SDT components of autonomy, competence, and relatedness.

Digital Platform Design and Build

The HELP Platform was developed using the Squarespace web-hosting service, following the purchase of relevant domain names (HELP-Platform.eu and related domains). The website was designed to provide a user-friendly and visually accessible interface. Individual pages were created to correspond with each determinant of self-management, incorporating a combination of multimedia resources, including embedded videos, explanatory text, and signposting activities linking to credible external materials (e.g., EFIC, HSE resources, and other international research-based pain education resources). In addition, eight original three-minute educational videos were created, based on topics identified through public and patient involvement (PPI) in Stages 1 and 2, to ensure relevance and engagement.

Table 5.3 Determinant Definitions

Determinant	Definition
The challenges of living with chronic pain	This section will focus on validating your experience with pain by detailing the many challenges of living with an invisible illness, including how it affects both our mind and body, our identity and can lead to isolation and suffering
Pain science	This section will provide information on how pain affects different systems in our body, and an overview of the biology of chronic pain
Your role in managing pain	This section will detail the skills and knowledge that will help support you to live well with your pain
Physical activity	This section will cover topics such as pacing, and how to exercise well with pain
Psychological wellbeing	This section will cover the impact of pain on psychological health as well as techniques to overcome psychological challenges associated with pain
How to engage in society/ maintain an active social life	This section will highlight the risk of pain in causing feelings of isolation and offer suggestions to overcome the isolation of pain and maintain an engaging and enjoyable social life
Navigating the healthcare system	This section will cover how to prepare for appointments, how to find the right team for you and how to communicate your needs to your healthcare professionals
Research dissemination	This section will take up to date research and summarise it in easy-to-understand language so that you can easily understand the latest research relating to pain.

Table 5.4 Ranking of Determinants by PPI (n=14)

Ranking by PPI	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12	P13	P14	Total Score
The challenge of living with chronic pain	1	1	1	1	1	2	4	2	3	1	2	1	4	7	31
Your role	2	2	1	3	3	4	5	6	4	4	4	2	1	2	43
Psychological Wellbeing	5	3	2	7	5	5	1	4	1	5	6	5	2	4	55
Physical Activity	4	5	1	4	4	3	3	5	6	3	5	3	7	3	56
Pain Science	3	7	2	2	2	1	7	8	5	2	3	6	8	1	57
Social Factors	6	4	2	5	6	6	2	7	7	6	7	4	5	6	73
Navigating the Healthcare System	7	6	1	6	7	7	8	3	8	7	1	7	3	8	79
Research Dissemination	8	8	2	8	8	8	6	1	2	8	8	8	6	5	86

PPI (Public Patient Involvement), P (Person)

Table 5.5 Matrix of objectives guiding intervention design

Determinants	Details of determinants	Learning objective	Theoretical framework SDT	Practical reviews in self-management support taxonomy (Pearce et al., 2016)
1. The challenge of living with chronic pain	Validate the multidimensional experience of pain and its effects on the whole person. <ul style="list-style-type: none"> • Stigma • Isolation • Blame • Guilt 	Increase understanding and validation of the lived experience of pain and promote self-compassion.	Relatedness – reducing isolation by supporting a sense of belonging and cared for	A1. Information about condition and /or its management A2. Information about available resources
2. Your role in pain management	An introduction to self-management strategies by learn effective coping skills and making life bigger. <ul style="list-style-type: none"> • Empowerment • Managing flares • Advocating for self • Building confidence 	Empower individuals to take an active role in managing their pain and life choices	Autonomy – self-directed care; Competence – building confidence;	A11. Training/ rehearsal for practical self-management activities A14. Lifestyle advice and support
3. Psychological wellbeing	Understand the emotional impact of pain and introduce management strategies to support psychological health. <ul style="list-style-type: none"> • Knowledge of psychological disorders associated with pain 	Build emotional and cognitive awareness and equip individuals with coping mechanisms to improve mental health	Autonomy – choice in strategies; Competence – skill-building in psychological management strategies; Relatedness – support	A1. Information about condition and /or its management A2. Information about available resources

	<ul style="list-style-type: none"> • Where to get help • Self-treatment and professional help strategies 		networks for ongoing professional support	<p>A12. Training/ rehearsal for psychological strategies</p> <p>A8. Provision of easy access to advice or support when needed</p>
4. Physical wellbeing	<p>Understand the physical impact of pain and introduce strategies to support physical health.</p> <ul style="list-style-type: none"> • Knowledge of exercise therapies • Avoid comorbidities • Community program awareness 	Promote physical activity and understanding of safe movement and body awareness.	<p>Autonomy – choosing activity levels and meaningful activity</p> <p>Competence – skill-building in using physical activity to maintain health and reach physical activity guidelines</p> <p>Relatedness – support through group/community exercise options</p>	<p>A1. Information about condition and /or its management</p> <p>A2. Information about available resources</p> <p>A14. Lifestyle advice and support</p>
5. Pain science	Understanding pain science and how pain effects multiple systems in the body	Provide a foundational understanding of the science behind pain to reduce fear and misconceptions	Competence – understanding the role of neuroscience and pain;	<p>A1. Information about condition and /or its management</p> <p>A2. Information about available resources</p>
6. Social wellbeing	<p>Understand the social impact of pain and introduce strategies to maintain social connection and support.</p> <ul style="list-style-type: none"> • Knowledge of social impact • Community programs 	Promote social connection and reduce isolation through support and community awareness	<p>Relatedness – social inclusion, support through community programs;</p> <p>Autonomy – choosing meaningful social engagements</p>	<p>A2. Information about available resources</p> <p>A14. Lifestyle advice and support</p>
7. Navigating the healthcare system	Understanding the infrastructure of pain management services and the impact of health literacy.	Equip users with the knowledge to confidently access and engage with healthcare systems	<p>Autonomy – directing care choices;</p> <p>Competence – system navigation and advocacy skills</p>	A9. Training/rehearsal to communicate with health-care professionals

8. Research dissemination	Access to up-to-date research through dissemination of published articles, podcasts and books	Improve understanding of evidence-based approaches and increase user engagement with evolving knowledge	Competence – staying informed; Autonomy – choosing what resources to engage with	A2. Information about available resources
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Table 5.6 SDT-Based Strategies Supporting Autonomy, Competence, and Relatedness across the HELP-Platform

Principles of SDT	SDT Taxonomy
Autonomy	SDT1:Choice SDT3:Provide a rationale SDT4:Use of non-controlling language SDT7:Emphasise responsibility
Competence	SDT13.Provide information SDT14.Barrier identification SDT15:Provide support and encouragement
Relatedness	SDT17.Encourage social support seeking

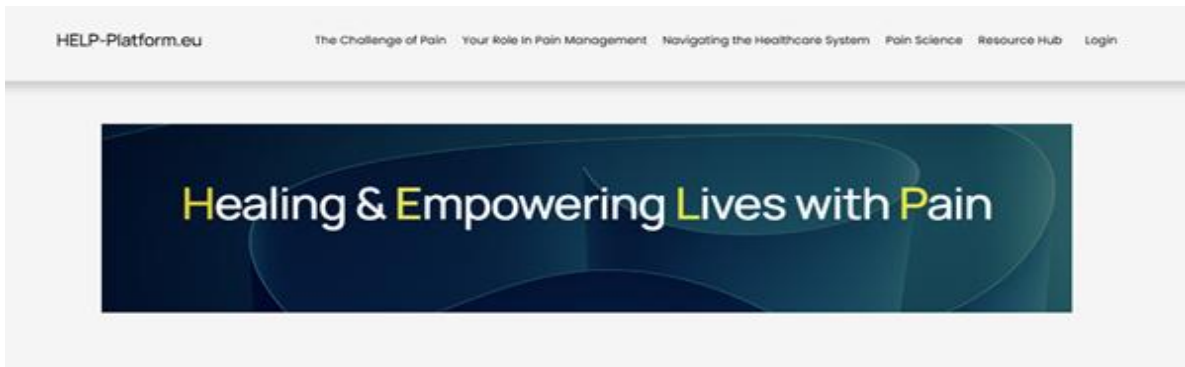


Figure 5.2 Example of HELP-Platform (See more images in Appendix C.10)

Step 2 Heuristic Testing Results

The average Enlight ratings of the five reviewers were used to calculate a score for each of the seven domains (Table 7). Using the Enlight formula, the total quality score for the HELP-Platform was 3.1, indicating a ‘fair’ result (Mindtools.io, 2023). The resource was cited as clear, welcoming, and thoughtfully structured, but some users felt it could be more interactive and layered, especially for people at different stages of their pain journey. A full overview of the feedback received is available in Appendix C.11.

Table 5.7 Results of ENLIGHT Assessment Tool

Reviewer	Usability Score	Visual Design Score	User Engagement Score	Content Score	Therapeutic Persuasiveness	Therapeutic Alliance Score	General Subjective Evaluation Score	Total Quality Score*
PPI 1	4.3	4	3	3.75	2.2	4	3.6	2.8
PPI 2	4	4.3	4	4	2.4	4	3	3.1
PPI 3	4.3	4.3	3.8	4.5	1.7	3.3	3.3	2.7
R 1	4.3	4.3	3.8	4.5	3	4.6	4	3.6
R 2	4.6	3.6	4	4.75	2.1	3.6	5	3.1
Mean	4.3	4.1	3.8	4.3	2.3	3.9	3.8	3.1

PPI = Public Patient Involvement, R =Researcher, *ENLIGHT Quality Score = If Usability ≥ 3 and Visual Design ≥ 3 and Content ≥ 3 , then Quality Score = $(3*TP+1*Content + 1*UE + 0.5*TA)/5.5$

Step 3 Usability Testing

There was a 100% task success rate for both activity tasks (sourcing information on physical activity while living with pain & sourcing links to exercise programs to support practical engagement in exercise). The average time to completion was 6.2 ± 2.2 minutes (range 4-9). Common feedback included an overload of text on some educational pages and a lack of text to link text to videos. Participants valued the inclusion of lived experience on each page, noting that the quotes were relatable and added a sense of authenticity. They also appreciated the overall tone of the site including the ‘warm’ and ‘friendly’ delivery of the messages. The inclusion of the word *hope* was particularly significant, with all three PPI contributors commenting specifically on its impact. One contributor became visibly emotional, emphasising how powerful and important it was to convey this message. When exploring the wider website after completing the task, all three PPI contributors discovered new pain self-management resources they had not previously encountered. The quotes below illustrate some of the key findings from the PPI 'think aloud' sessions focusing on content. Full feedback is available in Appendix C.12.

“There’s hope here. It doesn’t feel like it’s telling you what to do, it’s showing you options.” (Darren – pseudonym)

“I didn’t even know these resources existed. If my GP had given me this at diagnosis, I’d have had a better start.” (Jenny – pseudonym)

The SUS results are detailed in Table 8. The mean score was 96.5 ± 7.8 , which is interpreted as an excellent usability rating (Bangor et al., 2009). All five assessors rated their likelihood of recommending the website highly, with scores of 9, 10, 10, 10, and 10 on a 0–10 scale (0 = not at all likely, 10 = extremely likely).

Table 5.8 Results of the SUS (N=5)

Statement	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
I think I would like to use this tool frequently.					5
I found the tool unnecessarily complex.	5				
I thought the tool was easy to use.				1	4
I think that I would need the support of a technical person to be able to use this system.	5				
I found the various functions in this tool were well integrated.				1	4
I thought there was too much inconsistency in this tool.	4	1			
I would imagine that most people would learn to use this tool very quickly.				1	4
I found the tool very cumbersome to use.	4	1			
I felt very confident using the tool.				1	4
I needed to learn a lot of things before I could get along with this tool.	5				

4. Discussion:

This study details the formation of the HELP-Platform, an eHealth resource designed to support self-management behaviours in individuals living with chronic pain. Informed by the first three phases of the evidence based CeHRes Roadmap 2.0 (contextual enquiry, value specification and design) (Kip et al., 2025), this new eHealth resource combines the input of persons living with pain, clinicians working in pain services and behaviour change theory. Adopting a user-centred design and a bottom-up approach, it is hypothesised that this design method may result in enhanced usability, acceptability and greater improvements on outcomes than conventional top-down approaches (Altman et al., 2018). This is particularly important given that healthcare resources that fail to meet the contextual needs of end-users are more likely to remain unused (Robertson et al., 2024). In Ireland, adults with chronic non-cancer pain face a chronic shortage of publicly funded resources, with just five multidisciplinary pain teams available to meet high clinical demand (Purcell et al., 2022). This limited-service provision highlights a significant gap in care, underscoring the potential value of an eHealth resource to support individuals in managing their pain condition.

The aim of the HELP-Platform is to empower individuals living with pain by prompting behaviour change through knowledge and action. In the context of chronic disease, eHealth has been shown to positively impact end users by increasing knowledge, enhancing perceived support, and improving behavioural outcomes (Murray et al., 2005). The concept of eHealth literacy refers to an individual's ability to locate, appraise, and understand health information from electronic sources to manage a health-related issue (Norman & Skinner, 2006b). Designing eHealth services to be accessible to individuals with low literacy levels should be a priority (Kim & Xie, 2017). By including PPI contributors with both high and low levels of eHealth literacy, we aimed to design a resource that meets the needs of diverse cohorts.

The involvement of PPI at each stage of the development process was central to designing a resource that reflects the needs of end users and fosters relevance and authenticity, a strategy increasingly used in chronic pain eHealth self-management programs (Marier-Deschenes et al., 2024). Outcomes of both the heuristic testing and the usability testing provided positive feedback relating to the inclusion of PPI quotes on each page of the website. Peer support plays an important role in self-management and has been deemed as valuable as professionally delivered support (Stenberg et al., 2022). Although participants expressed an interest in incorporating a peer support forum or interactive peer component into the resource, current funding constraints prevent this from being implemented at this stage.

