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Exploring stakeholders' perceptions of peer support for adults with chronic pain: a mixed methods study.

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2023

Exploring stakeholders’ perceptions of peer support for adults with chronic pain: a mixed methods study

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A thesis submitted in partial fulfilment of the requirements of the
Robert Gordon University for the degree of Doctorate of Physiotherapy

This research was carried out in collaboration with NHS Grampian

October 2023

DECLARATION OF AUTHORSHIP

I, Rachel Arnott, declare that this thesis titled, “Exploring stakeholders’ perceptions of peer support for adults with chronic pain: a mixed methods study” and the work presented in it are my own. I confirm that:

- This work was done as a candidate for the Doctorate of Physiotherapy degree at Robert Gordon University.
- Where I have consulted the published work of others, this is always clearly attributed.
- Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work.
- I have acknowledged all main sources of help.

Signed: Rachel Arnott

Date: 11 October 2023

ABSTRACT

Rachel Elise Arnott

Doctorate of Physiotherapy

Exploring stakeholders’ perceptions of peer support for adults with chronic pain: a mixed methods study

Background: Peer support interventions could play a pivotal role in the management of chronic pain, yet there has not been a study to assess the preferences of adults with chronic pain or healthcare professionals regarding intervention components. Critical gaps in the current research base include understanding the perceptions of those that develop and participate in peer support interventions. This information is crucial for healthcare services, charities and community groups to be able to develop and implement interventions that are both feasible and optimally beneficial for those involved.

Aims: The aim of this study was to explore the preferences of stakeholders surrounding peer support interventions (PSIs) in order to make recommendations for the design and development of peer support interventions tailored to adults with chronic non-cancer pain. Stakeholders included adults with chronic non-cancer pain and individuals with experience of managing chronic pain or delivering peer support interventions.

Methods: This research was a mixed methods sequential explanatory study with two phases. Both phases were conducted with two participant groups: 1) adults with chronic non-cancer pain and 2) individuals with experience of treating chronic pain or delivering peer support interventions. The first phase consisted of an online survey and subsequent analysis with descriptive statistics to determine participant preferences regarding intervention components. The second phase consisted of qualitative semi-structured interviews with framework analysis. This aided in exploring these preferences in greater depth and determining any common similarities or differences amongst and within the participant groups.

Key findings: The key findings from the mixed method study were focussed on participants expressing a desire for PSIs to be flexible and delivered in multiple ways. Participants wanted programmes with flexible scheduling, offered in as many delivery modes as possible (face-to-face, online, option for follow up via messaging or phone calls) and without obligation or judgment when pain flares prevented their attendance. Participants also expanded on the reasons for wanting flexible offerings as barriers to attendance such as physical and logistical barriers made it difficult to consistently attend in-person gatherings. Participants shared how chronic pain can affect people across the lifespan, so it is valuable to talk with someone from a similar life stage (retired versus working, with or without children). Finally, participants placed high value on individual preferences and suggested whenever a programme is being developed, for organizers to receive input from potential attendees.

Conclusions: This research generated new knowledge which can be used to make recommendations for the design and development of peer support interventions tailored to adults with chronic pain. The NHS and other healthcare systems can utilise PSIs as an alternative way to support people living with pain and value person-centred care. Additional exploratory work is required to coproduce, pilot and evaluate a PSI incorporating the key findings from this research.

Key Words: chronic pain, peer support, self-management, person-centred practice

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And lastly, to those I've loved and lost in these recent years. Life can take unexpected turns so it's important to cherish the moments you have.

OUTPUT SUMMARY

Poster Presentations

JBI European Symposium (24 June 2021)

> *"Exploring the Experience of Participating in a Peer Support Intervention for Individuals with Chronic Non-cancer Pain"*

NHS Scotland Half-Day National Allied Health Professional (AHP) Research Virtual Conference (8 November 2022)

> *"Exploring the Experiences and Perceptions of Participating in a Peer Support Intervention for Adults with Chronic Non-cancer Pain: a qualitative systematic review"*

Oral Presentations

Robert Gordon University 3 Minute Thesis Competition (9 June 2021)

> *"Isolation Sucks: Peer support and chronic pain" (3rd place)*

Robert Gordon University 3 Minute Thesis Competition (9 June 2022)

> *"I'll be there for you: the Power of Peer Support" (People's Choice Award)*

Journal Publication

JBI Evidence Synthesis (2 February 2023)

> *Arnott R, Park V, Rhind N, Cooper K. Exploring the experiences and perceptions of participating in a peer-support intervention for adults with chronic non-cancer pain: a qualitative systematic review. JBI Evid Synth. 2023 Aug 1;21(8):1509-1548. Doi: 10.11124/JBIES-22-00137.*

LIST OF ABBREVIATIONS (IN ORDER OF APPEARANCE)

PSI	Peer Support Intervention
NHS	National Health Service
JBI	[Formerly known as Joanna Briggs Institute]
AHP	Allied Health Professional
UK	United Kingdom
WHO	World Health Organization
IASP	International Association for the Study of Pain
ICD	International Classification of Diseases
MDT	Multidisciplinary Team
PSV	Peer Support Volunteer
MRC	Medical Research Council
COM-B	Capability, opportunity and motivation behaviour system
RCT	Randomised Controlled Trial
AHRQ	Agency for Healthcare Research and Quality
SUMARI	System for the Unified Management, Assessment, and Review of Information
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-analyses
CLBP	Chronic Low Back Pain
JIA	Juvenile Idiopathic Arthritis
RA	Rheumatoid Arthritis
MSK	Musculoskeletal
PwCP	Participant with Chronic Pain
IMD	Indices of Multiple Deprivation
PMH	Past Medical History
PS	Peer Support
F2F	Face-to-face
GDPR	General Data Protection Regulation
RGU	Robert Gordon University

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1 CHAPTER 1: INTRODUCTION

1.1 Introduction to Chapter 1

This chapter introduces the thesis. It begins with a definition of chronic pain then explores several related topics such as aetiology, classification, epidemiology, financial burden and management. Self-management is then defined and the current research base and theoretical underpinnings are discussed, along with an examination of United Kingdom (UK), international and global health frameworks. Finally, peer support is defined, intervention variations are explored and strengths and limitations are observed. Peer support is also discussed in relation to populations and effectiveness, theoretical underpinnings and frameworks and quality of evidence and debates in the literature. This will set the scene for a review of the current evidence base as justification for this thesis.

1.2 Chronic Pain

1.2.1 Definition

Both the World Health Organization (WHO) and the International Association for the Study of Pain (IASP) classify pain as chronic when it persists beyond 12-weeks (Treede, Rolf-Detlef et al. 2015; Merskey and Bogduk 1994), as this is the normal time for tissue healing (Turk and Melzack 2010). Chronic pain is also known as persistent pain or long-term pain (NICE 2021) and is distinguishable from acute pain which lasts less than 12-weeks (Lavand'homme 2011). Both the term and definition for chronic pain have evolved over time, along with an understanding of the prominent clinical features of pain and what that means for clinical practice (Mailis, Tepperman and Hapidou 2020). The term chronic pain is be used in this thesis as it appears to be the most widely accepted term in the UK, although usage of persistent and long-term pain does continue in some circles.

Considering the definition of pain, until the 1960s, pain was understood to occur as a result of tissue damage (Loeser and Melzack 1999). In 1959 Engel proposed that pain could have a psychogenic component and tissue damage was not necessary for a person to experience pain (Engel 1959). Today, it is evident that psychosocial factors contribute to the experience of pain (Mailis, Tepperman and Hapidou 2020) and the IASP has acknowledged that the experience of pain is not exclusive to those with proven tissue damage:

> *"Many people report pain in the absence of tissue damage or any likely pathophysiological cause; usually this happens for psychological reasons. There is usually no way to distinguish their experience from that due to tissue damage if we take the subjective report. If they regard their experience as pain, and if they report it in the same ways as pain caused by tissue damage, it should be accepted as pain."* (Merskey and Bogduk 1994 p. 67)

1.2.2 Aetiology and classification

Beneath the umbrella term of chronic pain are multiple levels of division. Broadly, pain syndromes can be broken into the categories of primary and secondary (which can also coexist), as categorized by the International Classification of Diseases (ICD-11) (Treede, R. et al. 2019). Figure 1.1 displays the classification of primary and secondary pain syndromes. Chronic primary pain syndromes conceive of pain itself as a disease, while in chronic secondary pain syndromes, pain is initially manifested as a symptom of another disease (e.g., osteoarthritis, rheumatoid arthritis or endometriosis) or a physically traumatic incident (e.g., motor vehicle accident) (Treede, R. et al. 2019). After successful management or spontaneous healing of the underlying disease or trauma, chronic pain may persist; in such cases, this is the moment when chronic pain becomes a problem in its own right (Treede, R. et al. 2019). As the pain persists beyond successful treatment of the initial cause, the pain diagnosis remains, even after the underlying disease or trauma is no longer present (Treede, R. et al. 2019).

Secondary pain syndromes can be further divided into six subtypes that comprise the most common clinically relevant disorders. These groups are: (1) cancer-related pain, (2) postsurgical or posttraumatic pain, (3) neuropathic pain, (4) headache or orofacial pain, (5) visceral pain, and (6) musculoskeletal pain (Treede, Rolf-Detlef et al. 2015). Table 1.1 displays the subtypes of chronic pain.

1.2.3 Epidemiology and cost

Chronic pain is a global issue and has been recognized as one of the most prominent causes of disability worldwide (Abrams, Elissa M. et al. 2020). The global prevalence of chronic pain is high, affecting up to 40% of American adults, (Gaskin and Richard 2012) 50% of adults in

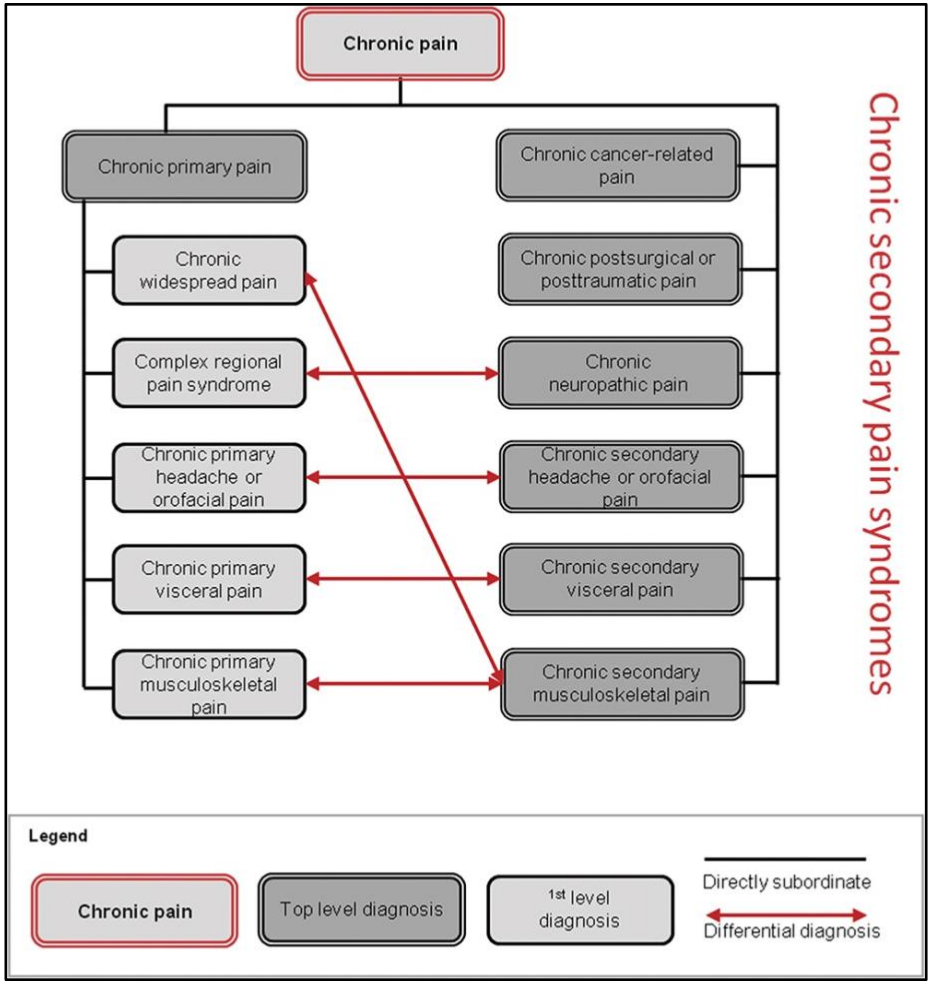


Figure 1.1 The IASP Classification of Chronic Pain (Treede et al. 2019, used with permission)

Table 1.1 Subtypes of Chronic Pain

Subtype of chronic pain	**Definition**
Primary	pain that cannot be better accounted for by another chronic pain condition (Nicholas et al. 2019)
Secondary: cancer –related	pain caused by the cancer itself (by the primary tumour or by metastases) or by its treatment (surgery, chemotherapy, and radiotherapy (Bennett et al. 2019)
Secondary: postsurgical or posttraumatic	pain that develops or increases in intensity after a surgical procedure or a tissue injury and persists beyond the healing process, ie, at least 3 months after the surgery or tissue trauma (Schug et al. 2019)
Secondary: neuropathic	pain caused by a lesion or disease of the somatosensory nervous system (Scholz et al. 2019)
Secondary: headache or orofacial	headaches or orofacial pains that occur for more than 2 hours per day on at least 50% of the days during at least 3 months (Benoliel et al. 2019)
Secondary: visceral	pain that originates from internal organs of the head/neck region and the thoracic, abdominal, and pelvic cavities (Aziz et al. 2019)
Secondary: musculoskeletal	pain that arises as part of a disease process directly affecting bone(s), joint(s), muscle(s), or related soft tissue(s) (Perrot et al. 2019)

the UK (Fayaz et al. 2016), 20% of Australian adults, (Australian Government 2020) and 33% of adults across 28 low- and middle-income countries (Jackson et al. 2015).

The financial cost of chronic pain is substantial, not only for the individual but also for healthcare systems and economies. There is a greater economic impact of chronic pain compared with most other health conditions due to its impact on work absence, reduced levels of productivity and increased risk of altogether leaving the labour market (Hoy et al. 2012). The Global Burden of Disease identified low back pain as the leading cause of years lived with disability in 2019 (Abrams, E. M. et al. 2020). Total costs of chronic pain have been estimated between $560 to 635 billion in the US (Gaskin and Richard 2012) $73.2 billion in Australia (Deloitte 2019) and €300 billion on back pain alone in the EU (European Pain Federation 2010).

Beyond the financial cost, chronic pain has a substantial and multidimensional impact on the individual. Having chronic pain is associated with interference in physical functioning, professional life, relationships and family life, social life, sleep and mood (Hadi, McHugh and Closs 2019). Additionally, people with chronic pain have significantly poorer quality of life (Hadi, McHugh and Closs 2019). Chronic pain is also felt unequally in society with more women affected and prevalence increasing with age, deprivation and certain ethnic minority groups (Fayaz et al. 2016). With such a high global prevalence, economic and personal impact, developing methods of managing and supporting people with chronic pain remains a priority.

1.2.1 Management

Some of the key clinical recommendations for managing chronic pain include pharmacological management, psychologically based interventions, physical therapies and supported self-management (Scottish Intercollegiate Guidelines Network 2019). Members of the multidisciplinary team (MDT) such as nurses, physiotherapists, psychologists, anaesthetists and pharmacists all play vital roles in the implementation of these management strategies. Pharmacological management can include a range of medications such as non-opioids, opioids, anti-epilepsy drugs and antidepressants (Scottish Intercollegiate Guidelines Network 2019). Psychologically based interventions can include behavioural therapies, mindfulness, and acceptance and commitment therapy (Scottish Intercollegiate Guidelines Network 2019). Physical therapies can include exercise prescription, manual therapy, and electrical physical modalities (only transcutaneous electrical nerve stimulation and low-level laser) as recommended by Scottish and UK guidelines (National Institute for Heath and Care Excellence 2021; Scottish Intercollegiate Guidelines Network 2019). As chronic pain is a lifelong condition, self-management is a key component of chronic pain management. Self-management interventions for chronic pain are not new, and there is a significant body of research on the topic (Taylor et al. 2014; Oliveira et al. 2012). Despite this, further research is required to determine the optimal method of facilitating self-management (Thompson, Dean M. et al. 2022).

1.3 Self-management

1.3.1 Definition

Self-management is defined as “the 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 can be taught and supported through various platforms, such as interventions led by healthcare professionals (Coleman et al. 2012), community-based networks for skill training and support (Davies et al. 2008), virtual options such as telehealth (Hanlon et al. 2017) and increasing access to health information (Dean et al. 2017). Common components of self-management include pain education, physical activity, lifestyle modification, psychological therapy and mind-body therapy (Ersek et al. 2008). Self-management programmes can be community-based and affordable interventions to help patients better manage their condition (Du et al. 2011). These programmes are structured, with the aim of allowing participants to become active in the management of their own chronic conditions (Foster et al. 2007).

1.3.2 Current research base

As the global prevalence and cost of chronic pain is evident from the discussion above, self-management has become a frequently explored solution to aid both people with chronic pain and healthcare systems struggling to cope with high service demands. Self-management is aimed at helping people reduce the impact pain has on their mood, function and quality of life. Increasing participant engagement in care and education on preventative strategies could both contribute towards less reliance on healthcare services by optimizing an individual's management of their existing condition. Evidence has shown that programmes with an element of self-management have assisted those living with a chronic condition by enhancing their symptom control and thus improving health outcomes (Whitehead and Seaton 2016). Improved well-being and adaptive lifestyle changes have also been obtai3ned through psychological adjustment in the circumstance of a chronic condition (Kamper et al. 2015). Furthermore, the effects of self-management (specifically for low back pain) have been found to be similar to more costly and intensive interventions such as behavioural therapy, spinal manipulative therapy and nonsteroidal anti-inflammatory drugs (Oliveira et al. 2012).

While there is evidence for the benefits of self-management, some studies reported inconclusive or unsupported evidence regarding its use. Nolte and Osborne found self-management to be marginally effective for the outcomes of pain, disability and depression for adults with osteoarthritis, although more significant improvements were noted for self-efficacy and knowledge (Nolte and Osborne 2013). Jordan et al. reported inconclusive results for the use of self-management with adults with osteoarthritis as three out of seven studies reported improvement in pain intensity and only one in five studies found improvements for functional disability and quality of life (2010). Elbers et al. reported a marginal impact on self-efficacy, pain intensity, physical function and physical activity for patients with chronic musculoskeletal pain but did note this could be attributed to interventions that were generic in nature instead of specific to a particular condition (2018). Additionally, Keogh et al. attributed both the limited effectiveness along with the great variety in content and delivery of self-management interventions to the inconsistent use of behaviour change theory (Keogh et al. 2015).

1.3.3 Theory

While very few studies on self-management explicitly identify a theoretical underpinning for their interventions, there are several that can be used with interventions aiming to improve self-management. These theories include cognitive behaviour theory, collaborative decision making, social cognitive theory, theory of planned behaviour, acceptance and commitment therapy, social learning theory and social comparison theory (Nicholl et al. 2017). Other approaches commonly used as rationales for self-management interventions include empowerment and person-centredness (Nicholl et al. 2017).

In order to optimally design and implement a self-management intervention, it is crucial to possess a strong theoretical understanding of how the intervention will cause change (Hancock and Hill 2016). Without this, the study may be weakened as the development of the intervention could be driven by pragmatics instead of a solid theoretical foundation. This could in turn impact the overall effectiveness of the intervention.

1.3.4 UK, International and Global Health Frameworks/Guidelines

In recent years, countries such as the UK, Canada and Australia have published national frameworks focused on empowering patients to improve self-management skills (Connell, Mc Carthy and Savage 2018). In addition, the WHO issued a 2021 guideline calling for future research to be focused on the development of self-care interventions; specifically determining optimal design features (World Health Organization 2021). Numerous studies have been conducted which show that self-management skills can be improved with the use of peer support (Stubbs, Brendon et al. 2016; Matthias, Marianne S. et al. 2015; Qi, Li et al. 2015). Furthermore, Scottish health policies such as the Framework for Pain Management Service Delivery 2021 (Scottish Government 2022b), 2020 Vision (Scottish Government 2010) and The Active and Independent Living Programme (Scottish Government 2017) focus on empowering people to manage the impact of pain on their lives. Improving skills with self-management are key in these policies along with improving access to services, realistic medicine and targeting researching and collecting meaningful data to shape services (Scottish Government 2022a).

1.4 Peer support

1.4.1 Definition

Peer support is based on individuals with similar conditions supporting one another by providing emotional, appraisal and informational assistance (Dennis 2003a). Peer support emerged from the mental health consumer movement of the 1970s, (Patrick 2013) with published research originating in 1991 (Sherman and Porter 1991). Since that time, researchers have studied the use of peer support with a variety of populations, and the interventions themselves can vary in numerous ways.

So far, this chapter has defined and examined both chronic pain and self-management. As this next section is focussed on peer support, a review of the literature is presented here, and a more comprehensive systematic review will be provided in the following chapter.

1.4.2 Literature Review

Conducting a literature review is important for several reasons as discussed by DePoy and Gitlin (2019). These include recognizing previous research on the topic of chronic pain and peer support, examining the level of theory and knowledge development, determining the relevance of the current knowledge base to the problem area of the primary research and providing a rationale for the research strategy of the primary research (DePoy and Gitlin 2019).

The author conducted a literature review in order to provide a foundational understanding of the research conducted to date on peer support for people with chronic pain. This was achieved by identifying relevant studies and synthesizing the information in order to provide an overview and locate gaps in the research base.

1.4.3 Search Strategy

The databases that were searched included AMED, CINAHL and Medline (all EBSCO). Search terms included “chronic pain” and “peer support” and variations of each term, which were adapted for each information source. Databases were searched from inception to January 21, 2021 and updated on September 27, 2022. The full search strategy is provided in Appendix I.

1.4.4 Results of Literature Review

The results of the literature review are presented below and pertain to PSI variations, strengths and limitations, populations and effectiveness, theoretical underpinnings and frameworks and quality of evidence and debates in the literature.

1.4.5 Variations

These variations include the format, which can vary from a one-to-one interaction, (Matthias, Marianne S. et al. 2016a) a group (Tse, Mimi et al. 2020a) or a hybrid of the two (Shadick et al. 2018). Another variation includes delivery, which can range from a face-to-face interaction, (Tse, Mimi et al. 2020a) audio call, (Shadick et al. 2018) video call, (Jeffrey et al. 2020) social media platform, (Young et al. 2018) online discussion forum, (Gavin et al. 2014) or a combination of two or more of these interaction types (Cooper, Kay et al. 2020). The length of a PSI can vary from as littl6e as a singular interaction (Kumar et al. 2011b) to two years (Johansson et al. 2017). Another important component is the role and training of the peer support volunteer (PSV), as formal interventions may provide extensive training (Cooper, Kay et al. 2018) while less formal interventions may provide no training whatsoever (Young and Heinzerling 2017).

1.4.6 Strengths and Limitations

Peer support interventions (PSIs) could play a pivotal role in the management of chronic pain as their purpose is to empower patients by equipping them with self-management skills which can aid in improving health outcomes (Anderson and Funnell 2010). Indeed, improved condition management can be attained by ensuring adequate amounts of social support, particularly support that is condition-specific (Miller and Dimatteo 2013).

Examining the literature on the use of PSIs for adults with chronic non-cancer pain has shown promising effects. Effectiveness studies on PSIs have shown improvements in psychological outcome measures, (Tse, Mimi et al. 2020b) self-efficacy, pain centrality and patient activation, (Matthias, Marianne S. et al. 2015) and several other health outcomes (Cooper, Kay, Kirkpatrick and Wilcock 2014). An increase in patient activation is particularly notable, as higher levels are associated with improved adherence to treatment recommendations and self-management behaviours (Hibbard and Greene 2013). Decreases in pain centrality are also significant as this results in pain becoming less of a focal point for patients post-intervention, possibly aiding patients to better cope with their pain (Nicolaidis, Chianello and Gerrity 2011). A 2015 evidence summary by Nesta synthesised information from 1023 studies and overall found that peer support can help participants feel more confident, knowledgeable and happy and less isolated and alone (Nesta 2015). Table 1.2 below summarizes the key findings about the impact of different types of peer support (Nesta 2015). As evidenced below, the components of peer support can vary greatly, along with the types of benefits. This evidence summary also found notable gaps in the research such as why some types of peer support are more effective than others and what kinds of PSIs are most appealing to potential participants (Nesta 2015).