The prototype is designed to facilitate self-management support by introducing knowledge on self-management strategies, recommending actions to begin these strategies, and offering a centralized location for evidence-based pain resources for individuals living with pain. A centralized platform that provides easy access to pain-related information is crucial, rather than having such information dispersed across the internet (Wilson et al., 2025). Despite an average of 28 years of lived experience with pain, all PPI reported discovering new resources or links from their interaction with the HELP-Platform that they were previously unfamiliar with. This suggests that, based on the experiences of our PPI group, online pain support resources can be difficult to locate, further emphasizing the importance of a centralized point of access. Overall, the PPI contributors helped ensure the content was relevant, practical, and reflective of real-world challenges faced by people living with chronic pain in an urban community setting in Ireland.

Of the 8 identified determinants, 'The challenge of living with pain' was ranked as the most valued with 10 of the 14 PPI contributors voting it most important. The challenges associated with living with pain were identified as a central discussion point across all focus groups and interviews in Step 1 (content creation). PPI contributors expressed their desire for validation and for information that acknowledges the suffering associated with living with an invisible illness. The importance of validating the distress associated with chronic pain is powerfully captured by Joletta Belton: '*Once my pain was validated, once I, as a human being, was validated, it opened up capacity to take on new information. I could finally begin to think again, to plan, to remember, to act on what I'd learned.*' (Belton et al., 2022, p4). It is proposed that individuals living with pain need specific reassurance to engage in self-management, as reflected in the addition of a validation component to the reassurance model (Belton et al., 2022; Braeuninger-Weimer et al., 2019). Our findings, along with those of Belton et al. (2022) and Braeuninger-Weimer et al. (2019), align with previous research highlighting the importance of affirming a person's experience of pain in order to support them to move forward (Toye et al., 2013).

The Enlight Quality Assessment tool scored well (>3.5) on all components except for 'Therapeutic Persuasiveness' which was rated as poor (2.3). These findings are consistent with other chronic pain resources, which highlight the challenge of achieving high scores in therapeutic persuasiveness on eHealth resources (Sirohi et al., 2024). It is important to address therapeutic persuasiveness as it correlates with real-world usage of internet-based health resources (Baumel & Kane, 2018). However, in this current study, website elements such as user rewards, feedback, and data-driven interactions, which could potentially enhance therapeutic persuasiveness, were not possible to include due to funding limitations. Future iterations would benefit from their inclusion as funding

allows. Despite this, the SUS results showed an excellent usability rating, with each of the PPI assessors in step 3 reporting that was extremely likely that they would recommend the website.

The co-design of the HELP-Platform has resulted in an intervention that employs diverse viewpoints and practical solutions that are fit for purpose. However, the HELP-Platform's feasibility, acceptability, and preliminary efficacy have yet to be established. Future studies should evaluate the clinical efficacy of the intervention when implemented as part of a blended care approach for individuals with chronic pain attending secondary pain services, where it serves as an adjunct to self-management support. Blended care allows for additional support to implement behaviour changes in a personalised context (Poolman et al., 2024). Physiotherapists in primary care reported that introducing an eHealth intervention through a blended care model supported them in delivering a biopsychosocial approach, helping to move away from their bias towards a biomedical model of care (Bijker et al., 2022). While research appears to support the benefits of a blended care approach, it is important to also investigate the potential efficacy of standalone eHealth interventions in contexts where healthcare resources limit the implementation of blended model. Specific to an Irish context where secondary health services promoting supported self-management are limited, the HELP-Platform efficacy should be assessed in both a blended approach, in secondary specialised pain services and amongst primary care settings where there is no access to specialised pain services. It is hoped the resource will reduce burden on healthcare professionals, while also delivering an improved care plan to support the person living with pain.

Larger effects on behaviour change have been recorded when eHealth resources incorporate behavioural theories (Webb et al., 2010). The application of SDT was well-suited to this study, aligning with PPI contributors' expressed need for validation and reflecting the theory's emphasis on relatedness, promoting acceptance, connection and a sense of belonging. A strength of this study is the application of two behaviour change taxonomies which enabled a more systematic design and reporting of active intervention components (Michie et al., 2015). On completion of the HELP-Platform prototype, we applied 6 of the 19 SDT taxonomy components and 8 of the 14 PRISMS taxonomy. According to Gillison et al., (2019), there is no evidence that increasing the number of SDT related taxonomy components will result in more significant outcomes. This view is echoed by Pearce et al. (2016), who emphasised the importance of incorporating several, but not necessarily all, components within interventions.

While the development of this resource with PPI offers several strengths, it is important to acknowledge certain limitations that may have influenced its design, implementation, and overall impact. Despite efforts to include PPI contributors with low eHealth literacy, we acknowledge that the screening method used may not have been appropriate for individuals with extremely low

literacy skills or no internet access, thereby limiting inclusivity. The age profile of PPI contributors was 62.0 ± 5.9 years, and although recruitment was attempted through three different environments, hospital, community, and a PPI network, the community-based strategy proved most successful. As this resource has not yet received input from younger individuals living with pain, future development should involve both younger and middle-aged adults to ensure the platform meets their contextual needs. On reflection, an opportunity to conduct a second round of recruitment specifically aimed at including younger participants would have been favourable, however, time constraints during the project limited the opportunity. While the older age profile may limit transferability, we view the average duration of living with pain among contributors (28.0 ± 16.8 years) as a strength, as it reflects deep lived experiences of chronic pain in Ireland. Finally, in Step 1, content creation and value specification, clinicians and PPI contributors were placed in separate focus groups. While homogenous focus groups offer certain benefits, combining both stakeholder groups may have enhanced data richness, as suggested by Then et al. (2014).

5. Conclusion

The HELP-Platform is a digital self-management resource for chronic pain, designed to empower individuals through structured education, behaviour change support, and strategies that support autonomy and competence, while also fostering a sense of relatedness. Due to the inclusion of PPI at each design stage, it prioritises the voice of those with a rich lived experience of pain. The dual emphasis on experiential insight and theoretical rigour positions the HELP-Platform as a promising, evidence-informed tool with the potential to improve self-management outcomes and guide future eHealth interventions in chronic pain care. To explore its practical implications the feasibility, acceptability, and preliminary efficacy of the HELP-Platform now needs to be tested in a real-world clinical environment.

The HELP-Platform can be viewed in full at www.HELP-Platform.eu

Chapter 6:
Thesis Summary and Conclusion

6. Discussion

This thesis aimed to explore the lived experiences and support needs of individuals living with chronic pain in Ireland in order to inform the development of a supported self-management intervention. Worldwide chronic pain is a complex, under resourced public health issue with significant socioeconomic consequences and Ireland is no exception. Through a mixed method approach, combining quantitative, qualitative and co-design methodologies, this research contributes to both the academic and practical understandings of how self-management support is experienced and delivered by individuals navigating the Irish health system. In line with the recently published European Pain Research Strategy, this thesis addresses Theme 6: *Incorporating the patient voice into research*, and Theme 9: *Improving the translation and implementation of best evidence*, closing the gap between scientific research and its real-world application to enhance public and patient knowledge (Pickering et al., 2025). The following section critically interprets the main findings of this thesis collectively and discusses the implications of this research in relation to: 1) the existing literature, 2) its impact on Irish pain services, and 3) its influence on my development as a practitioner.

6.1 Implications to literature

6.1.1 The Lived Experience of Pain

It is challenging to contextualise the findings of this thesis due to the limited research exploring the lived experiences of individuals accessing pain services in Ireland. To our knowledge, no Irish-based studies have specifically examined how autonomy support or supported self-management are experienced or implemented within chronic pain services through the perspective of individuals living with pain. In the existing literature, just one other Irish-based study has investigated the lived experience of chronic pain among individuals with diverse chronic conditions, including chronic pain (Mahon et al., 2014). Despite the eleven-year gap between this thesis and Mahon et al.'s (2014) study, several shared themes emerge, including frustration with the healthcare system, long wait times, difficulties navigating fragmented services, and a desire for community-based care that addresses the whole person. Of particular interest both the findings of this thesis and those of Mahon et al. (2014) underscore the importance of regaining control for individuals living with a chronic illness, indicating the motivation and desire for management strategies that support living well. Given the lack of substantial progress over this eleven-year period, it is clear that decisive action is urgently needed to improve pain care in Ireland.

Our findings of predominantly negative healthcare experiences and pain invalidation align with those reported in Irish studies on fibromyalgia (Diviney & Dowling, 2015), abdominal pain (Windrim et

al., 2024), and endometriosis (Lightbourne et al., 2024). These results are concerning, as validation of a person's pain experience, particularly in the early stages of pain management, is considered critical for fostering engagement with treatment strategies and achieving therapeutic goals (Nicola et al., 2022). Similar to our findings, individuals living with fibromyalgia in Ireland reported that a predominantly biomedical approach offered limited symptom relief and often failed to address their diverse needs (Diviney & Dowling, 2015). From a broader perspective, international evidence also echoes these concerns. A meta-ethnography of patients' experiences of chronic musculoskeletal pain highlights comparable challenges, including difficulty navigating fragmented healthcare systems and feeling undervalued and disbelieved (Toye et al., 2013). Similarly, in UK primary care settings, poor communication with healthcare professionals was linked to negative emotional responses and a perceived lack of legitimacy, whereas positive experiences were characterised by feeling listened to, supported, and cared for (Gordon et al., 2017).

While self-management appears valued in persons living with pain in Ireland, both our findings and previous Irish research (Lightbourne et al., 2024; Windrim et al., 2024) indicate it often emerged through trial and error rather than structured support. Inadequate guidance from healthcare professionals led individuals to seek their own information, an empowering but often frustrating process marked by lost time and a desire for earlier access to helpful knowledge. These patterns are not unique to Ireland. For instance, in the Netherlands, individuals living with chronic pain often initiated help-seeking behaviours and explored new pain management strategies not as a result of system support, but in response to prolonged suffering (Beetsma et al., 2025). Similarly, in Scotland, self-management was commonly used as a way to fill gaps in service provision when healthcare was inaccessible (Gordon et al., 2017). Taken together, these findings highlight a troubling pattern in which negative healthcare experiences, both in Ireland and internationally, impact individuals' motivation, potentially delaying their engagement in self-management, reinforcing the urgent need for more supportive, person-centred approaches to pain care (Beetsma et al., 2025; Nicola et al., 2021).

While Lightbourne et al. (2024) and Windrim et al. (2024) importantly focus on gender-specific pain conditions in Ireland, they also highlight a broader pattern of insufficient support and a lack of information regarding symptom management and treatment for women in Ireland. Although we acknowledge the gendered dimensions of healthcare and the importance of its investigation to support women in pain, our findings suggest that issues such as inadequate support and information may extend beyond gender-specific conditions and affect the wider chronic pain population, regardless of gender or diagnosis. Future research should continue to explore the lived experiences of

those with gender-specific conditions, while also addressing the broader systemic shortcomings reported by individuals across the chronic pain spectrum

6.1.2 The Emergence of Digital Self-Management Support

The research presented in this thesis differs from the eHealth design approaches of Kelly et al., (2024b) and O'Brien-Kelly et al., (2023) and aligns more closely with Deegan et al. (2023), in that it addresses chronic pain in a general, non-condition-specific manner. While condition-specific interventions have the advantage of tailoring content to meet unique clinical needs, healthcare professionals in both primary and specialised care settings routinely support individuals with a broad spectrum of chronic pain conditions. From a practical perspective, there is value in providing an inclusive, adaptable online resource that supports self-management across pain types, while still offering pathways to condition-specific information. Unlike O'Brien-Kelly (2023), who recruited solely from a tertiary-level urban pain clinic, both Kelly et al. (2024b) and the HELP-Platform recruited from hospital and community settings, enhancing population diversity. Furthermore, a key strength of this thesis is the inclusion of PPI contributors with low eHealth literacy, deliberately recruited for this research. Although Kelly et al. (2024b) recorded eHealth literacy scores, reported median scores were above the low-literacy threshold (Richtering et al., 2017).

The HELP-Platform is the first non-specialist, PPI-informed online self-management intervention for chronic pain developed specifically for the Irish context. Unlike Kelly et al. (2024b), whose resource targets musculoskeletal physiotherapy follow-up, the HELP-Platform like FibromyalgiaMatters.ie by O'Brien-Kelly (2024) offers flexible, stand-alone or blended care options, supporting a wider range of pain experiences. Although embedding an intervention within physiotherapy services, like Kelly et al., (2024b) may aid implementation, it may also limit accessibility for individuals with complex pain or those without access to such services. Unlike condition-specific interventions, Deegan et al. (2023) evaluated a combined online mindfulness and exercise program (MOVE) for adults living with chronic pain, comparing it to a self-guided online self-management resource. The latter closely resembles the HELP-Platform. However, unlike the HELP-Platform, the self-management guide used in the MOVE study was not co-designed through PPI. Instead, it was developed using recommended resources from the Scottish Intercollegiate Guidelines Network (SIGN 136, 2013), which offers evidence-based guidance for chronic pain management. While the original development of SIGN 136 (2013) included input from patient representatives to ensure alignment with both evidence and patient values, it was not designed specifically for an Irish context. Given that contextual factors, such as personal, social, economic, and cultural influences, play a critical role in

how pain is experienced (Rossettini et al., 2018; Zimmer et al., 2022), we argue that the HELP-Platform offers a more context-sensitive approach.

The eHealth interventions by Kelly et al. (2024b) and O'Brien-Kelly (2024) included advanced features like personal data storage, peer support forums, and direct contact with healthcare providers, supported by web designers. These were absent in the HELP-Platform due to funding limitations but will be addressed in future iterations. Despite the lack of available resources, the HELP-Platform achieved excellent usability scores, suggesting strong user-friendliness comparable to higher-funded resources. Next, the HELP-Platform needs to be piloted to assess its feasibility, acceptability, usage, and preliminary efficacy across diverse clinical settings. There is ongoing debate in the literature about the optimal number and combination of behaviour change techniques in interventions. Some research suggests that a greater number of techniques is associated with improved adherence (Eisele et al., 2019), while other studies have found no relationship between the number of techniques and intervention efficacy (Gillison et al., 2019). Our inclusion of eight SDT behaviour change techniques and seven PRISMS components aligns with current research (Gillison et al., 2019, Kelly et al., 2022). Further investigation is now required to evaluate the efficacy of these selected behaviour change techniques within the HELP-Platform intervention.

In conclusion, the findings of this thesis expand on the limited available Irish research by highlighting widespread dissatisfaction with healthcare services, a central theme of pain invalidation, and a strong desire among individuals to regain control when living with chronic pain. These insights deepen our understanding of the systemic barriers faced by people with chronic pain and underscore the urgent need for more person-centred, integrated models of care. The findings have important implications not only for future research but also for clinical practice and health service design. The following section explores these implications further, focusing on opportunities for system-level improvements in supporting individuals living with chronic pain in Ireland.

6.2 Implications for pain services

As we approach twenty years since the call for a national pain strategy to reduce costs, standardize education, and increase pain clinic resources in Ireland (Fullen et al., 2006), the consequences of fragmented services, long waiting times, and limited resources are clearly reflected in our findings. These findings strongly suggest that a biomedical approach continues to dominate pain care in the Irish healthcare system, an approach that disempowers service users and undermines their ability to engage in self-management strategies. While Purcell et al. (2022) provide a quantitative account of the limited staff and resources within Irish pain services, this thesis extends that work by exploring

the consequences of these limitations for both individuals living with pain and the clinicians who support them. By focusing on these lived realities, the research enhances our understanding of the systemic gaps in chronic pain services and underscores the urgent need for integrated, adequately resourced, and person-centred models of care in Ireland. From a clinical perspective our findings indicate that individuals seeking healthcare for chronic pain often feel unsupported and poorly informed, which they perceive as limiting their ability to regain control over their condition. Our findings indicate that people living with pain in Ireland feel invalidated, which can hinder their engagement in self-management programs (Nicola et al., 2021). Validation is a fundamental, low-cost element of compassionate, person-centred care that must be prioritised by Irish healthcare professionals.

Similarly, healthcare professionals reported feeling under-resourced, with limited access to information on non-pharmacological management strategies. Notably, participants in our research expressed empathy for these professionals working within a flawed system, recognising the systemic pressures they face, an insight also reported by Windrim et al. (2024). This is particularly relevant given that emotional exhaustion and symptoms of burnout have been documented among clinicians working in pain care internationally (Ashton-James et al., 2021; Kroll et al., 2016; Riquelme et al., 2018). Despite these challenges, both service users and clinicians in Ireland expressed openness to eHealth resources as a way of supporting care where traditional service delivery is constrained.

Our findings suggest that, despite policy endorsement (NICE 2021), the biopsychosocial model is not being meaningfully implemented in Irish chronic pain services. This aligns with international evidence indicating that healthcare professionals expected to support self-management in chronic pain often lack the confidence to do so (Penlington et al., 2024). Globally, limited education and training hinder clinicians' ability to deliver care grounded in the biopsychosocial model, despite widespread acknowledgement of its potential benefits in clinical practice (Cowell et al., 2018; Holopainen et al., 2020; Zangoni & Thomson, 2017).

There is an urgent need to reflect on and revise our approach to pain care in Ireland, identifying actionable solutions that shift the balance toward a biopsychosocial, person-centred model. Findings from Chapter 3 suggest that AHPs are well-positioned to support individuals' autonomy and competence in chronic pain self-management. One potential solution, therefore, is to increase access to AHPs, with a particular emphasis on community-led care. However, Chapter 4 highlights a key barrier; healthcare professionals such as GPs and consultants often lack clear referral pathways to AHPs who could provide such support. As a result, frontline professionals are overburdened and unable to connect patients with empowering self-management services, largely due to the absence of community-led pain services and the high demand on limited hospital multidisciplinary teams. Our

findings support the Irish Pain Strategy's call for enhanced training and increased resources to ease this burden (Faculty of Pain Medicine, 2022). Addressing these systemic gaps will require not only improved referral pathways and resources but also targeted community engagement to validate and empower individuals living with pain.

Community outreach education programs are one strategy that could help address the overarching theme of invalidation identified in this thesis, exemplified internationally by initiatives such as Flippin' Pain (United Kingdom) and the Pain Revolution (Australia). Interestingly, a qualitative analysis of individuals living with chronic pain who attended the Flippin' Pain public health campaign identified three themes that closely mirror our findings from Chapter 4 and Chapter 5: frustration with a biomedical approach, the challenge of living with pain, and a strong desire for validation (Livadas et al., 2025). While public awareness campaigns internationally have aimed to improve knowledge and shift beliefs about pain, addressing the unique cultural needs of people living with pain in Ireland requires the development of a tailored, Ireland-specific public campaign (Reis et al., 2022).

In Ireland the gold standard multidisciplinary pain treatment services are not readily available to meet clinical needs. Developing an evidence-informed, patient centred, user-friendly online resource that can support self-management behaviours seems a pragmatic response to support Irish pain services in the long term. Although the HELP-Platform offers a partial solution to some of the care gaps in Ireland, in order for digital health to be successful it relies on its recommendation by clinical partners. Future research should explore Irish healthcare professionals' knowledge and attitudes toward recommending eHealth resources for chronic pain, given concerns elsewhere about safety, accessibility, and the lack of a therapeutic relationship eHealth solutions present (Devan et al., 2019c).

The findings of this thesis suggest that in Ireland, we must pursue change on multiple levels simultaneously. The successful implementation of a biopsychosocial approach to pain care is reliant on a complex interaction of microlevel, mesolevel and macrolevel healthcare factors (Ng et al., 2021). In Ireland, this would involve coordinated efforts across all levels of the healthcare system. At the individual level, people living with pain can be supported through education and tools like eHealth resources. At the healthcare professional level, validation and the delivery of a biopsychosocial model of care can be strengthened through patient-centred approaches, collaboration, and developing a strong therapeutic alliance. At a systems level, improvements are needed in access and resources, particularly by expanding the role of allied health professionals in the community. Ultimately, comprehensive reviews and reform are needed at in the Irish health system to ensure more integrated, accessible, and person-centred support for pain care.

6.3 Reflections on Practice, Identity, and Learning

Completing this thesis has implications for my professional identity as an early career researcher, an educator of healthcare students and as a clinician. As both a person living with pain and a clinician working in chronic pain care, I hold a unique dual perspective. This allows me to see both sides of the coin, navigating the healthcare system as a service user while also understanding its challenges from within. In this sense, I am uniquely positioned to bridge the gap between service users and healthcare systems, with interpretations that may hold particular value for informing both practice and policy. At the same time, I remain aware that my lived experience could introduce bias. As a clinician-researcher, it is essential that I approach my work reflexively, continually questioning my assumptions and grounding interpretations in the participants' words, rather than projecting my own experiences (Greene, 2014).

6.3.1 Clinician-Researcher

This thesis marks the development of my clinician–researcher identity, merging my clinical knowledge and experience with a new perspective gained through research. As I detailed in Chapter 1, clinical practice often requires artistry, the ability to navigate the grey areas where no two individuals or situations are the same. Concurrently, there is a need for research that is scientifically rigorous and structured, offering the clarity and evidence needed to inform clinical practice. This work represents a foundational step toward bridging those two worlds.

Engaging in mixed methods research has been valuable for my development as a researcher, offering a broader perspective on data collection and analysis that aligns with my epistemological and ontological positions. However, the process also revealed some of the underlying tensions between research and clinical practice. I am committed to research that explores the nuances of individual experience and provides meaningful insight into the realities of both those living with pain and those delivering pain care. A key challenge facing qualitative research is the persistent assumption that all research must be transferable, often leading to the inappropriate dismissal of context-specific findings and the universalisation of concepts across diverse settings (Clarke et al., 2025). While qualitative findings may not be transferable, I view this as a strength, one that more authentically captures the complexity of pain and its deeply personal impact. Moving forward, my research will continue to reflect my philosophical stance, prioritising methods that honour personal meaning, contextual complexity, and the lived experience of pain. As a clinician-researcher, I am continually challenged to balance academic rigour with a commitment to authentically represent the multifaceted

and individualised nature of pain, ensuring that my work remains both scientifically credible and grounded in clinical reality.

I find myself at a pivotal point where I am drawing on my significant clinical experience while openly acknowledging my limitations as an early-career researcher with much still to learn. While achieving peer review success and building academic relationships are important goals, my foundational commitment is to pragmatism, ensuring that the clinical value and practical application of my research guides public policy and enhanced care for those living with pain. Dissemination of findings to both public and clinical audiences is, to me, the most meaningful measure of success. This thesis journey has led to opportunities to present my findings to a variety of community-based groups living or working with pain (Dissemination of Research p.121) who found the content relatable and impactful, particularly in terms of feeling validated. I see great value and importance in building on this approach as detailed in the section 6.2 above highlighting the importance of educational public campaigns delivered in community settings.

While my primary goal of supporting individuals living with pain remains unchanged following the completion of this thesis, an unexpected personal implication from my experience conducting research alongside clinicians working in pain services is the urgent need to support healthcare professionals as they navigate the provision of pain care in a challenging workplace filled with numerous burdens and systemic barriers. Understanding their experiences has prompted me to reflect deeply on my own clinical journey, the challenges and pressure to provide optimal pain care and to alleviate suffering within a healthcare system that lacks clear pathways and the necessary resources for comprehensive, whole-person care. This insight has inspired a new research focus for me, exploring how best to support healthcare professionals in delivering effective, person-centred pain care and I am committed to advancing this important work in the future.

While it is difficult to assign a tangible value to the role of the clinician-researcher (Buttrum et al., 2025), their dual perspective is believed to enhance the translation of theory into practice, enabling the development of innovative strategies that address real-world problems. As an Irish clinician, it has been encouraging to connect with the work of other clinician-researchers in pain care who are developing practical, patient-centred approaches that support self-management (Deegan et al., 2023; Kelly et al., 2024b; O'Brien-Kelly et al., 2024). This thesis builds on their contributions by offering additional self-management resources, while also underscoring a critical insight: the practice gaps I have encountered throughout my career are not isolated. Instead, they reflect a broader pattern of unmet needs identified by others working at the intersection of research and clinical care, revealing a shared struggle in a system where, until now, I often felt alone

As noted in Chapter 1, my professional values include respect for the person in pain, recognition of their unique context, and a commitment to shared decision-making. By exploring the lived experiences of people with chronic pain and embedding PPI throughout the co-design of the eHealth resource, I have placed the person in pain at the centre, not just as a participant, but as a driving force shaping the intervention to reflect their needs, priorities, and lived reality. Throughout the research program I focused on creating a safe collaborative space, where myself as the therapist and the PPI contributors could interact as equals. The relationships formed, and the value and richness of the data provided by individuals living with pain, have significantly deepened and enriched my professional perspective. The completion of this thesis has further enhanced the value I place on research that delivers action at a community level. Although a knowledge practice gap is commonly reported in chronic pain services, the findings from all three studies in this thesis put a magnifying glass on the width and depth of that gap negatively impacting both persons living with pain and healthcare professionals working in pain.

6.3.2 Clinician-Educator

Within my role as an educator of third level students, highlighting the narratives of individuals seeking pain care in Ireland throughout my teaching has been an important outcome of this thesis. It has highlighted not only the importance of behaviour change strategies but also the need to develop the skills to address suffering associated with pain and to validate the lived experience in a compassionate manner. This thesis reinforces the need to educate students on fostering high-quality therapeutic relationships and developing the necessary skills, rather than focusing primarily on pain relief or reduction (Gruß et al., 2020). Importantly, this work has also served as a catalyst for developing additions to the curricula I deliver that address the challenges clinicians may face in the current healthcare climate. From this research it is critical to explore barriers to care, such as current pain pathways and to educate healthcare students on the importance of maintaining their own health as a clinician while working with complex cases. These insights have shaped my pedagogical approach, leading me to introduce innovative, practical, and engaging teaching methods, including elements of play, humour, reflection and interactive activities, to help students reconceptualize chronic pain and critically examine their potential biases toward the biomedical model.

6.3.3 Clinician in Practice

As outlined in Chapter 1, the philosophy of pragmatism holds that knowledge is only meaningful when coupled with action (Long et al., 2018). The value of the knowledge generated through this thesis lies in its practical application, its usefulness in daily clinical practice and in the everyday lives

of people living with pain. While I began this thesis eager to explore strategies to enhance self-management in the Irish context through behaviour change supports, the findings relating to the challenges of navigating the Irish healthcare services prompted me to step back and reconsider the foundational conditions required for individuals to engage meaningfully in self-management. This thesis underscores the importance of care, acceptance, and the creation of safe spaces, reflected in the strong desire for relatedness discussed in Chapters 5 and 6. It reaffirms the value of so-called ‘soft skills’ and the need to centre the person in pain in all care approaches. Although these were principles I had already embraced in my clinical work, I now hold a deeper appreciation for their impact and how often they are dismissed from clinical practice. Ultimately, this thesis has reinforced for me the critical importance of establishing a therapeutic alliance in which individuals feel heard, validated, and genuinely supported. Building this foundation of trust is essential before introducing any behaviour change strategies, a practice I will continue to prioritise in my own clinical work and advocate for across pain services in Ireland.

6.4 Practical Implications

Given the pragmatic research philosophy employed in this thesis and the desire to provide practical recommendations this section identifies several key actions to support the improvement of pain care in Ireland. We recommend that future investment be directed toward developing scalable, context-sensitive, and supportive self-management solutions that empower both individuals living with pain and the professionals who care for them. Our findings support the following actions:

- **National education and public awareness:** A community-led national campaign to support individuals living with pain and raise public understanding with a primary focus on validating the pain experience and incorporating the biopsychosocial model into pain care strategies.
- **Education and support strategies for healthcare professionals:** Promote the adoption of the biopsychosocial model within a person-centred framework, in line with current clinical guidelines for chronic pain. This should include curriculum changes in third-level healthcare education and the expansion of continuing professional development (CPD) opportunities.
- **Optimising the role of Allied Health Professionals:** AHPs demonstrate strong potential in delivering emotionally validating, whole-person care and should be better integrated into community care strategies to support individuals living with pain and to provide the opportunity for introducing supported self-management early in the pain journey.
- **Digital health as a complementary or stand-alone solution:** In both resource-rich and resource-limited settings, digital health tools can offer accessible, evidence-based, and user-

friendly support to people living with pain either as part of blended care models or as independent interventions. The HELP-Platform offers a new resource suitable for all non-cancer chronic pain conditions that now needs to be tested for feasibility and efficacy.