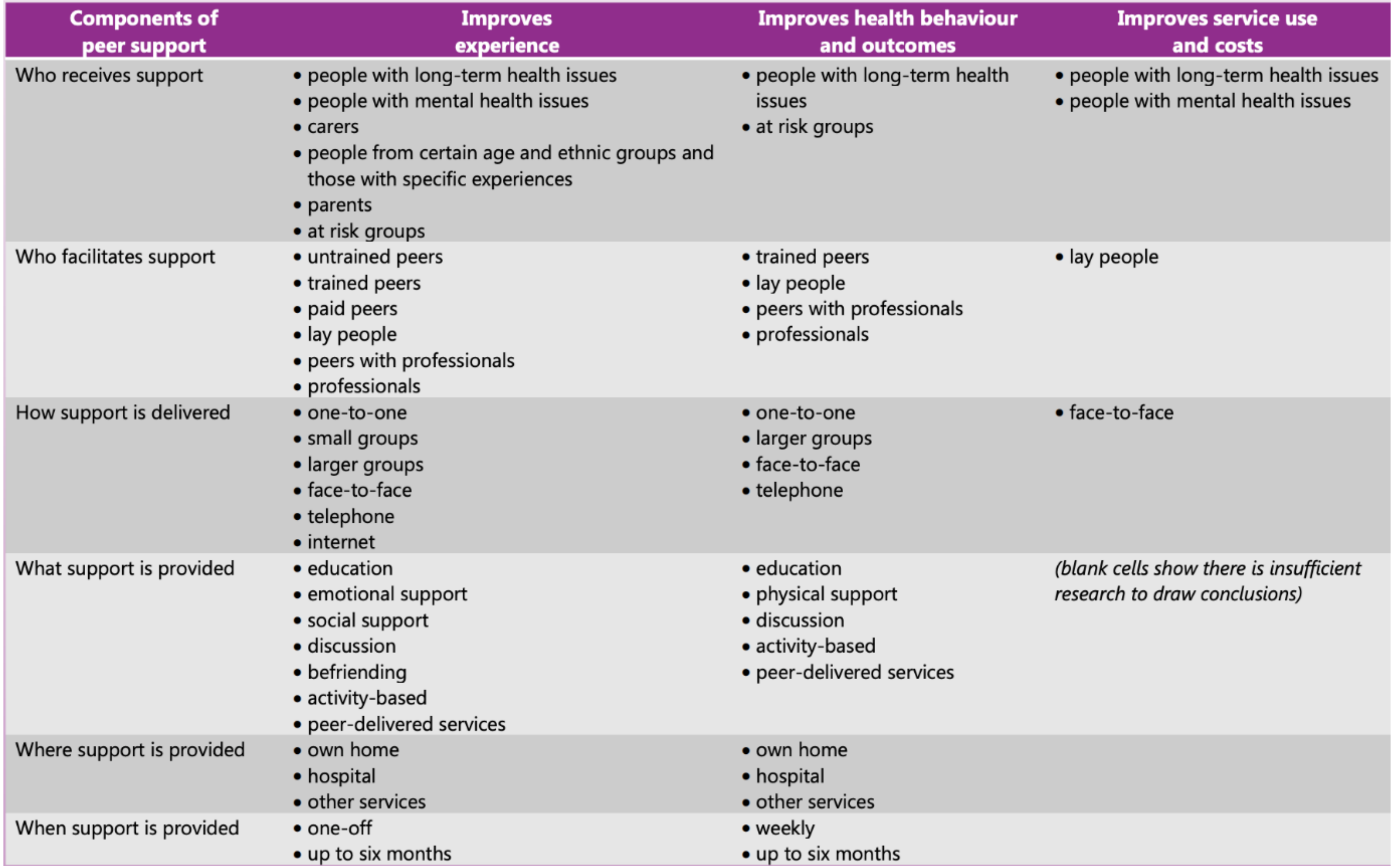
While healthcare providers play a vital role in patient care, the reality of increasing numbers of ageing and complex patients has resulted in strained healthcare systems such as the NHS (Papanicolas et al. 2019). Peer support can be a valuable adjunct to healthcare providers who may not have adequate time and resources to address all of a patient's needs. As previously mentioned, there are numerous variations across PSIs, and it is crucial to consider how these variations may impact the patient experience.

1.4.7 Populations and Effectiveness

PSIs were first used with people with chronic conditions such as mental illness, cancer, and diabetes; as such, there is a substantial research base with these three populations. A number of systematic reviews have been conducted to synthesize the information on PSIs with each of these populations. Topics of these systematic reviews include analysing the effect on specific health outcomes (Kong, L. et al. 2019; Stubbs, B. et al. 2016; Qi, L. et al. 2015; Dale, Williams and Bowyer 2012; Hoey et al. 2008), determining facilitators and barriers to implementation of peer support (Ibrahim, N. et al. 2019), and examining the use of peer support across the care continuum (Kowitt et al. 2019).

Considering the effect of peer support with these populations, systematic reviews have reported improvements for participants in a variety of health outcomes. The most notable improvements will be explored briefly. Participants with mental illness demonstrated significant improvements across several health outcomes such as attitudinal (patient activation and self-efficacy), behavioural (illness self-management), and functional (physical and emotional well-being) (Goldberg et al. 2013). With regard to diabetes, peer support increased scores for participants in the areas of self-efficacy, self-management and quality of life (Dale, Williams and Bowyer 2012). Greater glycaemic control was another major benefit amongst patients with diabetes (Dale, Williams and Bowyer 2012). Patients with

Table 1.2 Key findings about the impact of different types of peer support *(Nesta 2015)* used with permission



Components of peer support	Improves experience	Improves health behaviour and outcomes	Improves service use and costs
Who receives support	• people with long-term health issues • people with mental health issues • carers • people from certain age and ethnic groups and those with specific experiences • parents • at risk groups	• people with long-term health issues • at risk groups	• people with long-term health issues • people with mental health issues
Who facilitates support	• untrained peers • trained peers • paid peers • lay people • peers with professionals • professionals	• trained peers • lay people • peers with professionals • professionals	• lay people
How support is delivered	• one-to-one • small groups • larger groups • face-to-face • telephone • internet	• one-to-one • larger groups • face-to-face • telephone	• face-to-face
What support is provided	• education • emotional support • social support • discussion • befriending • activity-based • peer-delivered services	• education • physical support • discussion • activity-based • peer-delivered services	*(blank cells show there is insufficient research to draw conclusions)*
Where support is provided	• own home • hospital • other services	• own home • hospital • other services	
When support is provided	• one-off • up to six months	• weekly • up to six months	

cancer expressed high satisfaction and acceptance of peer support interventions, along with improvements in emotional distress, decision-making skills, communication and psychological adjustment (Hoey et al. 2008).

While PSIs can result in improved health outcomes for participants, many researchers are hesitant to support a firm recommendation for the use of peer support, commonly citing the evidence base as too limited with a paucity of high-quality studies (Kong, L. et al. 2019; Dale, Williams and Bowyer 2012; Hoey et al. 2008) and the heterogenous nature of interventions (Stubbs, B. et al. 2016).

A number of variables could impact the effectiveness of peer support. These include poor attendance rates amongst participants (Kong, L. et al. 2019) and variance in follow-up from eight (McKay et al. 2002) to two years (Smith et al. 2011a). Also important to consider is the experience, competency and extent of involvement of the PSV (Kong et al. 2018) and wider contextual factors such as the social environment and culture (Zhang, X. et al. 2016). Finally, baseline values of self-efficacy and quality of life are significant as participants with lower values have the potential to improve significantly compared to those with higher values (Kong et al. 2018).

Research is also emerging on several other conditions such as stroke, spinal cord injury (SCI), and chronic pain (Clark et al. 2020; Hoffmann et al. 2019; Matthias, Marianne S. et al. 2019). These studies have explored whether self-management skills can be improved with the use of peer support. There is a body of literature on adolescents with chronic pain (Tolley et al. 2020; Brown 2017; Goldenberg et al. 2013) although it should be noted there are differences in management strategies and particular guidelines for children and young people compared with adults (Scottish Government 2018a).

1.4.8 Theoretical Underpinnings and Frameworks

PSIs can be underpinned by various theories, dependent on how organisers aim to impact behaviour change. Simoni et al. found that there are five main ways that PSIs can impact behaviour, which are education, social support, self-efficacy, social norms and patient advocacy (2011). Each of these methods to impact behaviour change will now be explored, along with an explanation of the theoretical foundation.

Many PSIs involve some level of didactic teaching to offer health information and peers can be well positioned to deliver tailored health information. For PSIs that involve peers as providers of education, this is supported by dynamic social impact theory, which states that communication can more effectively improve a person's likelihood of changing behaviour if the communicator is credible and similar (Latane 1996). Dynamic social impact theory also stresses the importance of communication being social which aides in providing multiple effective change agents (or peers) delivering information (Latane 1996).

Oftentimes PSIs offer a level of social support, which is supported by social comparison theory. According to social comparison theory, there are at least three primary uses for the knowledge people gather from their interactions with others (Festinger 1954). First, people utilise it for self-evaluation to determine whether their opinions are accurate and their capacity for change and emotional states are reasonable (Festinger 1954). Secondly, self-enhancement or self-protection can be functions: people compare themselves to those who are worse off (downward comparisons) to boost their own self-esteem (Festinger 1954). Finally, people may prefer to compare themselves to those who are doing better (upward comparisons) for self-improvement reasons in order to inspire hope or discover information that will help them (Festinger 1954). Three reviews on PSIs for adults with cancer included several interventions underpinned by social comparison theory (Walshe and Roberts 2018; Meyer, Coroiu and Korner 2015; Dunn et al. 2003).

PSIs with the aim of improving self-efficacy can be founded on social cognitive theory, which states that self-efficacy is developed through social persuasion, observational learning or mastery experiences (Bandura 1986). Peer interactions provide opportunities for peers to model health behaviours. Social cognitive theory was the foundation for these two PSIs for people living with chronic pain and HIV respectively (Merlin et al. 2018; Parker, Jelsma and Stein 2016).

PSIs can be focussed on changing social norms or at least perceptions of them, presuming that social norms and values are involved with the development of normative behavioural standards that impact the adoption and maintenance of health behaviours (Simoni et al. 2011). The theory of reasoned action (also known as the theory of planned behaviour) supports this kind of PSI; this theory states that intentions, attitudes (beliefs about a behaviour), and subjective norms (beliefs about other people's attitudes towards a behaviour) are what determine behaviour (Ajzen and Fishbein 1980). For example, in the case of a PSI, a peer may share their belief that physical activity has helped their back pain, leading others to a positive view of physical activity, an intentional desire to try physical activity and eventually a behaviour of engaging in some form of physical activity.

The final type of PSI is advocacy-based whereby peers aim to engage targeted populations in active learning, empowering them to promote their collective interests beyond a singular behavioural change (Simoni et al. 2011). Advocacy-based PSI is underpinned by empowerment theory, which has the purpose of employing intervention methods to help lead individuals towards gaining control and autonomy over their life (Rappaport 2000). Three studies with PSIs for people with HIV, chronic pain and diabetes respectively, all used empowerment theory as a foundation (Boucher et al. 2020; Cooper et al. 2020; Qi et al. 2015).

While not included in Simoni et al.’s list of five ways PSIs impact behaviour and associated theories, self-determination theory is important to discuss as a common theory used to support PSIs. Self-determination theory posits that behaviour is influenced by both intrinsic and extrinsic motivation. Intrinsic motivation is driven by a person’s core values and interests whilst extrinsic motivation is based on external sources and external rewards such as grading systems, awards and respect from others (Ryan and Deci 2017). PSIs aim to impact these motivations and have been used with adults with chronic conditions (Enriquez and Conn 2016; Qi et al. 2015).

Theory is particularly important to consider with regard to complex interventions, which are widely used to improve health. An intervention is classified as complex when it has multiple interacting components, attempts to impact multiple outcomes or targets multiple groups

(Craig et al. 2008), therefore PSIs can be considered as complex. A good theoretical understanding of how the intervention causes change is required, in order to identify and reinforce weaknesses in the causal chain (Craig et al. 2008). If an intervention is not effective or successful in reaching its outcomes, it may be due to implementation failure, rather than genuine ineffectiveness (Craig et al. 2008).

With the complexity of such interventions, a framework has been published by the UK Medical Research Council (MRC) in order to guide researchers in the development and evaluation of complex interventions. This framework was originally published in 2000 (Campbell et al. 2000) with an update in 2008 (Craig et al. 2008) and a further update in 2021 (Skivington et al. 2021). This framework continues to be used widely and is also accompanied by several pieces of guidance on particular areas of the research process. This includes guidance on complex interventions specific to healthcare (O'Cathain et al. 2019), evaluating population health interventions (Craig et al. 2012) and a process evaluation of complex interventions (Moore et al. 2015). The MRC framework will be discussed further in the methods chapter.

1.4.9 Quality of Evidence and Debates in the Literature

In order to ascertain the quality of the research on PSIs with chronic pain, the risk of bias and methodological shortcomings should be duly noted. This is particularly significant in research which includes subjective outcomes such as pain and functional status (Higgins et al. 2011). Across several studies identified in the literature review, there was no concealment of allocation and analysis did not include the outcomes of participants who withdrew (Parry et al. 2009; Wegener et al. 2009; Hughes et al. 2006; Brattberg 2006). Additionally, one study had unequal baseline values for the treatment and control groups (Wegener et al. 2009). Outcome data that is missing due to attrition could lead to an overestimation of effects (Higgins et al. 2011). Concerning RCTs, blinding was simply not possible due to the complex nature of PSIs. Therefore, a high risk of bias for both participants and researchers was apparent. This could potentially distort the measurement of outcomes and the validity of the results.

It should be noted that some studies did implement strategies to optimise fidelity of the intervention. These strategies included standardised training for PSVs, supervision calls with a study psychologist and a detailed study manual to guide PSVs (Tse et al. 2019; Matthias et al. 2015). This aided with standardisation of PSV training and delivery of the intervention.

With consideration of all these factors, the author believes the current state of the quality of the research is lacking in methodological rigor. A recent systematic review of reviews on the topic of PSIs for people with chronic conditions also found methodological weaknesses in the literature; noting many reviews did not assess risk of bias (Thompson et al. 2022). This systematic review of reviews also reported a lack of consistent statistically significant effects (Thompson et al. 2022). This leads into a prominent debate in the literature on the effectiveness of PSIs being unclear, which was discussed earlier in this chapter in Sections 1.3.2 and 1.4.7.