- **Embedding Public and Patient Involvement:** Future healthcare innovations in Ireland must continue to actively involve patients and the public at every stage to ensure that context-specific challenges are addressed through relevant, acceptable, and widely adopted solutions.

6.5 Thesis Limitations:

These findings should be interpreted with consideration of several limitations.

- A fundamental limitation of Study 1 (Chapter 3) is that it did not specifically measure relatedness. While autonomy support and competence were assessed in line with SDT, all three components, autonomy, competence, and relatedness are essential to fully support internal motivation. Given that relatedness, including themes of feeling valued and validated, emerged consistently in the qualitative findings from Study 2 (Chapter 4) and Study 3 (Chapter 5), we recommend that future quantitative research in this area explicitly measure all three SDT components to provide a more complete evaluation.
- In Study 2 (Chapter 4), a pre-existing clinical relationship with some participants introduced potential concerns such as confirmation bias and power dynamics (Creswell & Creswell, 2017). To address this, reflexivity was actively applied to acknowledge and mitigate personal biases and values stemming from my clinical and personal experiences that could influence data interpretation (Palaganas et al., 2017). While this posed limitations, we also considered it a strength of the study; the existing clinical relationships likely fostered trust and openness, contributing to deeper insights and richer data that enhanced the overall depth and quality of the research.
- In Study 3 (Chapter 5), although we aimed to include PPI contributors with varying levels of eHealth literacy, our eligibility criteria, requiring access to an electronic device and internet connectivity, were unintentionally exclusionary. As a result, only four individuals with low eHealth literacy were recruited. While we highlight the potential of eHealth to support intervention delivery, we also emphasise the continued importance of enhancing in-person clinical care and advocate for the consideration of multiple delivery models for pain services in Ireland.
- In this thesis, we chose to include individuals accessing both public and private pain services, as many people living with pain and clinicians working in these services reported engaging

with both sectors. Ireland operates a two-tiered healthcare system, comprising both public and private services (Heavey, 2019; Murphy et al., 2020). The healthcare system is complicated by the overlap between public and private sectors, as private healthcare services are often delivered within public hospitals using public infrastructure and resources (Heavey, 2019) and public care is sometimes outsourced to private providers through the National Treatment Purchase Fund (NTPF) (Burke et al., 2019). This overlap between systems makes it challenging to study either sector in isolation, and thus, our study includes both public and private healthcare settings. Future research could explore each sector individually to enable a direct comparison of pain care services.

- This thesis did not explore gender differences across any of the studies. This is particularly important given emerging evidence that women in Ireland frequently report experiences of invalidation when seeking healthcare for chronic pain (Windrim et al., 2024; Lightbourne et al., 2024). Failing to account for gendered experiences may overlook important disparities in access and engagement with pain management supports. Therefore, future research should prioritise examining both the barriers and facilitators to self-management support across genders.
- This thesis included individuals with self-reported non-cancer chronic pain across a variety of conditions. While many other studies focus on a single specific pain condition, allowing for more targeted analysis and clearer attribution of findings to that particular diagnosis, we chose to include a broad range of conditions for two key reasons. First, this approach reflects the realities of clinical practice, where patients often present with diverse pain conditions. Second, many associated comorbidities, such as anxiety, depression, and fatigue are common across different diagnoses (Aaron et al., 2025; Glette et al., 2024) and many self-management strategies are a universal approach to chronic pain relevant to all pain types.
- This thesis collected and analysed data from an urban setting, and Studies 2 (Chapter 4) and 3 (Chapter 5) primarily recruited individuals over the age of thirty-five. Further research is required to explore the lived experiences of individuals in rural settings and of young adults living with chronic pain, to better understand and meet the needs of these cohorts.
- Although the findings from this thesis informed the development of an online intervention that offers scalability and potential integration across various clinical settings, including specialist pain services and primary care, it is important to acknowledge the current lack of evidence regarding its clinical efficacy. While the co-design methodology employed in the intervention is a notable strength, future research must now focus on evaluating its preliminary impact.

- For eHealth resources to be implemented and sustained over time, long-term financial support is essential. While pilot projects can often be developed at relatively low cost, their long-term sustainability requires a clear and realistic funding plan (Bente et al., 2024). In addition to demonstrating efficacy, future work on the HELP-Platform should prioritise the development of a financial strategy to support its implementation and integration into routine care.
- As a physiotherapist with extensive clinical experience in chronic pain services, my position as a researcher offered insider insight into the perspectives of clinicians, facilitating rapport and depth in interviews. Additionally, having personal experience of chronic pain fostered empathy and understanding with PPI contributors. However, this dual insider status also introduced potential bias, and I remained an outsider to certain participant experiences given the group's diversity of pain conditions.

6.6 Conclusion

This thesis contributes to the limited body of research in Ireland exploring the lived experience of chronic pain and the accessibility of self-management support. By integrating the voices of individuals living with diverse chronic pain conditions and examining their experiences of engaging in self-management strategies with the support of healthcare professionals, we have gained valuable insights into the key barriers and facilitators to effective self-management in the Irish context. Findings suggest that individuals with chronic pain often feel disempowered, invalidated, and unsupported, while healthcare professionals report feeling overwhelmed, under-resourced, and ill-equipped to deliver the kind of person-centred, psychologically informed care that is clearly needed.

In Ireland, systems-level change is needed to provide supportive, tailored pain care, particularly in resource-limited settings. The HELP-Platform addresses a critical gap in chronic pain services by offering accessible, evidence-informed support to people waiting for, or unable to access, specialised care, or as an extra resource for specialised pain services. While not intended to replace clinical services, the HELP-Platform represents a scalable, evidence-based tool that could contribute to establishing a minimum standard of care, ensuring that all individuals living with pain have access to credible and supportive information.

Supported self-management is widely recognised as a key direction for pain care, and our research indicates that both people living with pain and clinicians in Ireland are open to this approach, provided that the necessary resources and infrastructure are in place. These findings highlight the urgent need for system-level change and reinforce the potential of innovative, patient-centred

solutions like the HELP-Platform to improve chronic pain care in Ireland. This thesis exemplifies the critical role clinician-researchers can play in translating clinical realities into meaningful, scalable innovations, ensuring that research not only informs policy but transforms care for those living with chronic pain.

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Appendix

Appendix A

Appendix A.1: Plain Language Statement – Study 1

DUBLIN CITY UNIVERSITY

Plain Language Statement

Introduction to the Research Study

An investigation into perceived autonomy and pain interference in individuals living with persistent pain in Ireland

Principal Investigator: Ms. Kate Sheridan

Contact details: Kate.sheridan@dcu.ie

Other Investigators: Dr. Siobhán O'Connor, Dr. Enda Whyte

Introduction to the Research Study

This study is being conducted to facilitate a greater understanding of the level of support that individuals living with persistent pain receive from their healthcare professionals. Research has suggested that being supported to make your own treatment decisions can help develop self-management skills and enhance psychological well-being. This study will ask you to complete an anonymous questionnaire that will ask you questions relating to the support you receive from healthcare professionals, your psychological well-being and your self-management skills in relation to your pain experience.

Privacy Notice

The anonymous data collected will be used to create a data set as a reference for the population living with persistent pain. The data will be used to examine the association between the level of healthcare support, psychological well-being and self-management skills in individuals living with pain. Summated data, with no identifiable information may be published in peer-reviewed journals and presented at conferences. DCU will be the Data Controller in this project and the DCU Data Protection Officer is Mr. Martin Ward (data.protection@dcu.ie Ph.: 01-7005118 / 01-7008257). You have a right to lodge a complaint with the Irish Data Protection Commission.

Data Retention

Your responses will be confidential, and we do not collect identifying information such as your name, email address or IP address. All data will be stored and handled in compliance with GDPR guidelines in a password protected file on the DCU Google Drive. Data will be stored indefinitely for publication purposes.

What this research study involves

You will be asked to complete a number of anonymous online questionnaires examining components of, support from your healthcare professionals, your psychological well-being, pain interference and self-management skills. You will also be asked to provide information related to your age, gender, years of pain and diagnosed pathologies. You will not be required to disclose any personal identifiable information (e.g. name, date of birth). The survey should take approximately ten minutes to complete.

Potential benefits

Participation in this study will assist in expanding the knowledge base of current service provision in persistent pain services in Ireland.

Potential risks

It is possible that participation in this research study will initiate or exacerbate symptoms of a mental health issue. We expect the risk to be minimal but if you experience any adverse effects as a result of participating, we recommend you consult your GP, or Chronic Pain Ireland on 01-8047567. Alternatively the HSE provide a text support line called 'Text about it' 5808

Confidentiality of the data

Confidentiality and anonymity is of upmost importance in this study. All data will be stored in a password protected file on DCU Google Drive. Confidentiality of information can only be protected within the limitations of the law - i.e., it is possible for data to be subject to subpoena, freedom of information claim or mandated reporting by some professions.

Voluntary Research Study

Involvement within this research is purely voluntary. As all collected data will be anonymous, once you have participated in the research, your data cannot be identified and withdrawal cannot be facilitated at this point.

If participants have concerns about this study and wish to contact an independent person, please contact:

The Secretary, Dublin City University Research Ethics Committee, c/o Research and Innovation Support, Dublin City University, Dublin 9. Tel 01-7008000, e-mail rec@dcu.ie

Appendix A.2. Consent Form – Study 1

DUBLIN CITY UNIVERSITY **Anonymous Online Consent Form**

Research Study Title

An investigation into perceived autonomy and pain interference in individuals living with persistent pain in Ireland

Principal Investigators: Ms. Kate Sheridan

Contact details: kate.sheridan@dcu.ie; 01-7007388

Other Investigators: Dr. Siobhán O’Connor, Dr. Enda Whyte

I am aware that this research project involves completing questionnaires related to components of perceived autonomy, pain interference and psychological wellbeing. I understand that I will be asked to disclose personal information related to my persistent pain, perceived autonomy, psychological well-being and self-management skills.

I understand my participation is voluntary. I am aware that my responses to the questionnaires will be submitted anonymously. I understand I cannot withdraw from the study once my responses have been submitted.

I understand the anonymised data will be retained for processing and will be stored in a password protected file on the DCU Google Drive. This online file will be kept indefinitely for publication purposes. I understand that confidentiality of information can only be protected within the limitations of the law - i.e., it is possible for data to be subject to subpoena, freedom of information claim or mandated reporting by some professions.

I have read the Plain Language Statement (or had it read to me) *

Yes

No

I understand the information provided *

Yes

No

I have had an opportunity to ask questions and discuss this study *

Yes

No

I have read and understand the arrangements to be made to protect confidentiality of data, including that confidentiality of information provided is subject to legal limitations *

Yes

No

I have read and understand confirmations relating to any other relevant information as indicated in the PLS *

Yes

No

I understand the information provided in relation to data protection *

Yes

No

I consent to participate in this research study *

Yes

No

I have received satisfactory answers to all my questions *

Yes

No

Appendix A.3 Survey Items Study 1

Demographic Information

What is your gender? Male / Female / Non-Binary / Prefer not to say

Age in years: _____

Please list the condition/diagnosis resulting in your persistent pain (you can list more than one condition)

How many years have you had persistent pain? (persistent pain is pain that has lasted > 3 months)

Health-Care Climate Questionnaire

This questionnaire contains items that are related to your visits with your doctor. Physicians have different

styles in dealing with patients, and we would like to know more about how you have felt about your encounters with your physician. Your responses are confidential. Please be honest and candid.

Please indicate the extent to which you agree or disagree with the following statements, using the following 7-point scale:

(Strongly Disagree) 1 2 3 4 5 6 7 (Strongly Agree)

1. I feel that my physician has provided me choices and options.
2. I feel understood by my physician.
3. I am able to be open with my physician at our meetings.
4. My physician conveys confidence in my ability to make changes.
5. I feel that my physician accepts me.
6. My physician has made sure I really understand about my condition and what I need to do.
7. My physician encourages me to ask questions.
8. I feel a lot of trust in my physician.
9. My physician answers my questions fully and carefully.
10. My physician listens to how I would like to do things.

11. My physician handles people's emotions very well.
12. I feel that my physician cares about me as a person.
13. I don't feel very good about the way my physician talks to me.
14. My physician tries to understand how I see things before suggesting a new way to do things.
15. I feel able to share my feelings with my physician.

Treatment Self-Regulation Questionnaire (TSRQ)

(Concerning Motivation for Healthy Behaving)

The following question relates to the reasons why you would either start to exercise regularly or continue to do

so. Different people have different reasons for doing that, and we want to know how true each of the following

reasons is for you. All 15 responses are to the one question.

Please indicate the extent to which each reason is true for you, using the following 7-point scale:

(Not at all) 1 2 3 4 5 6 7 (very true)

The reason I would exercise regularly is:

1. Because I feel that I want to take responsibility for my own health.
2. Because I would feel guilty or ashamed of myself if I did not exercise regularly.
3. Because I personally believe it is the best thing for my health.
4. Because others would be upset with me if I did not.
5. I really don't think about it.
6. Because I have carefully thought about it and believe it is very important for many aspects of my life.
7. Because I would feel bad about myself if I did not exercise regularly.
8. Because it is an important choice I really want to make.
9. Because I feel pressure from others to do so.

10. Because it is easier to do what I am told than think about it.
11. Because it is consistent with my life goals.
12. Because I want others to approve of me.
13. Because it is very important for being as healthy as possible.
14. Because I want others to see I can do it.
15. I don't really know why.

Perceived Competence Scales (PCS)

Scoring Information. This scale has 4 items, and an individual's score is simply the average of his or her responses on the 4 items.

Perceived Competence (Exercising Regularly)

Please indicate the extent to which each statement is true for you, assuming that you were intending either to

begin now a permanent regimen of exercising regularly or to permanently maintain your regular exercise regimen.

Use the following scale:

(Not at all) 1 2 3 4 5 6 7 (very true)

1. I feel confident in my ability to exercise regularly.
2. I now feel capable of exercising regularly.
3. I am able to exercise regularly over the long term.
4. I am able to meet the challenge of exercising regularly.

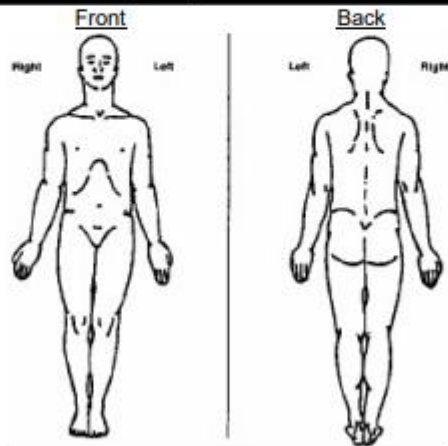
Brief Pain Inventory (BPI)

Brief Pain Inventory (Short Form)

1. Throughout our lives, most of us have had pain from time to time (such as minor headaches, sprains, and toothaches). Have you had pain other than these everyday kinds of pain today?

Yes No

2. On the diagram, shade in the areas where you feel pain. Put an X on the area that hurts the most.



3. Please rate your pain by marking the box beside the number that best describes your pain at its **worst** in the last 24 hours.

0 1 2 3 4 5 6 7 8 9 10
 No Pain Pain As Bad As You Can Imagine

4. Please rate your pain by marking the box beside the number that best describes your pain at its **least** in the last 24 hours.

0 1 2 3 4 5 6 7 8 9 10
 No Pain Pain As Bad As You Can Imagine

5. Please rate your pain by marking the box beside the number that best describes your pain on the **average**.

0 1 2 3 4 5 6 7 8 9 10
 No Pain Pain As Bad As You Can Imagine

6. Please rate your pain by marking the box beside the number that tells how much pain you have **right now**.

0 1 2 3 4 5 6 7 8 9 10
 No Pain Pain As Bad As You Can Imagine

General Anxiety Disorder (GAD-7)

Over the last 2 weeks, how often have you been bothered by the following problems?

Please circle the number that best applies.

No.	Question	Not at all (0)	Several days (1)	More than half the days (2)	Nearly every day (3)
1	Feeling nervous, anxious, or on edge	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	Not being able to stop or control worrying	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	Worrying too much about different things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	Trouble relaxing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	Being so restless that it is hard to sit still	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	Becoming easily annoyed or irritable	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7	Feeling afraid as if something awful might happen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Scoring:

Add the scores for each item (0 to 3 per item).

Total Score Range: 0–21

Patient Health Questionnaire (PHQ-9)

Over the last 2 weeks, how often have you been bothered by any of the following problems?

For each question, circle the number that best applies.

No.	Question	Not at all (0)	Several days (1)	More than half the days (2)	Nearly every day (3)
1	Little interest or pleasure in doing things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	Feeling down, depressed, or hopeless	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	Trouble falling or staying asleep, or sleeping too much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	Feeling tired or having little energy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	Poor appetite or overeating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	Feeling bad about yourself—or that you are a failure or let yourself or your family down	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7	Trouble concentrating on things, such as reading or watching TV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8	Moving or speaking so slowly that other people could have noticed? Or the opposite—being so fidgety or restless that you have been moving around a lot more than usual	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9	Thoughts that you would be better off dead or of hurting yourself in some way	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Scoring: Add up the numbers for each response.

- **0–4:** Minimal or no depression
- **5–9:** Mild depression
- **10–14:** Moderate depression
- **15–19:** Moderately severe depression
- **20–27:** Severe depression

Appendix B

Appendix B.1: Participant Information Sheet - Study 2

DUBLIN CITY UNIVERSITY

Plain Language Statement

Introduction to the Research Study

An investigation into the lived experience of chronic pain services in Ireland: A comparison between service users and service providers.

Principal Investigator: Ms. Kate Sheridan

Contact details: Kate.sheridan@dcu.ie

Other Investigators: Dr. Siobhán O'Connor, Dr. Enda Whyte

Introduction to the Research Study

This study is being conducted to develop a greater understanding of the level of support that individuals living with persistent pain receive from their healthcare professionals. Secondly, this study is exploring the experience of clinicians in providing support to individuals living with chronic pain. Research has suggested that being supported to make your own treatment decisions can help develop self-management skills and enhance well-being.

What is involved?

This study will ask you to complete a one-hour interview. Interviews will take place on zoom or if requested in person at a time convenient for you. The interviewer will ask you questions about your experience in chronic pain services in Ireland. The interview will be audio recorded only.

Confidentiality & Privacy

Confidentiality is of utmost importance in this study. Any identifying information about you (such as your name or clinic you attend) will not be published. Audio recordings will be pseudonymised, any identifying data will be removed and replaced with a pseudonym (a fictitious name). Audio recordings will be deleted once they are transcribed and pseudonymised. Pseudonymised data will be retained indefinitely. Pseudonymised data is intended to be published and presented at conferences.

Discussion transcriptions will be protected on a password encrypted secure Google drive. It must be noted that protection of this data is subject to legal limitations. DCU will be the Data Controller in this project and the DCU Data Protection Officer is Mr. Martin Ward (data.protection@dcu.ie Ph.: 01-7005118 / 01-7008257). You have a right to lodge a complaint with the Irish Data Protection Commission.

Benefits & Risks

There are no direct benefits for your participation in this research study, however, research gathered in this study will inform the health care service of the current levels of support available for persons living with chronic pain and this information can be used to enhance the experience and treatment of chronic pain service users in Ireland. The results of this study will be disseminated by publication in a peer-reviewed journal, a copy of this publication will be sent to all participants. There are no serious potential risks for you. If you develop concerns regarding your mental health challenges, or feelings of discomfort prompted by participation in this survey you should contact your GP or Chronic Pain Ireland on 01-8047567. Alternatively the HSE provide a text support line called 'Text about it' 5808

Withdrawal of participation

Involvement within this research is purely voluntary. There will be no penalty enforced on any participant wishing to quit prior to the study being completed. There is no obligation to participate, and should you choose to do so you can refuse to answer specific questions, or decide to withdraw from the interview. You may withdraw from the research project at any point prior to transcription being complete. Your involvement/non-involvement in this research project will in no way affect any on-going relationship with Dublin City University or any professional association of which you are a member or any clinical health services that you are currently engaged in.

If participants have concerns about this study and wish to contact an independent person, please contact:

The Secretary, Dublin City University Research Ethics Committee, c/o Research and Innovation Support, Dublin City University, Dublin 9. Tel 01-7008000, e-mail rec@dcu.ie

Appendix B.2 Consent Form – Study 2

DUBLIN CITY UNIVERSITY
Anonymous Online Consent Form

Research Study Title

An investigation into the lived experience of chronic pain services in Ireland: A comparison between service users and service providers.

Principal Investigators: Ms. Kate Sheridan

Contact details: kate.sheridan@dcu.ie; 01-7007388

Other Investigators: Dr. Siobhán O’Connor, Dr. Enda Whyte

Aims of the Research Study

The purpose of this research is to examine what helps or hinders the implementation of supportive healthcare environments in Irish chronic pain services.

The requirements to participate in this study involve taking part in an audio-recorded interview with one researcher, lasting approximately one hour.

Participant - please complete the following by indicating YES/NO for each question by placing an ‘x’ after your answer

Q1) I have read the Plain Language Statement *

- Yes
- No

Q2) I understand the information provided *

- Yes
- No

Q3) I understand the information provided in relation to data protection *

- Yes

- No

Q5) I have read and understand the arrangements to be made to protect confidentiality of data, including that confidentiality of information provided is subject to legal limitations *

- Yes
- No

Q6) I have read and understand confirmations relating to any other relevant information in the Plain Language Statement. *

- Yes
- No

Q7) I consent to participate in this Research Study *

- Yes
- No

Q8) I consent to audio recordings of the interview *

- Yes
- No

Participant Signature

Date

Appendix B.3 Interview Guides.

Appendix B.3a Interview Guide Service Users

Introduction and definitions

Research suggests that supportive healthcare environments enhance pain rehabilitation. That is, informed options and support relating to available therapies and lifestyle changes could enhance your quality of life. The purpose of this interview is to help us understand more about the barriers and facilitators to support in chronic pain services.

I'm going to ask you a few questions about your perspective on the support and therapy options you received from your healthcare professional. Please describe as much of your experience as possible. If there is a question that you would prefer not to answer or you need a break, that is no problem and it will not affect your relationship with DCU or any organisation that you may be associated with.

Before we start do you have any questions for me?

Are you happy to start the interview?

Demographic Details: Chronic Pain Patient

1. What is your age (in years)? _____
2. What is your gender? *Circle below*
 - a. Male
 - b. Female
 - c. Non-binary
 - d. Other
 - e. Prefer not to say

4. How long have you had your pain? ____years ____ months

5. What is the cause of your chronic pain? _____

6. Who do you consider your primary Healthcare Professional?* _____

(E.g GP, consultant, nurse, physiotherapist etc)

*Your Primary Healthcare Professional is the person you consider has the most input and influence on your chronic pain treatment.

7. Do you see them in the public or private Healthcare system? _____

8. Have you been on a Pain Management Program? _____

Definition		
Autonomy Supportive Healthcare Environment	Autonomy supportive environments support a person's autonomy (feeling free to engage in a behaviour), competence (feeling effective to engage in a behaviour) and relatedness (feeling cared for and valued).	Ntoumanis et al. (2020) Williams et al. (1998)
Barriers	Factors that make it harder for your healthcare professional to provide autonomy support	Fuller et al., (2019)
Facilitators	Factors that make it easier for your healthcare provider to provide autonomy support	Fuller et al., (2019)

Question	Prompt	Rationale
<p>Opening Question:</p> <p>Tell me about your experience with chronic pain services in Ireland?</p>	<p>Who is your primary health professional?</p> <p>How long have you seen them?</p>	Opening Question, Ice Breaker
<p>Do you feel that your healthcare professional has provided you with choices and options to treat your chronic pain?</p>	<p>Can you describe the choices you were given to treat your condition?</p> <p>You mentioned _____ were any further treatments discussed?</p>	<p>Autonomy Support / shared decision making</p> <p>Biomedical Healthcare versus Biopsychosocial care</p>
<p>Do you feel your healthcare professional has made sure you really understand about your condition and what you need to do to reduce your pain and optimise your rehabilitation?</p>	<p>Can you give an example of how they did/ didn't do this?</p> <p>What do you understand is happening with your condition?</p>	Autonomy Support / shared decision making
<p>Do you feel that your healthcare professional cares about you as a person? Why?</p>	<p>Does your healthcare professional listen to how you would like to do things?</p> <p>Do you think your healthcare professional considers your emotions?</p>	Relatedness
<p>Are you able to be open with your healthcare professional during your appointments? Why/Why not?</p>	<p>What things do you feel you can't express in your appointments?</p>	Autonomy support/ value led rehabilitation

In your opinion what are the main barriers to you receiving (autonomy) support from your healthcare professional?	How do you think these barriers can be overcome? What is missing from the pain service you received?	Shared decision making / patient centred care
What are the main facilitators to you receiving autonomy support from your healthcare professional?		
Do you feel motivated to manage your chronic pain?	Are you doing it for yourself (internally motivated) or doing it for other people (externally motivated)	Internal versus external motivation
Do you feel competent to manage your chronic pain?	i. What other factors influence your competence? ii. What does competence mean to you?	Competence / valued care / self-management
What does competence mean to you?		Competence / valued care / self-management
Do you feel competent to engage in physical activity?		Competence / valued care / self-management
Do you feel like you have a shared partnership with your healthcare professional in deciding the best treatment and lifestyle changes for your pain?	Are your values and lifestyle considered when a treatment plan is formulated?	

Appendix B.3b Interview Guide Service Providers

Introduction and definitions

Read consent form:

Research suggests that supportive healthcare environments enhance pain rehabilitation. The purpose of this interview is to help us understand more about the barriers and facilitators to supporting chronic pain service users.

I'm going to ask you a few questions about your perspective on the support and therapy options you offer as a healthcare professional. Please describe as much of your experience as possible. If there is a question that you would prefer not to answer or you need a break, that is no problem and it will not affect your relationship with DCU or any organisation that you may be associated with.

Before we start do you have any questions for me?

Are you happy to start the interview?