A significant contributing factor to the varying effectiveness of PSIs is the variability of interventions, as discussed in Section 1.4.5, and also noted by Thompson et al. (2022). In particular, the role of the PSV can vary greatly and can fluctuate based on the design of the intervention. Several interventions in this literature review designated a PSV that received training and was matched with an individual who desired some kind of support. While the interventions are termed “peer support,” this type of partnership does reveal a slight hierarchy. The PSVs are usually chosen due to their experience at managing their condition well, thus they take on somewhat of a mentorship role towards the participant. This contrasts other interventions which construct partnerships that are reciprocal in nature; each participant completes the same training, and both are offering and receiving support (Heisler et al. 2010; Heisler et al. 2007).

Another variable is the amount of training provided to the PSVs. The author believes this should be given due consideration, as the training, along with the content that is covered, could potentially impact the quality of the relationship between the PSV and participant. Researchers must consider what material is most relevant to prepare PSVs, such as communication and approaching sensitive topics.

Another debate worth noting is the varying use of theories to underpin PSIs, which is evidently important if an intervention is aiming to cause behaviour change. Thompson et al. also observed the complexity of PSIs and yet only a minority of reviews included in the study described a foundational theory or mechanism of effect (2022). The significance of theory and the lack of citing it in the literature is also discussed in Sections 1.3.3 and 1.4.8.

Finally, there is much literature on PSIs with four major chronic conditions (diabetes, cancer, cardiovascular and chronic respiratory disease) but there is a lack of high-quality primary research and reviews on several other chronic conditions with different lived experiences and pathologies (Thompson et al. 2022). There is a need for further research to be conducted with other populations, such as chronic non-cancer pain.

1.5 Summary of Chapter 1

This chapter provided definitions and discussions of several topics related to chronic pain, self-management and peer support. A literature review was conducted on chronic pain and peer support and found many variations in the design and delivery of PSIs. Results of the literature review also pertained to PSI’s strengths and limitations, effectiveness and use in other populations. Theoretical underpinnings and frameworks and quality of evidence and debates in the literature were also discussed. A notable gap in the evidence was observed as to what kinds of PSIs are most appealing to potential participants (Nesta 2015). The next chapter will provide a comprehensive analysis of the evidence regarding the experiences and perceptions of participating in a PSI for adults with chronic pain.

2 CHAPTER 2: EXPLORING THE EXPERIENCES AND PERCEPTIONS OF PARTICIPATING IN A PEER SUPPORT INTERVENTION FOR ADULTS WITH CHRONIC NON-CANCER PAIN: A QUALITATIVE SYSTEMATIC REVIEW

2.1 Introduction

The previous chapter (Chapter One: Introduction) provided an overview of the existing literature on PSIs for adults with chronic pain. Chapter one illustrated the numerous variations across PSIs, such as delivery, format and frequency of contact and duration of a PSI. The literature in chapter one provided the direction for this thesis on the topic of perceptions of peer support for adults with chronic pain. A systematic review was first conducted before the primary research and this chapter presents this qualitative systematic review exploring adults' experiences and perceptions of participating in a PSI for chronic non-cancer pain in order to make recommendations for future research and practice with respect to the content and delivery of PSIs. The systematic review is published in the JBI Evidence Synthesis (Arnott et al. 2023) and sections of this chapter have been reproduced from the published article with permission of the publisher.

Literature searching of MEDLINE and CINAHL identified a body of evidence regarding the experience of participating in PSIs, (Kohut, Sara Ahola et al. 2017; Matthias, Marianne S. et al. 2016a; Sandhu, Sharron et al. 2013; Arnstein, P. et al. 2002). Further searching of PROSPERO, the Cochrane Database of Systematic Reviews, and JBI Evidence Synthesis was conducted and no current or in-progress systematic reviews on the topic of participating in PSIs were identified. Other systematic reviews have explored effectiveness (Thompson, Dean M. et al. 2022; Cooper, Kay, Kirkpatrick and Wilcock 2014) and design and implementation (Maclachlan et al. 2020). Individual studies have addressed patients' experiences and perceptions of participation in PSI. However, none of the information on experiences and perceptions of PSIs for adults with chronic pain has previously been synthesised into a systematic review and this information is crucial for developing and delivering PSIs with optimal benefits for those involved. A synthesis of the information on experiences and perceptions of PSIs for adults with chronic pain could be used by health boards and charities with the intent to design and deliver PSIs that cater to the needs and preferences of potential participants.

2.2 Review questions

This review explored the experiences and perceptions of adults with chronic non-cancer pain who had either delivered or received a PSI. Experience can be defined as “the process of personally observing, encountering, or undergoing something” (Dictionary.com 2022). Likewise, perception can be defined as “the way in which something is regarded, understood or interpreted” (Oxford Dictionaries 2022).

The specific review questions were:

- What are the experiences and perceptions of adults with chronic non-cancer pain regarding the format, delivery, role and training of PSVs and duration of the PSI?
- What are the experiences and perceptions of adults with chronic non-cancer pain regarding the strengths and limitations of PSIs?
- What do adults with chronic non-cancer pain perceive to be the barriers and facilitators to implementation of PSIs?

2.3 Reviews and evidence-based practice

This section will begin with a brief look at the history of evidence-based practice as it is the dominant model of clinical decision-making in the UK (Thomas, Burt and Parkes 2010). In the 1990s, the emergence of evidence-based practice created a new landscape for healthcare research. As healthcare providers increasingly relied on literature to support their medical decisions, this resulted in an upsurge in studies and publications (Thomas, Burt and Parkes 2010). Summaries of evidence (i.e., reviews) quickly became desirable to aid healthcare providers in making informed decisions.

There are several types of reviews, illustrated in Table 2.1 and Table 2.2. Reviews share a common purpose: to synthesize information on a given topic, however they can vary in their methodology and structure. It is important to conduct effective literature reviews in order to comprehend the expanse of research on a particular topic, synthesize the empirical evidence, understand theories involved and create a conceptual background for future research (Paré et al. 2015). Perhaps most importantly, conducting a review of the literature helps the researcher to be cognizant of what has already been studied and what is well-established knowledge so that subsequent research successfully contributes something novel to the field. The tables below describe 14 different types of reviews; the following sections will examine the most common review types.

2.4 Different types of reviews

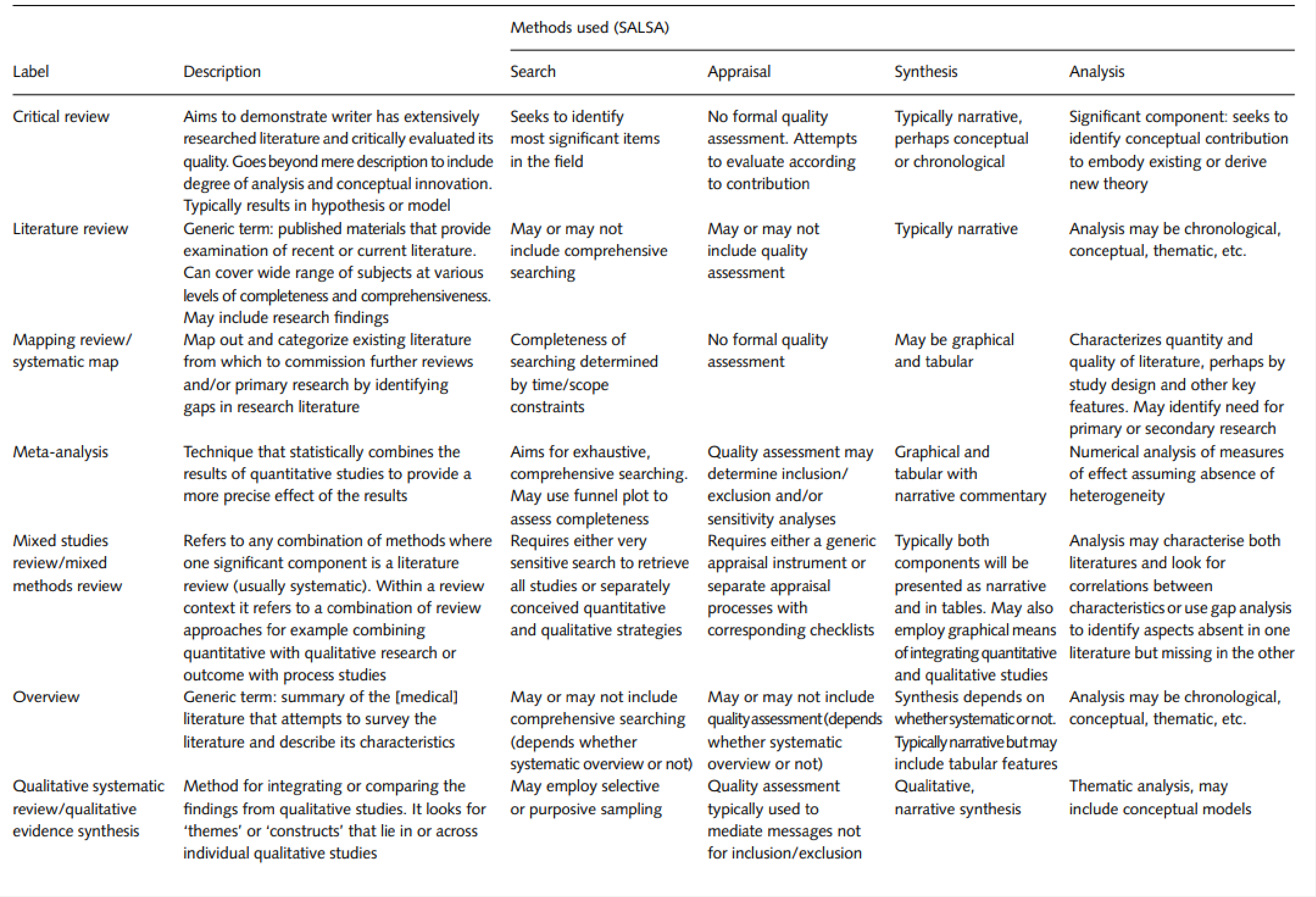
2.4.1 Literature review

The purpose of a literature review is to provide background information on a given topic. The search for literature is not comprehensive but there will be some process for identifying studies to be included (Snyder 2019). The summary of information is typically narrative and usually does not include critical appraisal of studies (Cooper, Chris et al. 2018). The strengths of a literature review are that the process is easier and takes less time than more systematic or comprehensive reviews. Considering limitations, since this type of review is lacking comprehensiveness and a systematic approach, some literature may not be identified which could impact the results of the review. Furthermore, authors can be unknowingly biased by choosing literature that aligns with their worldview (Snyder 2019). Finally, without critical appraisal of studies, this type of review is not able to provide information on methodological quality.

2.4.2 Scoping review

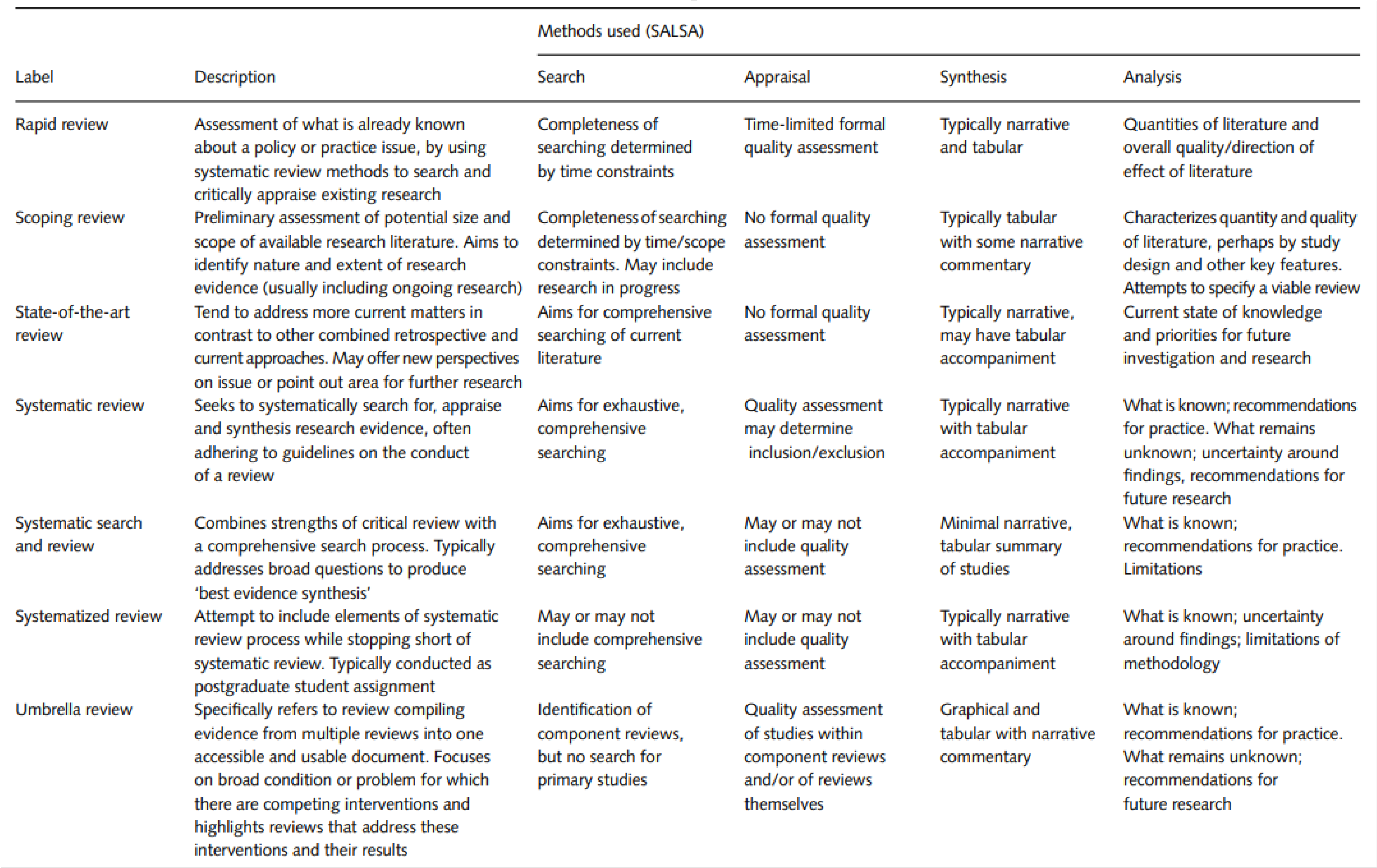
The purpose of a scoping review is to provide a preliminary appraisal of the size and extent of available research on a given topic (Grant and Booth 2009). This type of review aims to be systematic, replicable and transparent, which are all evident strengths. Another strength is that researchers or policy-makers can use scoping reviews to decide whether a full systematic review is necessary (Munn, Zachary et al. 2018a). Scoping reviews do not include critical analysis, therefore are limited in not being able to comment on the methodological quality of the literature.