Definition		
Autonomy Supportive Healthcare Environment	Autonomy supportive environments support a person's autonomy (feeling free to engage in a behaviour), competence (feeling effective to engage in a behaviour) and relatedness (feeling cared for and valued).	Ntoumanis et al. (2020) Williams et al. (1998)
Barriers	Factors that make it harder for your healthcare professional to provide autonomy support	Fuller et al., (2019)
Facilitators	Factors that make it easier for your healthcare provider to provide autonomy support	Fuller et al., (2019)

Question	Prompt	Rationale
<p>Opening Question:</p> <p>Tell me about your experience working in chronic pain services?</p>	<p>What type of patients do you often see with chronic pain?</p> <p>What experience have they had before they get to our clinic? Does that make your role harder?</p> <p>How challenging is it to manage chronic pain in your clinic?</p>	<p>Opening Question, Ice Breaker</p>
<p>Do you feel that in your clinic you are able to provide chronic pain patients with choices and options to treat their chronic pain?</p>	<p>As a GP/ consultant what choices can you offer to patients with chronic pain?</p> <p>You mentioned _____ are there any further treatments available that your clinic can't offer? Why?</p>	<p>Autonomy Support / shared decision making</p> <p>Biomedical Healthcare versus Biopsychosocial care</p>
<p>In your clinic do you feel that patients understand their chronic pain condition and what role they can take to reduce their pain and optimise their rehabilitation?</p> <p>Any patient advocacy groups you recommend?</p>	<p>Can you give an example of how they did/ didn't do this?</p>	<p>Autonomy Support / shared decision making</p>

<p>What resources do you think would support chronic pain patients being able to take control of their pain?</p> <p>Are these resources available in your clinic?</p>		
<p>In your clinic are you able to talk to your patient about the emotional or psychological impact of their pain? Why, why not?</p> <p>Is there an available pathway for you to refer patients for psychological/emotional support?</p> <p>How important is psychological support in chronic pain?</p>	<p>Do you listen to how your patient would like to do things? Such as their treatment preferences</p>	<p>Relatedness</p>
<p>Do you think patients think they can be open with you during your appointments? Why/Why not?</p>		<p>Autonomy support/ value led rehabilitation</p>
<p>In your opinion what are the main barriers to you providing the support required to your patient when they are managing a chronic pain condition?</p>	<p>How do you think these barriers can be overcome?</p> <p>What is missing from the pain service we provide?</p>	<p>Shared decision making / patient centred care</p>
<p>What are the main facilitators to you providing chronic pain support/ treatment?</p>		

What is working well in your clinic to provide a good service for these patients?		
Do you feel patients with chronic pain are motivated to manage their chronic pain?	Are you doing it for yourself (internally motivated) or doing it for other people (externally motivated)	Internal versus external motivation
Do you think in Ireland we support people to become competent to manage their chronic pain?	iii. What factors influence a person to develop competence? iv. What does competence mean to you?	Competence / valued care / self-management
What does competence mean to you?		Competence / valued care / self-management
Do you think patients with chronic pain are competent to engage in physical activity?	What services are missing to allow this to happen?	Competence / valued care / self-management
Do you have resources/ support available to assist you to support chronic pain patients to engage in physical activity?	Do you have pathways you can advice patients to follow to get support with this?	
Do you feel like you are able to offer a shared partnership with your patients where you both decide the best treatment and lifestyle changes for their pain?	Are their values and lifestyle considered when a treatment plan is formulated?	

What do we need to do next for chronic pain services?

Demographic Details: Service Provider

1. What is your age (in years)? _____

2. What is your gender? *Circle below*

- f. Male
- g. Female
- h. Non-binary
- i. Other
- j. Prefer not to say

4. How long have you worked in chronic pain services? _____ years _____ months

5. What clinic do you work in? _____

7. Do you see service users in the public or private Healthcare system? _____

8. Have you referred patients onto an MDT based Pain Management Program? _____ (Do you have access to PMP?)

Appendix C

Appendix C.1 GRIPP2 Short Form (Staniszewska et al., 2017)

Section and Topic	Item	Page Number
1. Aim	Report the aim of the PPI in the study	92
2. Methods	Provide a clear description of the methods used for PPI in the study	94
3. Study Results	Outcome – Report the results of PPI in the study, including both positive and negative outcomes	98
4. Discussion and Conclusion	Outcomes – Comment on the extent to which PPI influenced the study overall. Describe positive and negative effects	111
5. Reflections/Clinical Perspective	Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from the experience	114

Appendix C.2 Outcome Measures Recruitment:

STEP 1: Demographic Details

Demographic Questions

Personalised Code: (As provided by the study team)

Age:

Gender

- a) Female
- b) Male
- c) Non Binary
- d) Other _____

Section 2:

Please identify if you are

- a) A person living with chronic pain
- b) A healthcare professional working in pain services

Section 2a for persons living with chronic pain only

How long have you lived with pain?

What type of pain condition do you live with (please list all conditions)

What healthcare professionals are currently treating your pain?

Have you completed a pain self-management program before?

Section 2b for healthcare professionals only

How many years have you worked in the area of pain management?

What is your qualification?

- a) Medical Doctor
- b) Consultant in _____
- c) Physiotherapist
- d) Occupational Therapist

- e) Psychologist
- f) Other

What additional training have you completed in pain management?

- a) CPD courses _____
- b) Research MSc
- c) Taught MSc
- d) PHD/ Professional Doctorate

eHEALS Outcome Measure

I would like to ask you for your opinion and about your experience using the Internet for health information. For each statement, tell me which response best reflects your opinion and experience *right now*.

1. How **useful** do you feel the Internet is in helping you in making decisions about your health?

<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Not useful at all	Not useful	Unsure	Useful	Very Useful

2. How **important** is it for you to be able to access health resources on the Internet?

<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Not important at all	Not important	Unsure	Important	Very important

3. I know **what** health resources are available on the Internet

- 1) Strongly Disagree
- 2) Disagree
- 3) Undecided
- 4) Agree
- 5) Strongly Agree

4. I know **where** to find helpful health resources on the Internet

- 1) Strongly Disagree
- 2) Disagree
- 3) Undecided
- 4) Agree

5) Strongly Agree

5. I know **how** to find helpful health resources on the Internet

1) Strongly Disagree

2) Disagree

3) Undecided

4) Agree

5) Strongly Agree

6. I know **how to use** the Internet to answer my questions about health

1) Strongly Disagree

2) Disagree

3) Undecided

4) Agree

5) Strongly Agree

7. I know how to use **the health information** I find on the Internet to help me

1) Strongly Disagree

2) Disagree

3) Undecided

4) Agree

5) Strongly Agree

8. I have the skills I need to **evaluate** the health resources I find on the Internet

1) Strongly Disagree

2) Disagree

3) Undecided

4) Agree

5) Strongly Agree

9. I can tell **high quality** health resources from **low quality** health resources on the Internet

1) Strongly Disagree

2) Disagree

3) Undecided

- 4) Agree
- 5) Strongly Agree

10. I feel **confident** in using information from the Internet to make health decisions

- 1) Strongly Disagree
- 2) Disagree
- 3) Undecided
- 4) Agree
- 5) Strongly Agree

Thank you!

** Note: Questions #1 and #2 are recommended as supplementary items for use with the eHEALS to understand consumer's interest in using eHealth in general. These items are not a formal part of the eHealth Literacy scale, which comprises questions #3-10.*

Appendix C.3 Participant Information Sheet – Study 3

Plain Language Statement

This Plain Language Statement contains detailed information about the research project. Its purpose is to explain to you as openly and clearly as possible all the procedures involved in this project before you decide whether or not to take part in it.

Please read this Plain Language Statement carefully. Feel free to ask questions about any information in the document. You may also wish to discuss the project with a relative or friend. Feel free to do this. Once you understand what the project is about and if you agree to take part in it, you will be asked to provide online consent on the next page. By providing consent, you indicate that you understand the information and that you give your consent to participate in the research project.

Research Study Title

The development and content review of the HELP Intervention (**H**ealing and **E**mpowering **L**ives in **P**ain): An online chronic pain resource integrating public and patient involvement (PPI)

Principal Investigator: Ms. Kate Sheridan

Contact details: Kate.sheridan@dcu.ie

Other Investigators: Dr. Siobhán O'Connor, Dr. Enda Whyte, Dr. Sinead O'Keeffe

Contact Details: Siobhan.oconnor@dcu.ie, enda.whyte@dcu.ie, sinead.okeeffe@dcu.ie

Study Details

This study involves the review and critique of the HELP (Healing and Empowering Lives in Pain) intervention, a digital intervention that will be developed to support persons living with chronic pain. The online intervention will deliver informative videos and links to resources for individuals living with chronic pain in Ireland and support them to live well and develop competence while living with a diagnosis of chronic pain. This study involves public patient involvement meaning it will have an expert panel of patients and clinicians evaluate the intervention content for appropriateness and usability.

What this research study involves

You are eligible for this study as you are living with chronic pain or you are a healthcare professional working in chronic pain services. There are three steps to this study, you will be asked to participate in one or more of the steps. The details of each step are explained below.

Step One: In this step you will be asked to fill in two short surveys (10-minute duration) and then to take part in a focus group to discuss what content an online pain intervention should have. Focus groups will be held online, recorded and take 60minutes.

Step Two: In this step you will be asked to complete a review of a prototype of an online pain website and fill in a questionnaire assessing the content and how easy the website is to use. This process will take 1.5-2 hours.

Step 3: In this step you will be asked to complete a ‘think-aloud’ interview where you will attend an in-person interview with one of the website designers. In this session you will navigate and explore the website while giving feedback. After the session you will complete a satisfaction questionnaire. This session will take 60-70minutes.

Privacy Notice

Your name and email address will be collected as part of this research study however you will be provided with a unique participant code to use when completing the online questionnaire. Only KS (the Primary Investigator) will have access to the master documents linking your name to your unique ID code. This personal data will be used to link your responses between the online survey and your input in the online focus group. Following the final data collection day, the master list with your email address and name and the audio recording of your focus group interview will be deleted. At this point, your data will be fully anonymised.

DCU will be the Data Controller in this project. This study will be conducted in compliance with the General Data Protection Regulation (GDPR), and if you have any concerns regarding how your data in this study has been handled, you can contact: DCU Data Protection Officer, Mr. Martin Ward – (data.protection@dcu.ie Tel: 01-7005118/01- 7008257) who will handle any data protection concerns arising from this research. An individual also has the right to report a complaint concerning the use of personal data to the Irish Data Protection Commission: Data Protection Commissioner.

Data Retention

The anonymised data will be stored in a password protected file on the DCU Google Drive. The anonymised data will be held indefinitely and may be published in peer-reviewed journals and presented at conferences. The names of participants will not be published, and results will only be represented collectively as part of grouped participant results. The anonymised dataset may be shared with other researchers or made available in online data repositories, according to open access publishing guidelines.

Confidentiality of the data

Confidentiality and anonymity is of utmost importance in this study. All anonymised data will be stored in a password protected file on DCU Google Drive. Confidentiality of information can only be protected within the limitations of the law - i.e., it is possible for data to be subject to subpoena, freedom of information claim or mandated reporting by some professions.

Benefits

Direct Benefits: This research will allow you to access evidence-based research in a new format designed to support both persons living with pain and clinicians working in pain clinics. This intervention has the potential to improve your knowledge and competence in self-managing chronic pain

Indirect Benefits: Research has shown the importance of including public and patient involvement in developing new health interventions. Participation in this study will provide you with the opportunity to ensure that a new online pain intervention is fit for purpose and contains appropriate content for individuals living with pain.

Potential risks

It is possible that engaging in the content of the intervention may cause an exacerbation of mental health challenges related to living with chronic pain. We expect the risk to be low but if you experience any adverse effects as a result of participating, we recommend you engage in one of the following options

- Contact KS (pain specialist physiotherapist) for a review and treatment recommendations
- Consult your GP, your pain consultant
- Chronic Pain Ireland on 01-8047567
- HSE provide a text support 'Text about it' 5808

Voluntary Research Study

Involvement within this research is purely voluntary. You are free to withdraw at any time during data collection without having to explain why you wish to do so. If you wish to withdraw at this point, you may email a member of the research team and your request will be facilitated. However, after data collection is completed the data will be anonymised. It will not be possible to identify your responses when the data is anonymised and withdrawal cannot be facilitated at this point.

If you want to access a final copy of the study or would like information on where the results of this research have been published, this information will be provided once you email either of the researchers indicated above.

If participants have concerns about this study and wish to contact an independent person, please contact:

The Secretary, Dublin City University Research Ethics Committee, c/o Research and Innovation Support, Dublin City University, Dublin 9. Tel 01-7008000, e-mail rec@dcu.ie

Appendix C.4 Consent Form Study 3

Informed Consent Form

Research Study Title

The development and content review of the HELP Intervention (**H**ealing and **E**mpowering Lives in **P**ain): An online chronic pain resource integrating public and patient involvement (PPI)

Principal Investigator: Ms. Kate Sheridan, School of Health and Human Performance

Contact details: Kate.sheridan@dcu.ie

Other Investigators: Dr. Siobhán O’Connor, Dr. Enda Whyte, Dr. Sinead O’Keeffe School of Health and Human Performance

Contact Details: Siobhan.oconnor@dcu.ie, enda.whyte@dcu.ie, sinead.okeeffe@dcu.ie

Clarification of the purpose of the research

This research is being conducted to develop and review the content of a new online intervention designed to support individuals living with chronic pain. Data collection will require your name and email address but once data collection has ceased, your email address, name and audio recording following the focus group/think-aloud interview will be deleted and your responses will be anonymised.

Confirmation of particular requirements as highlighted in the Plain Language Statement

Requirements may include involvement in interviews, completion of questionnaire, audio/video-taping of events etc.. Getting the participant to acknowledge requirements is preferable, e.g.

Participant – please complete the following (Circle Yes or No for each question)

I have read the Plain Language Statement (or had it read to me) Yes/No

I understand the information provided Yes/No

I have had an opportunity to ask questions and discuss this study Yes/No

I have received satisfactory answers to all my questions Yes/No

I understand the information provided in relation to data protection Yes/No

I am aware that I will complete an online survey and a focus group Yes/No

I understand I may withdraw from the research study at any time during data collection but once my responses have been submitted and anonymised, it will not be possible for me to withdraw. Yes/No

I have read and understand the arrangements to be made to protect confidentiality of data, including that confidentiality of information provided is subject to legal limitations. Yes/No

I understand that once all identifiable information has been removed, my responses may be shared with other researchers or made available in online data repositories. Yes/No

I consent to participate in this research study. Yes/No

Signature:

I have read and understood the information in this form. My questions and concerns have been answered by the researchers, and I have a copy of this consent form. Therefore, I consent to take part in this research project

Participants Signature: _____

Name in Block Capitals: _____

Date: _____

Appendix C.5 Step 1: Focus Group Question Guide

Step 1: Content Creation and Value Specification question guide

Thank you for taking the time to attend this workshop. I am a physiotherapist who has specialised in pain care for over a decade and am now conducting research to improve the quality of care for people living with pain. I also have personal experience, having lived with a pain condition myself for the past seven years.