Table 2.1 Main review types characterized by methods used *(Grant and Booth 2009)* used with permission



		Methods used (SALSA)			
Label	Description	Search	Appraisal	Synthesis	Analysis
Critical review	Aims to demonstrate writer has extensively researched literature and critically evaluated its quality. Goes beyond mere description to include degree of analysis and conceptual innovation. Typically results in hypothesis or model	Seeks to identify most significant items in the field	No formal quality assessment. Attempts to evaluate according to contribution	Typically narrative, perhaps conceptual or chronological	Significant component: seeks to identify conceptual contribution to embody existing or derive new theory
Literature review	Generic term: published materials that provide examination of recent or current literature. Can cover wide range of subjects at various levels of completeness and comprehensiveness. May include research findings	May or may not include comprehensive searching	May or may not include quality assessment	Typically narrative	Analysis may be chronological, conceptual, thematic, etc.
Mapping review/ systematic map	Map out and categorize existing literature from which to commission further reviews and/or primary research by identifying gaps in research literature	Completeness of searching determined by time/scope constraints	No formal quality assessment	May be graphical and tabular	Characterizes quantity and quality of literature, perhaps by study design and other key features. May identify need for primary or secondary research
Meta-analysis	Technique that statistically combines the results of quantitative studies to provide a more precise effect of the results	Aims for exhaustive, comprehensive searching. May use funnel plot to assess completeness	Quality assessment may determine inclusion/ exclusion and/or sensitivity analyses	Graphical and tabular with narrative commentary	Numerical analysis of measures of effect assuming absence of heterogeneity
Mixed studies review/mixed methods review	Refers to any combination of methods where one significant component is a literature review (usually systematic). Within a review context it refers to a combination of review approaches for example combining quantitative with qualitative research or outcome with process studies	Requires either very sensitive search to retrieve all studies or separately conceived quantitative and qualitative strategies	Requires either a generic appraisal instrument or separate appraisal processes with corresponding checklists	Typically both components will be presented as narrative and in tables. May also employ graphical means of integrating quantitative and qualitative studies	Analysis may characterise both literatures and look for correlations between characteristics or use gap analysis to identify aspects absent in one literature but missing in the other
Overview	Generic term: summary of the [medical] literature that attempts to survey the literature and describe its characteristics	May or may not include comprehensive searching (depends whether systematic overview or not)	May or may not include quality assessment (depends whether systematic overview or not)	Synthesis depends on whether systematic or not. Typically narrative but may include tabular features	Analysis may be chronological, conceptual, thematic, etc.
Qualitative systematic review/qualitative evidence synthesis	Method for integrating or comparing the findings from qualitative studies. It looks for 'themes' or 'constructs' that lie in or across individual qualitative studies	May employ selective or purposive sampling	Quality assessment typically used to mediate messages not for inclusion/exclusion	Qualitative, narrative synthesis	Thematic analysis, may include conceptual models

Table 2.2 Main review types continued *(Grant and Booth 2009)* used with permission



		Methods used (SALSA)			
Label	Description	Search	Appraisal	Synthesis	Analysis
Rapid review	Assessment of what is already known about a policy or practice issue, by using systematic review methods to search and critically appraise existing research	Completeness of searching determined by time constraints	Time-limited formal quality assessment	Typically narrative and tabular	Quantities of literature and overall quality/direction of effect of literature
Scoping review	Preliminary assessment of potential size and scope of available research literature. Aims to identify nature and extent of research evidence (usually including ongoing research)	Completeness of searching determined by time/scope constraints. May include research in progress	No formal quality assessment	Typically tabular with some narrative commentary	Characterizes quantity and quality of literature, perhaps by study design and other key features. Attempts to specify a viable review
State-of-the-art review	Tend to address more current matters in contrast to other combined retrospective and current approaches. May offer new perspectives on issue or point out area for further research	Aims for comprehensive searching of current literature	No formal quality assessment	Typically narrative, may have tabular accompaniment	Current state of knowledge and priorities for future investigation and research
Systematic review	Seeks to systematically search for, appraise and synthesis research evidence, often adhering to guidelines on the conduct of a review	Aims for exhaustive, comprehensive searching	Quality assessment may determine inclusion/exclusion	Typically narrative with tabular accompaniment	What is known; recommendations for practice. What remains unknown; uncertainty around findings, recommendations for future research
Systematic search and review	Combines strengths of critical review with a comprehensive search process. Typically addresses broad questions to produce 'best evidence synthesis'	Aims for exhaustive, comprehensive searching	May or may not include quality assessment	Minimal narrative, tabular summary of studies	What is known; recommendations for practice. Limitations
Systematized review	Attempt to include elements of systematic review process while stopping short of systematic review. Typically conducted as postgraduate student assignment	May or may not include comprehensive searching	May or may not include quality assessment	Typically narrative with tabular accompaniment	What is known; uncertainty around findings; limitations of methodology
Umbrella review	Specifically refers to review compiling evidence from multiple reviews into one accessible and usable document. Focuses on broad condition or problem for which there are competing interventions and highlights reviews that address these interventions and their results	Identification of component reviews, but no search for primary studies	Quality assessment of studies within component reviews and/or of reviews themselves	Graphical and tabular with narrative commentary	What is known; recommendations for practice. What remains unknown; recommendations for future research

2.4.3 Systematic review

The purpose of a systematic review is to comprehensively search for, critically appraise and synthesize literature in order to answer specific research questions (Munn, Zachary et al. 2018a). This type of review shares the characteristics of a scoping review in that it is systematic, replicable and transparent. Furthermore, the inclusion of critical appraisal provides the strength of providing clarity on the methodological quality of the included literature.

There are different guidelines that researchers can adhere to when conducting a review, such as the JBI Manual for Evidence Synthesis (Aromataris E 2020), the Cochrane Handbook for Systematic Reviews (Cumpston et al. 2019) or the Centre for Reviews and Dissemination guidance (Centre for Reviews and Dissemination 2009). Several evidence hierarchies have systematic reviews at the top (Clarke et al. 2014; Evans 2003; Guyatt et al. 1995), proving the strength of such reviews. As systematic reviews require a rigorous and time-consuming process that can last up to 18 months or longer, a limitation is that results can become outdated by new evidence.

2.4.3.1 Types of systematic reviews

There are several types of systematic reviews, which vary depending on the kind of research question(s) being asked. Munn et al. describes as many as ten different kinds of systematic reviews used in medical and health sciences: effectiveness, experiential (qualitative), costs/economic evaluation, prevalence and/or incidence, diagnostic test accuracy, aetiology and/or risk, expert opinion/policy, psychometric, prognostic, and methodological (Munn, Zachary, Stern et al. 2018). Choosing an appropriate type of systematic review is essential in order to appropriately address the research question(s). The most common systematic review types will now be discussed.

In the health sciences, effectiveness reviews have the highest prevalence as they have traditionally been used to evaluate the effectiveness of interventions by synthesizing the results of RCTs (Munn, Zachary et al. 2018b). When researchers produce questions relating to anything other than effectiveness, another review type is required. Experiential or qualitative reviews have an emphasis on examining human experiences and social and cultural phenomena (Munn, Zachary et al. 2018b). Questions typically focus on a patient's experience and can help a health professional improve his or her understanding and interaction with patients (Munn, Zachary et al. 2018b). In order to measure a disease burden at a local, national or global level, prevalence and/or incidence reviews are used. These reviews are essential for governments, policy makers and health professionals to be informed for the development and delivery of healthcare services (Munn, Zachary et al. 2018b).

2.4.4 Justification for the chosen review type

As the strengths and limitations of the above review types have been discussed, a systematic review was chosen by the author. This was to minimize limitations associated with scoping and narrative reviews such as risk of bias and a lack of critical appraisal. A systematic review also provides the notable strength of being the highest level of evidence as it is comprehensive, transparent, replicable and systematic (Clarke et al. 2014). Furthermore, systematic reviews are the gold standard to critique and synthesize the evidence in order to answer clinical questions (Aromataris and Pearson 2014). As the aim of this research involved producing a recommendation for future research and practice, a systematic review was deemed appropriate as it provides the most valid evidence base to inform policy-makers in developing clinical guidelines (Aromataris and Pearson 2014). In this case, policy-makers could be informed of the current evidence base related to participant perceptions on the content and delivery of PSIs.

With respect to the type of systematic review, a qualitative or experiential systematic review was chosen in order to specifically answer the above-stated research questions. This was deemed suitable as the questions pertained to examining the human experience of participating in a PSI. Other systematic review types would not have been appropriate as the questions did not pertain to effectiveness, prevalence, aetiology or any of the other types of systematic reviews conducted in the health sciences.

2.5 Inclusion criteria

2.5.1 *Participants*

This review considered studies that included adults with chronic (over 12-weeks duration) non-cancer pain. The definition of adulthood was aligned with the country of origin for each publication as this can vary between 16-18 years. Due to differences in management strategies and particular guidelines for children compared with adults, (Scottish Government 2018b) children were considered outside the scope of this review. There was no upper age limit as chronic pain can impact adults of all ages. Conditions included, but were not limited to: low back pain, osteoarthritis, rheumatoid arthritis, fibromyalgia, chronic widespread pain, and lupus.

The following criteria were not clarified in the *a priori* protocol but were added as amendments and updated in PROSPERO (Arnott, Park and Cooper 2021). Chronic pain as a result of a traumatic experience was included, (i.e., burn victims, amputees). Studies with adolescents were included if more than 50% of participants were considered adults. Cancer pain, neurological conditions and opioid dependence were all excluded due to the specific nature and management of these conditions (Kosten and Baxter 2019; Howell, Doris et al. 2017; Carmeli 2017), which typically differs from other types of pain. The WHO recognizes pharmacological interventions as the “mainstay” of cancer pain management, (World Health Organization 2018) while other types of chronic pain utilize a variety of management techniques. Sickle cell and tinnitus were excluded as these conditions exhibit episodic rather than long-standing chronic pain and they also require specific management (Anupam Aich, Alvin J Beitz and Kalpna Gupta 2016; Levine and Oron 2015).

2.5.2 *Phenomena of interest*

This review considered studies that explored adults’ (either PSV or participant) perceptions of participating in a PSI. A PSI was defined as a gathering of two or more people with similar conditions with the goal of supporting one another by providing emotional, appraisal and informational assistance (Dennis 2003b). This intervention could be delivered by any mode including face-to-face, virtual (audio or video call, messaging/emailing, or social media platform) or a hybrid, and in any format including group, one-to-one or a hybrid. In order to differentiate a PSI from a support group, some amount of training had to be provided to the PSVs. Studies with peer support included as part of a multi-component intervention were included if peer support was the dominant component and/or the data on peer support could be extracted separately.

The following criteria were not clarified in the *a priori* protocol but were added as amendments and updated in PROSPERO (Arnott, Park and Cooper 2021). Peer support was included where it was a standalone intervention or where it was delivered alongside or embedded within a broader self-management program. Studies were excluded if the research questions were solely focused on the training experience of PSVs, as this was not directly related to the questions of this review.

2.5.3 *Context*

This review considered studies that offered PSIs in any setting, including but not limited to, hospitals, clinics, and community settings, and was not restricted by geographical location.

2.5.4 *Types of studies*

This review considered studies that focused on qualitative data, including but not limited to, designs such as phenomenology, grounded theory, ethnography, action research, and feminist research. Mixed methods studies were considered where the qualitative results were reported separately. Qualitative studies could include interviews, focus groups, case studies, exploratory, longitudinal studies, or cross-sectional surveys with reported free-text responses that were analysed qualitatively. Conference proceedings were excluded as it would not be possible to extract sufficient information on methodological quality or study findings, this was not clarified in the *a priori* protocol, but was added as an amendment and updated in PROSPERO (Arnott, Park and Cooper 2021).