Following research completed from 2021 to 2023 we have identified that persons living with pain felt they lacked the knowledge they needed to develop autonomy (where they could make educated decisions about the direction of their treatment) and competence (the ability to competently self-manage their condition). Short appointment times, long waiting lists, not feeling believed all led to the delay in knowledge and impacted their ability to self-manage their condition. The idea of the HELP -platform is to develop an eHealth resource that provides evidence-based information that supports people to self-manage their pain as an adjunct to your usual care.

This interview will be recorded. You can stop the interview at any time if you wish. Do you consent to go ahead with the interview?

Question	Prompt	Rationale
<p>What content do you believe should be on an online resource to support people living in pain?</p>	<p>Why do you suggest that?</p> <p>What resources would support you to live with chronic pain?</p> <p>What do you wish you knew when you were first diagnosed?</p> <p>What information has been hard for you to find?</p>	<p>Public patient suggestions on content.</p>
<p>What other resources have you found useful pain content on?</p>	<p>Was the content useful?</p> <p>What did you learn from the online content?</p> <p>What video contained the most/least helpful information</p> <p>Was content delivered in a clear and understandable manner?</p>	<p>Public patient experience of current resources</p>

<p>From this list of possible content what stands out as important?</p>	<p>Why is this of importance to you?</p> <p>What is not important on this list, why?</p>	<p>Public patient determining importance of suggested content based on behavioural change concepts</p>
<p>Have you any other ideas or feedback you would like to add?</p>		<p>Opportunity for final feedback and suggestions</p>

Appendix C.6 Step 2: Enlight Quality Assessment Tool

Quality Assessment

User Engagement

Assesses the extent to which the EHP's design attracts users to utilize it.

A. Content Presentation. Is the content presented in an engaging/interesting way (e.g., contains the right mix of video/audio/text/graphics)?

1. **Very poor.** The content is presented in the wrong way. For example, there is text throughout the program where narration would be more appropriate.
2. **Poor.** For the most part, the content is presented poorly, but some areas of presentation are adequate.
3. **Fair.** Some major areas are presented appropriately (e.g., via text or audio), but better ways to present the content are still needed.
4. **Good.** Content is delivered through the appropriate use of features, but something is still lacking.
5. **Very good.** The way the content is presented is well suited to the user's need and context (e.g., platform or time of use).

B. Interactive. Does the EHP include high-quality interactive features (which enable user input and reaction)?

1. **Very poor.** There are no interactive features.
2. **Poor.** There are few interactive features, or the interactive features are of poor quality.
3. **Fair.** There are interactive features, but they are of mediocre quality.
4. **Good.** The program presents a good interactive experience (but something is still missing).
5. **Very good.** The program presents a high-quality interactive experience.

N/A – The EHP is not (highly) interactive, and so this is not an appropriate way to examine such a program, for example, a trigger-based intervention.

C. Not Irritating. Does the program avoid irritation in the user's experience (e.g., by controlling notifications/alerts/sounds or avoiding irritating colors/fonts/sounds/expressions)? *Note: Consider pop-up advertisements.*

1. **Very poor.** It is annoying and irritating to utilize the program.
2. **Poor.** Some of the program's key features are irritating.
3. **Fair.** There are some irritating features.
4. **Good.** For the most part, the EHP is not irritating, and users are able to modify any irritating aspects.
5. **Very good.** The program is not at all irritating, and, if relevant, users are given the opportunity to control potentially irritating aspects at the outset in order to avoid an irritating experience.

N/A – The EHP is not irritating, and this is not an appropriate way to examine such a program. For example, a program is very lean (e.g., absent of reminders that it should have) and therefore does not have the potential to be irritating (i.e., giving it a high score would inappropriately skew the results).

D. Targeted/Tailored/Personalized. Are the features tailored to the usage context of the target group? If necessary, does the EHP enable the customization/personalization of the program (e.g., personalized goals/action items, online diary that maintains personal notes, choice of which content to receive)?

1. **Very poor.** The program does not have any targeted/tailored/personalized features.
2. **Poor.** The program includes a few targeted/tailored/personalized features.

3. **Fair.** The program incorporates a fair amount of targeting/tailoring/personalization.
4. **Good.** The program mostly provides a tailored/personalized experience based on users' needs.
5. **Very good.** The program is very well designed in terms of offering the user a targeted/tailored/personalized experience.

E. Captivating. Does utilizing the EHP pique the user's curiosity and interest (i.e., attract users to use it as needed)?

1. **Very poor.** The program is extremely boring and not desirable to use.
2. **Poor.** For the most part, the program features are boring, but there are some positives.
3. **Fair.** The program is neither boring, nor captivating.
4. **Good.** The program is interesting to use.
5. **Very good.** The program is highly attractive and piques the user's curiosity, excitement, and interest.

Content

Assesses the content provided or learned while using the EHP.

Note: As features (e.g., games) are a way of delivering information, the content conveyed within them should be examined.

A. Evidence-Based Content. Is the information provided accurate? Are there evidence-based techniques relevant for achieving the desired clinical aim of the program?

1. **Very poor.** The features/content do not reflect any evidence-based principles in this field.
2. **Poor.** The presentation of evidence-based techniques is sparse OR the program content is not very accurate.
3. **Fair.** There is some presentation of evidence-based techniques, and the content is mostly accurate.
4. **Good.** The program content is accurate and reflects evidence-based techniques (but is still not ideal).
5. **Very good.** The program content is accurate and based on sound evidence-based principles relevant to the clinical aim.

B. Quality of Information Provision. Is the information provided in a clear and appropriate way for the target audience?

Note: Users' age and cognitive and emotional abilities should be taken into account.

1. **Very poor.** None of the information is provided in a way that is clear or appropriate for the target audience.
2. **Poor.** Some of the information is provided in a clear and appropriate way.
3. **Fair.** The information is provided in a way that is mostly clear and appropriate, but could be better.
4. **Good.** The information is provided in a way that is clear and appropriate for the target audience, but still not ideal.
5. **Very good.** The information is provided in the most clear and appropriate way for the target audience.

C. Complete and Concise. Is there sufficient information throughout the program without any omissions, over-explanations, or irrelevant data?

1. **Very poor.** There is too much content that does not allow the user to grasp the relevant information, OR there is almost no content.
2. **Poor.** There is a great deal of content that interferes with the relevant information, OR the content is sparse.
3. **Fair.** There is some superfluous information, OR there are some omissions.
4. **Good.** The information is complete, but not concise enough, OR the information is concise, but not entirely complete.
5. **Very good.** The content is as complete and concise as it can be.

D. Clarity about the Program's Purpose. Is there sufficient and accurate information about the target audience, the clinical aim (e.g., potential outcomes), and appropriate ways to utilize the program (e.g., adjunct, standalone)?

Notes: Includes who should not use it; could be described in distribution channels such as app stores.

1. **Very poor.** There is no information at all about the program's purpose. / Information is either inappropriate or inaccurate.
2. **Poor.** There is little information or poor accuracy.
3. **Fair.** There are some explanations as to the program's purpose, but these might be insufficient for some users.
4. **Good.** The EHP explains who should use the program, what its purpose is, and how it should be utilized, but some information is still lacking.
5. **Very good.** The EHP provides a thorough explanation of who should use the program, what its purpose is, and how it should be utilized.

Therapeutic Persuasiveness

Assesses the extent to which the EHP is designed to encourage users to make positive behavior changes OR to maintain positive aspects of their life.

Note: Factors of social support (e.g., influence, facilitation, cooperation, recognition) should be taken into account while rating.

A. Call to Action. Does the EHP saliently set up measurable and relevant therapeutic activities and inspire/encourage users to complete them?

Notes: Includes sending out prompts if appropriate; does the user have to take part in the goalsetting for the desired action(s) to be relevant/agreeable in this program? If so, rate accordingly.

1. **Very Poor.** Action items are vague, implied, hidden, or non-existent.
2. **Poor.** Some action items exist, but the EHP doesn't inspire users at all
3. **Fair.** There are some relevant/targeted action items, and there is some degree of inspiration/encouragement.
4. **Good.** For the most part, there are relevant/targeted action items and the program stimulates/inspires users to meet their goals.
5. **Very good.** The desired therapeutic activities are well targeted, and the program clearly stimulates/inspires users to complete the activities.

B. Load Reduction of Activities. Are the therapeutic activities that users are required to complete sufficiently simple? Do the features of the EHP make it as easy as possible for users to complete the activities?

Note: This is related also to the features that support the completion of activities.

1. **Very poor.** The therapeutic activities are too complicated for target users to carry out AND the program features do not make the activities easier to complete.
2. **Poor.** The activities are somewhat simplified, but the program features do not make the activities easier to complete.
3. **Fair.** The activities are fairly simple and there are some features that make it easy for users to achieve their goals.
4. **Good.** The activities are simple and straightforward, and the program features make it easy for users to achieve their goals (but still not ideal).
5. **Very good.** The activities are as simple and relevant as possible, and the program features make it as easy as possible for users to engage in the therapeutic activities by providing them with the relevant tools "in house".

C. Therapeutic Rationale and Pathway. Is the therapeutic pathway clear? Is it clear how working through each action item provided by the EHP should lead to the desired therapeutic outcome(s)? *Note: This should also be considered from the user's perspective.*

1. **Very poor.** Users are asked to engage in activities without the therapeutic pathway being defined. The relationship between the activities and the desired outcome does not make sense.
2. **Poor.** While the relationship between the activities and therapeutic progress is understood, it is not clear how the EHP design and the way the action items are provided should lead to the desired therapeutic outcome.
3. **Fair.** It is somewhat clear how the EHP design and the way the action items are provided should lead to the desired therapeutic outcome.
4. **Good.** It is clear how the EHP design and the way the action items are provided should lead to the desired therapeutic outcome (but still not ideal).
5. **Very good.** It is very clear how the EHP design and the way the action items are provided should lead to the desired therapeutic outcome.

D. Rewards. Does the technology recognize desirable achievements and provide appropriate recognition?

Note: This includes documentation of "therapeutic investments," i.e., beneficial work done by the user that is documented in the program in a way that makes users want to stay committed to this pathway (e.g., acquiring points/badges for beneficial activities and showing them on a community board).

1. **Very poor.** The system does not reward users at all.
2. **Poor.** The system uses rewards sparsely/inappropriately.
3. **Fair.** The frequency/appropriateness of rewards is only fair.
4. **Good.** The technology pays attention to desirable achievements. There are rewards most of the time, but they are not ideal (e.g., the same rewards are used all the time, too many rewards, or rewards not creative/accurate enough).
5. **Very good.** The system does a very good job acknowledging when users reach desirable achievements and rewarding them appropriately/creatively/accurately.

E. Real Data-Driven / Adaptive Content. Is the program content influenced by the real user's state and/or achievements? *Examples: Content becomes available when the user is ready (i.e., has made appropriate progress); program content changes based on the user's real behavior/success/failures.*

Note: The user's state does not have to rely on self-assessment; other methods could include passive sensing and clinicians' input.

1. **Very poor.** The user's progress is not monitored, and content is available regardless of the user's state.
2. **Poor.** The user's progress is not well monitored, and content mostly disregards the user's state.
3. **Fair.** The user's progress is monitored but not in a way that has a strong impact on program content, OR the program is adaptive, but not based on an accurate evaluation of the user's state.
4. **Good.** The EHP appropriately monitors the user's state and relies somewhat on the user's progress to determine content.

5. **Very good.** The program adapts well to the user's state/progress by changing its available content accordingly.

F. **Ongoing Feedback.** Does the program provide appropriate ongoing feedback on the user's state?

1. **Very poor.** The program does not provide any feedback.

2. **Poor.** The program provides minimal feedback, for example, only after enrollment and taking baseline measurements.

3. **Fair.** Feedback is embedded within the program (e.g., graphs of outcome measures, calorie intake), but not in a way that provides users with a good understanding of their state.

4. **Good.** Feedback is embedded within the program, mainly in a way that provides users with an understanding of their state (e.g., via clear verbal explanation).

5. **Very good.** Feedback is embedded within the program with salient, accurate, and appropriate regard to the user's current state.

G. **Expectations and Relevance.** Does the program convincingly advocate for intervention's relevance, and explain the intervention framework and the general expectations of the user?

Note: Advocating entails relating to one's own state, difficulties in making/sustaining a change, motivation and consequences for using it.

1. **Very poor.** There is no explanation of the program's relevance and its expectations of the user.

2. **Poor.** The program offers only limited explanation of its relevance and expectations of the user.

3. **Fair.** The program offers an adequate explanation of its relevance and expectations of the user.

4. **Good.** The EHP advocates for its relevance, and explains the framework and general expectations appropriately (but something is still missing).

5. **Very good.** The EHP effectively advocates for its relevance, and explains the framework and general expectations.

N/A – The EHP does not explain its expectations/relevance, but this is not an appropriate way to examine such a program. For example, the targeting of a program makes it irrelevant to set up expectations.

Therapeutic Alliance

Assesses the ability of the program to create an alliance with the user in order to effect a beneficial change. *Note: Factors of social support (e.g., influence, facilitation, cooperation, recognition) should be taken into account while rating.*

A. **Basic Acceptance and Support.** Does the EHP make an effort to show that it understands and empathizes with the user; genuinely cares for the user; and relates to the user in a positive fashion? *Note: The EHP is not a person so this should be done appropriately within the limits of the medium.*

1. **Very poor (neutral).** There is no positive regard for OR effort to understand the user's perspective.

2. **Poor.** There is only a minimal gesture to demonstrate understanding/caring for the user's perspective.

3. **Fair.** In general, there is positive regard and care for the user (some degree of outreach is needed to receive 3).

4. **Good.** The EHP is designed to provide users with feelings of basic acceptance and support.

5. **Very good.** The EHP proactively shows users that they are accepted and supported as a salient aspect of the program.

B. Positive Therapeutic Expectations. Does the EHP encourage users to expect beneficial outcomes from utilizing the program and to rely upon it in the medical context?