2.6 Methods

This systematic review was conducted in accordance with JBI methodology for systematic reviews of qualitative evidence (Lockwood C, Porrit K, Munn Z, Rittenmeyer L, Salmond S, Bjerrum M, et al. 2020) and followed an *a priori* protocol registered in PROSPERO, (CRD42021245085) (Arnott, Park and Cooper 2021).

2.6.1 *Search strategy*

A systematic review search strategy is defined as “a comprehensive search to identify all relevant studies, both published and unpublished” (Munn, Zachary et al. 2018b). This search strategy was developed in consultation with a research librarian and was congruent with recent systematic reviews, (Berkanish, Patricia et al. 2022; Levy, Ben B. et al. 2019) including a large umbrella review, (Thompson, Dean M. et al. 2022) all of which focused on peer support for chronic conditions. The search strategy aimed to locate both published and unpublished studies. A three-step search strategy was utilized in this review. First, an initial limited search of MEDLINE and CINAHL (EBSCOhost) was undertaken, followed by analysis of the text words contained in the title and abstract and the index terms used to describe the articles. The search strategy, including all identified keywords and index terms, was adapted for each included information source and a second search was undertaken during April of 2021. The full search strategies are provided in Appendix II. In keeping with the focus of the review (peer support) and in accordance with the previous systematic and umbrella reviews described above, (Thompson, D. M. et al. 2022; Berkanish, P. et al. 2022; Levy, B. B. et al. 2019) the author did not include search terms for the broader concept of self-management, as it was not the purpose of the review to explore self-management *per se*. The author’s search strategy, using a combination of subject headings and keywords, was designed to identify peer support interventions either as stand-alone or components of broader self-management interventions.

Finally, reference lists of included studies were screened for additional studies. Searches were conducted using English databases and were open to all languages as translation services were available, however it transpired that the final articles for critical appraisal were all published in English. Databases were searched from inception to April 28, 2021, as the volume of qualitative studies was expected to be manageable due to the use of PSIs being a relatively recent occurrence.

The databases that were searched included AMED, CINAHL, MEDLINE, PsycArticles, SPORTDiscus (all EBSCOhost), EmBase, PsycINFO (both Ovid) and Web of Science (Clarivate Analytics). Sources of unpublished studies and grey literature included EBSCO Open

Dissertations (EBSCOhost), EThOS (British Library), the Networked Digital Library of Theses and Dissertations (Global ETD) and Google Scholar.

2.6.2 *Study selection*

Decisions related to study selection are considered part of the most significant stage of the review process (Stoll et al. 2019). The quality of this process is driven by two factors, (1) establishing clear and precise eligibility criteria and (2) systematically applying these criteria to every record (Stoll et al. 2019). It is a meticulous process and one which the Agency for Healthcare Research and Quality (AHRQ) recommends using two or more members of a research team (McDonagh et al. 2013). Having two reviewers involved helps reduce the risk of author bias by ensuring no reports are mistakenly excluded and also improves accuracy of inclusion (McDonagh et al. 2013).

The AHRQ also recommends study screening is performed in two stages and recommends some method of dual review should occur at each stage (McDonagh et al. 2013). The AHRQ deems it appropriate for the second reviewer to conduct dual review on a small percentage of records to resolve any confusion, and the first reviewer can then proceed with the rest of the screening (McDonagh et al. 2013).

Following the search, all identified citations were collated and uploaded to RefWorks (ProQuest, MI, USA) and duplicates removed. Citations were then uploaded to Covidence (Melbourne, VIC, Australia) to facilitate screening, additional removal of duplicates, and selection. Titles and abstracts were screened for eligibility using the inclusion criteria by two independent reviewers (RA and KC). As this review was conducted as part of an unfunded doctoral study, the following deviation from the protocol was made. After screening 24% of studies, substantial agreement was reached (93% agreement, Cohen's Kappa 0.62) (Landis and Koch 1977), therefore RA screened the remaining titles and abstracts, discussing with KC as required. As one of the reviewers (KC) has authored multiple studies on the topic of peer support and chronic pain, RA screened any studies by this author and discussed with another reviewer (VP) as required, in order to mitigate risk of author bias. Full-text studies were retrieved and imported to Covidence for screening by two independent reviewers (RA, KC). Studies that did not meet the inclusion criteria were excluded and reasons for their exclusion are provided in Appendix III. Any disagreements that arose between the reviewers were resolved through discussion.

2.6.3 *Assessment of methodological quality*

One of the strengths of systematic reviews over other types of reviews is inclusion of critical appraisal, which helps assess the quality of the current evidence base.

Eligible studies were imported into the JBI System for the Unified Management, Assessment, and Review of Information (JBI SUMARI; JBI, Adelaide, Australia). The studies were critically appraised by two independent reviewers (RA, KC) for methodological quality using the standard JBI critical appraisal checklist for qualitative research (Joanna Briggs Institute 2017). As one of the reviewers (KC) authored one of the included studies, it was appraised by RA and VP. It was not necessary to contact authors of any papers for missing or additional data for clarification. Any disagreements that arose between the reviewers were resolved through discussion. In order to ascertain a comprehensive understanding of the research phenomenon, both data extraction and synthesis were conducted for all studies that met the inclusion criteria, regardless of methodological quality, as both high- and low-quality studies can provide potentially valuable insights (Dixon-Woods, Booth and Sutton 2007).

2.6.4 *Data extraction*

Data were extracted from studies included in the review by the lead author (RA) using the qualitative standardized data extraction tool from JBI SUMARI (Munn, Zachary et al. 2019). A pilot data extraction was completed and no changes were necessary to the data extraction tool. A second reviewer (KC) conducted independent data extraction on 10% of studies and no discrepancies between reviewers were identified. The data extracted included specific details about study methods, country of origin, phenomena of interest, setting, participant characteristics, and a description of the main results. Study findings, and their illustrations were extracted from each paper verbatim, and assigned a level of credibility of unequivocal (U), credible (C), or not supported (NS), as per JBI levels of credibility (Lockwood C, Porrit K, Munn Z, Rittenmeyer L, Salmond S, Bjerrum M, et al.

2020). No further requests were needed for additional data from the authors of any of the included studies.

2.6.5 Data synthesis

Qualitative research findings were pooled using JBI SUMARI (Munn, Zachary et al. 2019) and the meta-aggregation approach (Lockwood C, Porrit K, Munn Z, Rittenmeyer L, Salmond S, Bjerrum M, et al. 2020). This involved the aggregation or synthesis of findings to generate a set of statements that represented that aggregation, through assembling the findings and categorizing these findings on the basis of similarity in meaning. These categories were then subjected to a synthesis in order to produce a single comprehensive set of synthesised findings that could be used as a basis for evidence-based practice. Where textual pooling was not possible, the findings were presented in narrative form. Only unequivocal and credible findings were included in the synthesis, and all findings were either unequivocal or credible.

2.6.6 Assessing confidence in the findings

The final synthesised findings were graded according to the ConQual approach for establishing confidence in the output of qualitative research synthesis and presented in a Summary of Findings table (Table *2.5*) (Munn, Zachary et al. 2014). The Summary of Findings includes the major elements of the review and justification for the ConQual score. The Summary of Findings also includes the title, participants, phenomena of interest and context for this systematic review. Each synthesised finding from the review is presented, along with the type of research informing it, scores for dependability and credibility, and the overall ConQual score.

2.7 Results

2.7.1 Study inclusion

After searching the databases, a total of 5016 reports were retrieved. From this, 1122 duplicates were removed leaving a total of 3894 titles and abstracts to be screened for inclusion. A total of 3808 of these were subsequently excluded as they did not meet inclusion criteria, leaving 86 reports for further review. After examining the full text of these

86 reports against the inclusion criteria, it was determined that nine met the criteria and were suitable for inclusion in the review. Reasons for exclusion at this stage were: wrong study design (n=30), wrong phenomena of interest (n=27), wrong patient population (n=16), and duplicate reports (n=4). The results of the search and selection process are displayed in the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) flow diagram (Figure *2.1*) (Page et al. 2021). Excluded studies, with reasons, are in Appendix III. Therefore, nine reports, which represented seven unique studies, and a total of 214 participants, were included in the review (Cooper, K. et al. 2020; Tse, M. et al. 2020; Tse, M. M. Y. et al. 2019; Kohut, S. A. et al. 2017; Matthias, M. S., Kukla, Bair et al. 2016; Matthias, M. S., Kukla, McGuire et al. 2016; Sandhu, S. et al. 2013; Kumar et al. 2011a; Arnstein, P., Vidal, Wells-Federman et al. 2002b). Two studies had two separate reports written on each. One RCT with an embedded qualitative component produced a report on participant perceptions (Tse, Mimi et al. 2020a) and an additional report on PSV perceptions (Tse, Mimi Mun Yee et al. 2019). Another mixed methods study produced two qualitative reports, one on facilitators and barriers (Matthias, Marianne S., Kukla, McGuire et al. 2016) and another on participant experiences (Matthias, Marianne S. et al. 2016a).

2.7.2 Methodological quality

As seen in Table 2.3, the quality of the studies varied. Five out of seven studies were of moderate to high quality as they scored “yes” on seven to eight out of the ten total questions. These studies all exhibited good amounts of detail and congruence on methods, methodology and data reporting. No studies clearly stated their philosophical perspective (Q1) and few included a statement locating the researcher culturally or theoretically (Q6) or discussed the influence of the researcher on the research (Q7). Most included studies could be categorized as qualitative descriptive, an approach increasingly common in applied health research, (Bradshaw, Atkinson and Doody 2017) which may account for the lack of stated philosophical perspective. Therefore, scoring “unclear” for Q1 was not considered to be a major limitation. The one study with the lowest score~~s~~ (4/10) was largely due to this study coming from an RCT with an embedded qualitative component, as such the qualitative content was a smaller part of the study. This resulted in a lack of clarity in reporting on the

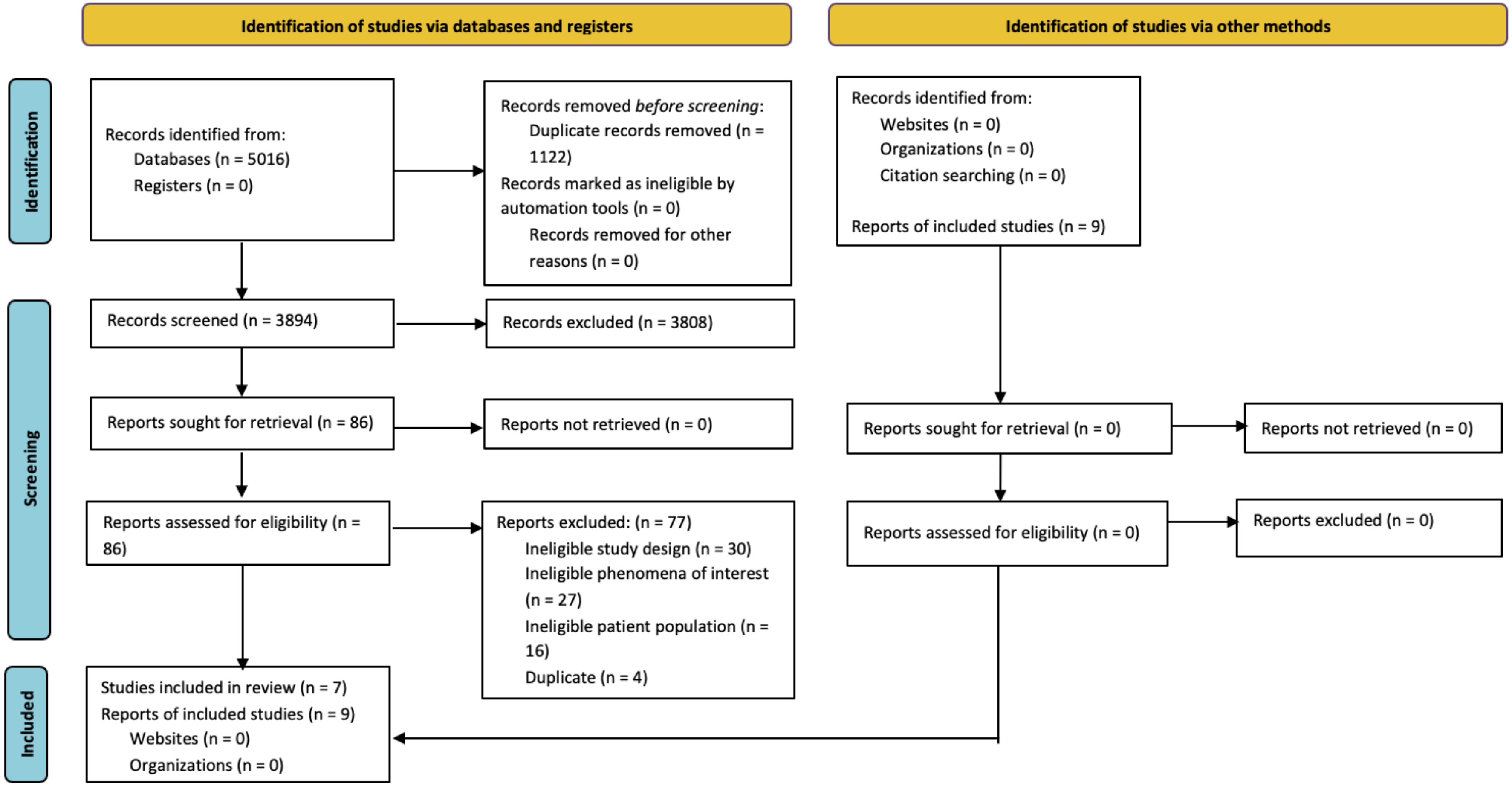


Figure 2.1 Search results, study selection and inclusion process ***(Page et al. 2021)***

Table 2.3 Critical appraisal results of eligible studies

Citation	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Total per record
Cooper et al. 2020	U	Y	Y	Y	Y	N	N	Y	Y	Y	7/10
Kohut et al. 2017	U	Y	Y	Y	Y	N	Y	Y	Y	Y	8/10
Kumar et al. 2011	U	Y	Y	Y	Y	Y	U	Y	Y	Y	8/10
Matthias et al. 2016*	U	Y	Y	Y	Y	N	Y	Y	Y	Y	8/10
Sandhu et al. 2013	U	Y	Y	Y	Y	N	N	Y	Y	Y	7/10
Tse et al. 2020*	U	Y	Y	U	U	N	Y	U	Y	U	4/10
Arnstein et al. 2002	U	Y	Y	Y	Y	N	N	U	Y	Y	6/10
Total % per question	0	100	100	86	86	14	43	71	100	86	

Key: Y = Yes, N = No, U = Unclear;
JBI Critical Appraisal Checklist for Qualitative Research
Q1 = Is there congruity between the stated philosophical perspective and the research methodology?
Q2 = Is there congruity between the research methodology and the research question or objectives?
Q3 = Is there congruity between the research methodology and the methods used to collect data?
Q4 = Is there congruity between the research methodology and the representation and analysis of data?
Q5 = Were those delivering treatment blind to treatment assignment?
Q6 = Is there a statement locating the researcher culturally or theoretically?
Q7 = Is the influence of the researcher on the research, and vice- versa, addressed?
Q8 = Are participants, and their voices, adequately represented?
Q9 = Is the research ethical according to current criteria or, for recent studies, is there evidence of ethical approval by an appropriate body?
Q10 = Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?
*Denotes 1 of 2 reports published on 1 study

research methodology and analysis and representation of data (Tse, Mimi et al. 2020a; Tse, Mimi Mun Yee et al. 2019).

2.7.3 *Characteristics of included studies*

Of the seven included studies published between 2002 and 2020 which included nine reports, two were conducted in the US (Matthias, Marianne S. et al. 2016b; Matthias, Marianne S. et al. 2016a; Arnstein, P. et al. 2002) and there were two each from the UK (Cooper, K. et al. 2020; Kumar et al. 2011a) and Canada, (Kohut, Sara Ahola et al. 2017; Sandhu, Sharron et al. 2013) and one from China(Tse, Mimi et al. 2020a; Tse, Mimi Mun Yee et al. 2019). Study designs included three mixed methods, (Cooper, Kay et al. 2020; Sandhu, Sharron et al. 2013; Arnstein, P. et al. 2002) three qualitative (Kohut, Sara Ahola et al. 2017; Matthias, Marianne S. et al. 2016b; Matthias, Marianne S. et al. 2016a; Kumar et al. 2011b) and one RCT with an embedded qualitative component (Tse, Mimi et al. 2020a; Tse, Mimi Mun Yee et al. 2019). Three studies employed semi-structured interviews, (Tse, Mimi et al. 2020a; Cooper, Kay et al. 2020; Tse, Mimi Mun Yee et al. 2019; Matthias, Marianne S. et al. 2016b; Matthias, Marianne S. et al. 2016a) while the remainder combined interviews with focus groups, (Kohut, Sara Ahola et al. 2017; Kumar et al. 2011b) written accounts, (Arnstein, P. et al. 2002) or questionnaires and diaries (Sandhu, Sharron et al. 2013). Sample sizes ranged from seven (Arnstein, P. et al. 2002) to 68 (Tse, Mimi et al. 2020a). The total sample size for participants in this review was 214. Populations varied from adults with arthritis, (Kohut, Sara Ahola et al. 2017; Sandhu, Sharron et al. 2013; Kumar et al. 2011b) chronic low back pain, (Cooper, Kay et al. 2020) chronic musculoskeletal pain (Matthias, Marianne S. et al. 2016b; Matthias, Marianne S. et al. 2016a) and more general chronic pain (Tse, Mimi et al. 2020a; Tse, Mimi Mun Yee et al. 2019; Kohut, Sara Ahola et al. 2017; Arnstein, P. et al. 2002). Concerning the aims of the included studies, three explored participant and PSV experiences of PSIs, (Tse, Mimi et al. 2020a; Tse, Mimi Mun Yee et al. 2019; Matthias, Marianne S. et al. 2016a; Kumar et al. 2011b) two examined the feasibility of PSIs (Cooper, Kay et al. 2020; Sandhu, Sharron et al. 2013) two explored the facilitators and barriers to participation in a PSI (Kohut, Sara Ahola et al. 2017; Matthias, Marianne S. et al. 2016b) and one evaluated the transition from participant to PSV (Arnstein, P. et al. 2002). Full characteristics of included studies are reported in Table *2.4*.

2.8 Review findings

A total of 53 findings, 47 unequivocal and six credible, were extracted from the nine included reports and combined to form 14 categories based on similarity of meaning. They were further organized into four synthesised findings. Narrative results are presented by synthesised finding and include a description of the categories and sample illustrations. Full details of study findings and illustrations are reported in Appendix IV. Table *2.5* shows the Summary of Findings. Figures 2-5 present the relationship between the findings, categories, and synthesised findings.

2.8.1 Synthesised finding #1

The peer-peer relationship is perceived as unique by those giving and receiving peer support, and important components include communication, a shared understanding and an ability to connect on a personal level. These components should be considered when matching participants with PSVs.

Participants and PSVs frequently reflected on the significance of relating to another person with chronic pain. The relationship was generally positive; both participants and PSVs felt they benefited from the social time spent together. Listening was a key component and helped participants convey their feelings in an atmosphere that was both welcoming and understanding. This synthesised finding was created from three categories and 14 findings (Table 2.6).

Category 1: Importance of mutual understanding from shared diagnosis/background

Four unequivocal findings (Cooper, Kay et al. 2020; Matthias, Marianne S. et al. 2016b; Kumar et al. 2011b) were combined to form this category, where participants noted that having a shared diagnosis of chronic pain or a shared background (e.g., as a veteran (Matthias, Marianne S. et al. 2016a) was highly impactful to building rapport and communicating openly. Participants consistently reflected on the difficulty of sharing their experience with medical professionals or family and friends; essentially people who have not actually experienced living with chronic pain. In contrast, conversations with peers who share a diagnosis were described as extremely valuable. In this context, it was commonly expressed among participants that there was a much greater understanding of the day-to-day challenges and the reality of living with chronic pain.

> *"You don't have to have a lot of other things in common if you both have back pain, both have an understanding" [PSV66, Male]* (Cooper, Kay et al. 2020(p. 159))

Category 2: Importance/benefits of making a connection

This category combined seven unequivocal findings (Kohut, Sara Ahola et al. 2017; Matthias, Marianne S. et al. 2016a; Sandhu, Sharron et al. 2013; Arnstein, P. et al. 2002) and demonstrated that both PSVs and participants noted the unique relationship that was formed during the intervention and how talking with someone who shared the same condition and experiences helped to validate feelings on both sides.

> *"The connection helps validate feelings for both involved, the whole thing was very gratifying."* (Arnstein, P. et al. 2002(p. 99))

The power of the connection was facilitated by similarities in age, gender, personality, interests, stage of life, level of responsibility at work, diagnosis and disease progression (Sandhu, Sharron et al. 2013). Some participants reflected that the relationship helped

Table 2.4 Characteristics of Included Studies

Study	Methods for data collection and analysis	Country	Phenomena of interest	Setting/context/culture	Participant characteristics and sample size	Description of main results
Cooper K, Schofield P, Smith BH, Klein S. 2020.	Sequential explanatory mixed methods design - Semi-structured interviews were transcribed and data mapped onto framework matrices, arranged according to interview topics. Due to the structured nature of the interviews, data was not coded prior to mapping. Data analysis with framework approach by 2 researchers.	UK	Examining the feasibility and acceptability of a PSI	Telephone/face-to-face peer support, community dwelling older adults with CLBP, North Scotland	18 older adults (aged 65-79) with CLBP and 6 PSVs aged 34-65	The peer support intervention was delivered as intended and acceptable to people with CLBP and PSVs. Most participants were satisfied with peer support intervention and would recommend it to someone else with CLBP.
Kohut SA, Stinson J, Luca S, Forgeron P, Harris L, Ahola Kohut S. 2017.	Qualitative descriptive - interviews and focus group. Interviews and focus group data were transcribed and analysed using inductive content analysis.	Canada	Exploring the perceived benefits and challenges of acting as a peer mentor	Skype-based peer mentoring program, adolescents with chronic pain or JIA	10 peer mentors (20.00 ± 1.49 years old, range 17–22 years; diagnosed with chronic pain [n = 4] or JIA [n = 6])	Four main categories were identified: social connection, personal growth, mentor role in mentee growth, and logistics of mentorship. Acting as a peer mentor online is a feasible and rewarding experience that supports the mentor's own illness self-management, social connection, and personal growth.
Kumar K, John H, Gordhan C, Situnayake D, Raza K, Bacon PA. 2011.	Qualitative descriptive - focus groups and semi-structured interviews. Transcripts were studied to look for similar themes; an inductive approach was applied, whereby the data were searched in detail for similar words, patterns and themes, which were then organized into categories.	UK	Exploring patient perceptions of educational resources and peer support	Clinical face-to-face meetings, patients with RA of South Asian origin living in the UK	15 participants; all female, median age 48 (range 35 to 69) years, median disease (RA) duration four (range 2 to 10) years. All participants of South Asian origin.	Four important themes were identified: (1) All patients agreed there was a need for more information about RA in order to know how to live with their disease. (2) Concerns about currently available approaches to education included a lack of time in clinic and language barriers. (3) Patients appreciated the support provided by a trained patient volunteer. (4) The audio CD was useful for patients to have information in a language they could understand.

Matthias MS, Kukla M, Bair MJ, McGuire AB. 2016.	Qualitative descriptive - semi-structured interviews. Data analysis was guided by an immersion/crystallization approach. Data analysis was guided by an immersion/crystallization approach and consisted of two broad phases: open coding and focused coding.	US	Exploring the experience of participants in a peer support intervention and identifying the most effective elements	Telephone/ face-to-face, male veterans with chronic musculoskeletal (MSK) pain, Indiana, USA	26 male veterans with chronic MSK pain (n = 9 peer coaches, n = 17 veterans) Peer coaches' ages ranged from 50–71 years (Mean = 60). White (n=7), black (n=1), Hispanic (n=1), Veteran patients' ages ranged from 35–66 (Mean = 58). White (n=9), black (n=8).	Qualitative analysis revealed three elements of the PSI that peer coaches and patients believed conferred benefit: 1) making interpersonal connections; 2) providing/receiving encouragement and support; and 3) facilitating the use of pain self-management strategies.
Matthias MS, Kukla M, McGuire AB, Damush TM, Gill N, Bair MJ. 2016.	Qualitative descriptive - semi-structured interviews. Data were analysed using an immersion/crystallization approach	US	Identifying the facilitators and barriers to participation in a PSI	Telephone/ face-to-face, male veterans with chronic MSK pain, Indiana, US	26 male veterans with chronic MSK pain (n = 9 peer coaches, n = 17 veterans) Peer coaches' ages ranged from 50–71 years (Mean = 60). White (n=7), black (n=1), Hispanic (n=1). Veteran patients' ages ranged from 35–66 (Mean = 58). White (n=9), black (n=8)	Facilitators were 1) having a shared identity as veterans, 2) being partnered with a person who also has chronic pain, and 3) support from the study staff. Barriers were 1) logistical challenges, and 2) challenges to motivation and engagement in the intervention.
Sandhu S, Veinot P, Embuldeniya G, Brooks S, Sale J, Huang S, et al. 2013.	Mixed methods - qualitative descriptive – questionnaires, interviews and diaries	Canada	Examining the feasibility and potential benefits of early peer support	Telephone/ face-to-face, adults with RA, greater Toronto area, Canada	9 peer mentors (all female) and 9 mentees (7 females, 2 males). All adults with RA aged 18-70	Intervention was well received. Mentees experienced improvements in the overall arthritis impact on life, coping efficacy and social support.
Tse MMY, Ng SSM, Bai X, Lee PH, Lo R, Cheung DSK, et al. 2019.	Cluster RCT- qualitative descriptive – semi-structured interviews. Thematic analysis, but not explicitly described as such by the researchers.	China	Exploring the experiences and perceptions of PSVs in a PSI	Face-to-face in nursing home, adults with chronic pain, Hong Kong	46 PSVs (34 females, 12 males), with a mean ±SD age of 61.0±5.1 years. 31/46 had chronic pain	The PSVs reported an improvement in their knowledge and skills after leading PAPs. No PSVs reported having received any negative comments about their role in leading the PAP but mentioned that they had received feedback on how to

						improve the program. This study provides further evidence that peer-led pain management programs are feasible and can lead to positive experiences for the PSVs
Tse M, Li Y, Tang SK, Ng SSM, Bai X, Lee PH, et al. 2020.	Cluster RCT - qualitative descriptive - semi-structured interviews. Qualitative data on the contents of the interview were analysed after each interview.	China	Examining the effectiveness of a PSI and to evaluate participant experiences	Face-to-face in nursing home, adults with chronic pain, Hong Kong	68 participants total, 50 females, 18 males, age range 60-100, experimental group (n=36), control group (n=32).	The nursing home residents were satisfied with the pain education they received.
Arnstein P, Vidal M, Wells-Federman C, Morgan B, Caudill M. 2002.	Mixed methods - qualitative descriptive - Interviews and written accounts - Data from interviews with peer volunteers, and their written logs, were analysed using Sandelowski's (1995) guidelines for qualitative data analysis.	US	Evaluating whether the transition from chronic pain patient to peer volunteer was beneficial or harmful	Phone/ face-to-face, assisting chronic pain patients enrolled in cognitive behavioural therapy	7 peer volunteers (1 male and 6 females), age range 41-70, with chronic pain >1 year.	Two themes, "making a connection" and "a sense of purpose," emerged from the narrative data. Descriptive data provided further support that volunteering benefited both patients and peers.