Note: Consider how well the program instills confidence in users that they are in “good hands” (projecting trustworthiness and professionalism through tone, narrative, convincing presentation, reliable “look and feel”, and meeting people’s exact needs at the right time).

1. **Very poor (neutral).** The program does not instill confidence in users that they will benefit from the program. No professionalism/trustworthiness is conveyed.
2. **Poor.** The program instills minimal confidence in the user and conveys limited professionalism/trustworthiness.
3. **Fair.** The program instills some confidence in the user and conveys some professionalism/trustworthiness.
4. **Good.** The program instills a good degree of confidence in the user and conveys a good degree of professionalism/trustworthiness, but something is still missing.
5. **Very good.** The program effectively instills confidence in users that they will benefit from the program through professionalism and trustworthiness.

C. Relatability. Does the EHP offer a good representation of a human factor that is easily relatable within the therapeutic context/process? Examples include a professional character who directs the user throughout the program; a peer who was in a similar situation and is now better (e.g., fitness); a vivid virtual character who leads the user; a community of people working together for change.

Notes: A community of people NOT “working” to positively support each other does not count; even text messages could create such projections through language, sender’s identity, and responsiveness.

1. **Very poor.** There is no relatable human factor.
2. **Poor.** Some representation of a human factor exists, but it is not really therapeutic or easily relatable.
3. **Fair.** There is a representation of a positive human factor, but no effort is made to communicate with the user on a personal level. The human factor seems somewhat distant from the user.
4. **Good.** There is a representation of a human factor that users can relate to throughout the therapeutic process. However, users might not be able to relate to this factor in an ideal way.
5. **Very good.** The representation of a human factor is salient throughout the therapeutic process; for example, users are potentially able to become really familiar with this human factor (e.g., professional character) or feel they are part of a community.

Note: When presenting/calculating only Therapeutic Alliance concept (without other concepts), the following items should be included: Therapeutic Rationale and Pathway & Targeting/Tailoring/Personalization.

General Subjective Evaluation of Program’s Potential

Examines the program’s general potential to benefit its target audience based on rater’s subjective evaluation.

A. Appropriate Features to Meet the Clinical Aim. Are the EHP features sufficient enough to meet its therapeutic goals?

1. Not at all.
2. Mostly not.
3. To some extent.
4. Appropriate.
5. Very appropriate.

B. Right Mix of Ability and Motivation. Is the target audience able and motivated to utilize the program as much as needed to reach the therapeutic aim?

Note: A change is created when people are able and motivated enough to make the change. If the change is easy, motivation doesn't have to be as high, and vice versa.

1. Not the right mix at all.
2. Mostly not the right mix.
3. To some extent.
4. Good mix.
5. Excellent mix.

C. I Like the Program.

1. Do not like it at all.
2. Mostly do not like it.
3. Like it to some extent
4. Like the program.
5. Like the program very much.

Evidence-Based Program

Assesses the quality of empirical research supporting program's efficacy.

1. **Very poor.** There is no research on the program OR poor (#2) research was done only by the developers (who are NOT active researchers working within a not-for-profit institute).
2. **Poor.** The research conducted is of low quality, for example, relying on users' attitudes toward using the program, or not conducted within this technology zeitgeist.
3. **Fair.** The research is of fair quality and was conducted within this technology zeitgeist. For example, it involved at least two pilots with the right outcome measurement OR one RCT, but did not utilize the most reliable/valid outcome measurement (e.g., not a pre-registered clinical trial, not a validated outcome tool).
4. **Good.** Some good research shows evidence of efficacy. For example, there have been several published pilot studies + one pre-registered RCT with sufficient power done by a credible source showing it is superior to wait list control condition OR one pre-registered RCT at the level of RCTs described in 5. Related research was conducted within this technology zeitgeist.
5. **Very good.** The program boasts strong research support, with at least two pre-registered RCTs with adequate statistical power conducted by at least two different credible sources, in which: the program was found to be superior to an appropriate placebo (wait list is not a placebo) or equivalent to acceptable evidence-based treatment groups. Related research was conducted within this technology zeitgeist.

Note: RCT – Randomized Controlled Trial

ENLIGHT SUGGESTED SUMMARY REPORT

EHealth Program Quality

Core Domains

Usability: _____ Design: _____
User _____
Engagement: _____

Content: _____ Therapeutic _____
Persuasiveness: _____

Therapeutic Alliance: _____

Reviewer's General Subjective _____
Evaluation: _____

Checklists Measures

Credibility: _____

Evidence-Based Program Score: _____

Explains Aspects of User Privacy: Yes / No / n/a

Secures Data Collected/Transmitted: Yes / No / n/a Third-Party Endorsement for Security: Yes / No / n/a

Verbal Recommendation

Who should use this program?

When should people use this program?

How should this program be used?

What kind of support/tools should users use off-product that might enable them to utilize the program well?

Appendix C.7 Step 3 Think Aloud Session – PPI Guide

Welcome and thank you for taking part in this session!

Today we are exploring how easy it is to use the **HELPP website**, especially when looking for information on **improving physical activity levels while living with chronic pain**.

What is a "Think Aloud" Session?

A *Think Aloud* session is a type of research where we ask you to use the website to complete a task **while speaking your thoughts out loud**. This helps us understand what you're thinking, noticing, or feeling as you move through the site.

There are **no right or wrong answers** – we're interested in your honest thoughts and reactions.

What You'll Do

Your Task:

Please use the HELPP website to find information on how someone living with chronic pain could improve their physical activity levels and find a link to extra resources you access to support your physical health.

As you do this, we ask you to say your thoughts out loud, such as:

- "I'm not sure where to click here..."
- "This seems helpful because..."
- "I didn't expect this page to show up..."
- "I'm looking for information about exercise, but I'm not sure where it is."

The session will be audio recorded, with your permission, so we can review your feedback afterwards.

Your Role

- Be **honest** and **open** – we're testing the website, not you!
 - Say whatever comes to mind as you complete the task.
 - Feel free to mention what you **like**, what you **don't like**, or **what's confusing**.
-

Why It Matters

Your feedback will help us improve the HELPP website so that it is more **useful, supportive, and easy to use** for people living with chronic pain.

Thank you again for your time and for helping us improve this resource!

**Appendix C.8 Step 3 System Usability Scale (SUS)
Systems Usability Scale (SUS)**

Please enter your participant number: _____

This is a standard questionnaire that measures the overall usability of a system. Please select the answer that best expresses how you feel about each statement after using the website today.

	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
1. I think I would like to use this tool frequently.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I found the tool unnecessarily complex.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I thought the tool was easy to use.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I think that I would need the support of a technical person to be able to use this system.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I found the various functions in this tool were well integrated.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I thought there was too much inconsistency in this tool.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I would imagine that most people would learn to use this tool very quickly.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I found the tool very cumbersome to use.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I felt very confident using the tool.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. I needed to learn a lot of things before I could get going with this tool.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How likely are you to recommend this website to others? (please circle your answer)

Not at all likely 0 1 2 3 4 5 6 7 8 9 10 Extremely likely

SUS yields a single number representing a composite measure of the overall usability of the system being studied. Note that scores for individual items are not meaningful on their own.

To calculate the SUS score, first sum the score contributions from each item. Each item's score contribution will range from 0 to 4. For items 1,3,5,7,and 9 the score contribution is the scale position minus 1. For items 2,4,6,8 and 10, the contribution is 5 minus the scale position. Multiply the sum of the scores by 2.5 to obtain the overall value of SU.

SUS scores have a range of 0 to 100.

Appendix C.9 Focus Groups and Interviews Content and Value Specification

Challenges of Living with Pain
An Invisible illness Isolation Suffering The vicious circle Comorbidities (Weight gain, BP, metabolic conditions) Whole body health Guilt and pain Pain is individual Self-blame - guilt Pain - a whole-body experience One size doesn't fit all You are the expert Building a toolbox for management Having hope Having an identity outside of pain Managing different levels of pain (traffic light system?) Invalidation Prevalence of pain - it is real Access to non-pharmacological management Impact on lifestyle

Pain Science
Understanding Pain - pain physiology Pain Science, nervous system Inflammatory response It's not in your head Role of non-pharmacological therapies imaging - and relationship to pain

Your Role in Pain
Empowerment Start self-management early Whole body approach Coping skills Make life bigger Regaining confidence

Being your own expert
Advocate for self
Managing pain is a journey and involves self-learning
Living an active fulfilling life
Working with pain
Managing flare ups
How to explain pain to friends
Understanding lifestyle pillars
Autonomy -choice of how to manage pain
Connecting with Values
Engage in supported self-management
Helping you to help yourself
Goal setting
Stress management

Physical Activity

Exercise videos
Exercise with pain
Pacing
Fatigue
Safe to move
Avoid rest
Sleep
Physical activity

Psychological Wellbeing

Emotions and pain - grief, loss, anger, sadness, depression, anxiety
Change to sense of self
Mind body connection
Resilience (lowered with pain)
Forest bathing
Meditation
Stress Management
Fear
Psychological support
Affirmations
Relaxation/ breath work
Somatic Tracking
Compassionate Body scan
Building a relationship with yourself
Spiritual health

--

Social Wellbeing

Social prescribing Socialising Avoid isolation Age friendly university program - creative writing, walks Maintaining a social life Valued Activity Peer Support

Navigating the system

Forming a partnership with Healthcare Professionals Practical supports - disability bathrooms, parking badges Family supports Advocating for self What to ask in appointments Cheat sheet for navigating the pain services Changing to automatic car What is covered on drug payment scheme Being able to describe your pain in appointments Understand healthcare professionals roles Acknowledge previous negative experiences with HCP

Research Dissemination

Easy to understand language Other resources, books, podcasts

Appendix C.11 Heuristic Testing Group Feedback Summary

1. General Impressions

- The resource was seen as clear, welcoming, and thoughtfully structured.
- Participants felt it reflected their lived experience and used a respectful tone.

2. Tone and Language

- The tone was praised as warm and friendly.
- A suggestion was made to make the site more personable, for example by including real or stock images alongside quotes to humanise the experience.
- One contributor recommended a short introductory video from the creator to humanise the homepage.

3. Content and Relevance

- The site is informative and evidence-based, but some users felt it could be more interactive and layered, especially for people at different stages of their pain journey.
- There was a suggestion to differentiate content for people newly diagnosed versus those with longstanding pain experience.
- One contributor suggested that each page should include a clearly defined knowledge point and an associated action step to enhance clarity and encourage practical application.

4. Navigation and Structure

- The layout was generally easy to follow, but some menus felt cluttered, and there were issues with having to navigate backwards rather than directly between pages.
- Some hyperlinks were not yet active, and a clearer visual structure was recommended.

5. Functionality and Future Potential

- Participants suggested that the platform could benefit from:
 - An interactive pain diary.
 - Features for logging pain triggers, diet, and flare-ups.
 - A forum or peer support element in future iterations

Appendix C.12 Summary of Think Aloud Feedback on the HELP Platform

Global Impressions

Participants responded positively to the HELP prototype. They described it as clear, accessible, and relevant to lived experiences of chronic pain. The tone and structure were described as hopeful, empowering, and encouraging, offering a sense of connection and validation. The platform was seen as especially valuable for those not familiar with existing pain resources.

Strengths Identified

- **Tone and Voice:** Users appreciated the non-clinical, supportive tone that felt realistic and non-judgemental.
- **Accessibility:** The layout and navigation were described as straightforward, even for users less confident with technology.
- **Content Quality:** The inclusion of real-life quotes, practical examples (e.g., “walk in your local park”), and non-exercise-based activity suggestions (e.g., swimming, dancing) were praised for relatability.
- **Videos and Links:** The short video clips and external links to credible resources (e.g., HSE, community groups) added perceived value and usability.

Key Suggestions for Development

1. **Swimming & Alternative Activities:** Participants stressed the need to include swimming and water-based activity options, especially for those with mobility limitations.
2. **Mental Health Integration:** Users highlighted the strong connection between mental and physical health. They recommended more integrated content, linking physical activity with mood, motivation, and depression.
3. **Stigma and Validation:** Suggestions were made to reframe content that might unintentionally reinforce stigma or threat. Participants wanted greater emphasis on compassion, pacing, and not “giving in” without promoting guilt.
4. **Social and Emotional Support:** Encouraging group or buddy systems for more demanding exercises was seen as helpful. Participants noted that doing activities with a partner can reduce fear and increase enjoyment.
5. **Content:** Some sections, particularly more clinical ones, were seen as abrupt or overly technical. Clear introductions and more user-friendly transitions were recommended.
6. **Family and Carer Content:** Participants recommended a section for family members to better understand chronic pain and how to provide balanced support without enabling inactivity.
7. **Diet and Weight Management:** Several users noted that diet is missing from the platform. They suggested including advice or resources on nutrition, weight maintenance, and its relationship to pain and energy.

Appendix C.10. Images from the HELP-Platform

The HELP-Platform can be viewed in full at www.HELP-Platform.eu


HELP-Platform.eu


Our Mission

Empower your journey: transform pain through knowledge and action.

Stigma and Pain

Chronic pain is often called an invisible illness and people living with pain often experience stigma. Being stigmatised means being unfairly judged or labelled negatively and it can lead to discrimination and exclusion. Conditions lacking clear medical explanations tend to be more associated with higher levels of stigma.






Learning to self manage pain:

“I’m doing the management and treatments that I want. But I’ve also done a huge amount of research with others to try and decide what is the right one currently and that might change over time.”

47 Neuropathic pain



Books

Pain is Really Strange Steve Haines
This short research-based graphic book reveals just how strange pain is and explains how understanding it is often the key to relieving its effects.

Manage Your Pain Michael Nicholas
Drawing on the latest research, Manage Your Pain explains the positive and practical ways you can adapt to chronic pain in order to minimise its impacts on your life.

The Way Out Alan Gordon
This book provides an easy-to-follow guide to ending your pain with Pain Reprocessing Therapy.