Key: UK=United Kingdom, PSI=peer support intervention, CLBP=chronic low back pain, PSVs=peer support volunteers, JIA=juvenile idiopathic arthritis, RA=rheumatoid arthritis, CD=compact disc, MSK=musculoskeletal, US=United States, RCT=randomised controlled trial, PAP=peer-led pain management programme

Table 2.5 Summary of Findings

Systematic review title: Exploring the Experience of Participating in a Peer Support Intervention for Adults with Chronic Non-cancer Pain: a qualitative systematic review
Population: adults with chronic non-cancer pain
Phenomena of interest: the experience of participating in a peer support intervention
Context: any setting where peer support interventions are offered, not limited by geographical location

Synthesised finding	Type of research	Dependability	Credibility	ConQual score	Comments
Synthesised Finding 1: The peer-peer relationship is perceived as unique by those giving and receiving peer support, and important components included communication, a shared understanding and an ability to connect on a personal level. These components should be considered when matching participants to PSVs.	Qualitative	High	High	High	Dependability: 11/14 findings came from studies with high dependability as they scored 4/5 yes responses for the questions relating to appropriateness of the conduct of the research. Credibility: All 14 findings were unequivocal
Synthesised Finding 2: PSVs and participants perceive a number of benefits from taking part in peer support interventions including developing a greater sense of purpose, feeling optimistic about the future, and an overall improvement in skills such as communication, knowledge and confidence. These benefits should be considered when developing and recruiting to future peer support interventions.	Qualitative	Moderate (Downgrade one level*)	Moderate (Downgrade one level**)	Low	Dependability: 9/14 findings came from studies with moderate dependability as they scored 3/5 yes responses for the questions relating to appropriateness of the conduct of the research. Credibility: Downgraded one level due to mix of unequivocal (12) and credible (2) findings.
Synthesised Finding 3: People developing or implementing peer support interventions should be cognizant of elements that are deemed essential by PSVs and participants, which includes specific discussion topics, a sharing of ideas and individual preferences.	Qualitative	High	High	High	Dependability: 8/13 findings came from studies with high dependability as they scored 4/5 yes responses for the questions relating to appropriateness of the conduct of the research Credibility: All 13 findings were unequivocal
Synthesised Finding 4: A number of physical, logistical and interpersonal barriers to successful implementation of peer support for chronic pain have been reported; ways of overcoming these barriers should be considered when developing future peer support interventions.	Qualitative	Moderate (Downgrade one level*)	Moderate (Downgrade one level**)	Low	Dependability: 6/12 findings came from studies with high dependability as they scored 4/5 yes responses for the questions relating to appropriateness of the conduct of the research. Credibility: Downgraded one level due to mix of

					unequivocal (8) and credible (4) findings.

Key: PSVs = peer support volunteers
* Downgraded one level due to common dependability issues across the included primary studies (the majority of studies had no statement locating the researcher and no acknowledgement of their influence on the research).
** Downgraded one level due to a mix of unequivocal and equivocal findings.

Table 2.6 Synthesised finding #1

Finding	Category	Synthesised Finding
The majority of patients also stated that there was mutual understanding between them and the volunteer, as they both suffered with RA (U)	Importance of mutual understanding from shared diagnosis/background	The peer-peer relationship is perceived as unique by those giving and receiving peer support, and important components include communication, a shared understanding and an ability to connect on a personal level. These components should be considered when matching participants with PSVs.
Facilitators to Participation: Shared veteran identity (U)		
Facilitator to Participation: Having a partner with chronic pain (U)		
Matching: Participants were generally positive about their matches. (U)		
Patients were particularly impressed by the fact that the volunteer listened to their story (U)	Importance of listening/communication	
They found it very helpful to be able to communicate with her directly in their spoken language (U)		
Listening was a key component of the peer support experience (U)		
Developing a relationship (U)	Importance/benefits of making a connection	
Benefits of connection (U)		
Participants valued the purely social nature of connecting with another veteran, being able to get to know one another, and having the opportunity to discuss common interests that were often unrelated to pain. (U)		
Participants' experience of peer support was informed by the unique relationship they forged with their peer (U)		
Making a connection (U)		
Mentor role (U)		
Mentee characteristics (U)		

Key: U=unequivocal, RA=rheumatoid arthritis, PSVs=peer support volunteers provide assurance that they were not the only one struggling with certain aspects of their diagnosis. Participants appreciated discussing topics related to their diagnosis along with talking about other common interests unrelated to pain. At times the mentor role of the PSV evolved into a more egalitarian friendship and PSVs also felt supported by the conversation (Kohut, Sara Ahola et al. 2017) PSVs also commented that making connections looked different between different peers; some were shy while others opened up more quickly.

Category 3: Importance of listening/communication

Three unequivocal findings (Matthias, Marianne S. et al. 2016a; Kumar et al. 2011b) indicated that participants greatly valued having a space to be heard and relay their experiences and feelings, especially in their own language. Participants who spoke more than one language stated they had not encountered another space to convey their story and emotions in their native tongue(Kumar et al. 2011b). Being able to fully express their experience was therefore a very impactful and gratifying moment. Participants also felt supported as they shared their story with someone who could relate to them. Participants liked the openness of the conversations with their PSVs and that it was not purely an exchange of advice but more a social exchange of experiences.

> *"It was good to talk to [N.L.] because she spoke my language and that really helped me to get my feelings across and this wouldn't happen otherwise" (56 years old, disease duration 10 years).* (Kumar et al. 2011b)

2.8.2 Synthesised finding #2

PSVs and participants perceive a number of benefits from taking part in PSIs including developing a greater sense of purpose, feeling optimistic about the future, and an overall improvement in skills such as communication, knowledge and confidence. These benefits should be considered when developing and recruiting to future PSIs.

PSVs reported numerous benefits from participating in PSIs, these benefits ranged from improvements in interpersonal skills, gaining knowledge about their condition and management strategies, and most notably a boost in their sense of self-worth. Participants were positive about their relationships with the PSVs, particularly appreciating their kindness and patience. Greater levels of optimism were also commented on by both parties, with PSVs illustrating how to live well with pain and participants feeling motivated to focus on what they could do, instead of their limitations. This synthesised finding summarizes four categories comprising 14 findings (Table 2.7).

Category 4: PSVs perceive a range of personal benefits from taking part in PSIs

Five findings (three unequivocal (Cooper, Kay et al. 2020; Tse, Mimi Mun Yee et al. 2019; Kohut, Sara Ahola et al. 2017) and two credible (Matthias, Marianne S. et al. 2016a; Arnstein, P. et al. 2002)) showed that PSVs noted several benefits from not only helping others but also helping themselves. As they interacted with participants, PSVs enjoyed having a positive influence, empowering the participants and watching them improve their quality of life and decrease levels of loneliness. PSVs also noted a sense of satisfaction as they experienced overall improvements in their own skills of communication, confidence, functioning and knowledge. Several PSVs reported learning new self-management techniques and coping strategies as well as appreciating reinforcement of familiar self-management techniques.

> *"Think I got as much out of it as the patients have. I learned a lot about pain and different people's pain thresholds, ways of managing. Think I'm more tolerant of back pain as a result of the study." [PSV40, Female]* (Cooper, Kay et al. 2020)

Category 5: PSVs experience a sense of purpose from taking part in PSIs

Three unequivocal findings (Tse, Mimi Mun Yee et al. 2019; Arnstein, P. et al. 2002) revealed that PSVs reported greater levels of satisfaction and self-worth by giving back to society and seeing participants improve their skills of self-management. PSVs described their involvement in the PSI as a meaningful experience and felt appreciated by the participants.

> *"When they started thinking of more ways to help themselves I felt good, I felt like I had purpose."* (Arnstein, P. et al. 2002)

Table 2.7 Synthesised Finding #2

Finding	Category	Synthesised Finding
Mentor growth (U)	PSVs perceive a range of personal benefits from taking part in a peer support intervention	PSVs and participants perceive a number of benefits from taking part in PSIs including developing a greater sense of purpose, feeling optimistic about the future, and an overall improvement in skills such as communication, knowledge and confidence. These benefits should be considered when developing and recruiting to future PSIs.
Mentors reported personally benefiting from the programme (C)		
Perceived benefits: helping themselves and helping others (U)		
Reported benefits (C)		
What I got out of it: participants reported benefit, although not always in the way they had anticipated. (U)		
PSVs described leading the pain management program (PAP) as a meaningful experience (U)	PSVs experience a sense of purpose from taking part in a peer support intervention	
Boosted my sense of self-worth (U)		
Sense of purpose (U)		
About the program (U)	Participant benefits/positive feedback	
About the peer volunteers (U)		
Feedback on the content of the PAP (U)		
Hope for the future (U)	Positive about future/changed attitude	
They found it helpful to talk to someone who had been through the experience of living with RA and had remained positive about the future (U)		
Changes in Attitude Toward and Acceptance of Pain (U)		

Key: U=unequivocal, C=credible, RA=rheumatoid arthritis, PSVs=peer support volunteers, PAP=peer-led pain management programme, PSI=peer support intervention

Category 6: Participant benefits/positive feedback

This category combined three unequivocal findings (Tse, Mimi et al. 2020a) to show that participants liked the PSVs and the intervention as a whole. These findings came from two reports on the same study, which implemented a face-to-face intervention for nursing home residents with chronic pain. The intervention consisted of weekly one-hour sessions; PSVs led 20 minutes of physical activity followed by 30 minutes of pain management education over a duration of 12 weeks. Participants described the PSVs as patient and nice and they enjoyed participating in the intervention.

> *"I feel happy and relaxed when taking part in the program every week"* (Tse, Mimi et al. 2020a)

Category 7: Positive about the future/changed attitude

Three unequivocal findings (Kohut, Sara Ahola et al. 2017; Matthias, Marianne S. et al. 2016a; Kumar et al. 2011b) indicated that both PSVs and participants reported improved levels of hope for the future, aided by sharing their experience with someone who understood their condition and provided motivation and encouragement. PSVs expressed familiarity with feelings of anxiety and fear of the future due to the very real impact of living with chronic non-cancer pain. They were *able* to pass on advice such as not letting pain be in control and focusing on what each person is capable of instead of how they are limited (Matthias, Marianne S. et al. 2016a). After conversing with PSVs, participants noted a greater acceptance of pain and felt motivated to see themselves as separate from their disease.

> *"Instead of thinking about what I can't do, I like to think about what I can do. That's more fun. It's a lot more fun. It gives the day a better outlook" (Veteran 213).* (Matthias, Marianne S. et al. 2016a)

2.8.3 Synthesised finding #3

People developing or implementing PSIs should be cognizant of elements that are deemed essential by PSVs and participants, which include specific discussion topics, a sharing of ideas and individual preferences.

Sharing of ideas was especially helpful amongst participants and PSVs in a particular life stage, such as entering university. PSVs from this study were able to provide specific advice regarding accommodation and accessing other resources. Notable discussion topics comprised of treatment options, exercise and navigating healthcare resources. Preferences for intervention components including stressing the overall significance of PSIs, the benefits of PSV training and having support from other PSVs and study staff and finally the importance of face-to-face interactions. This synthesised finding summarizes three categories comprising 13 findings (Table 2.8)

Table 2.8 Synthesised Finding #3

Finding	Category	Synthesised Finding
Illness self-management (U)	Sharing ideas on self-management	Synthesised finding #3: People developing or implementing PSIs should be cognizant of elements that are deemed essential by PSVs and participants, which include specific discussion topics, a sharing of ideas and individual preferences.
Sharing Ideas About Pain Self-Management Strategies (U)		
Discussing Exercises and Activity (U)	Types of support and discussion topics	
Helping Veterans to Navigate Health Care Resources (U)		
Challenging and Motivating (U)		
Emotional and informational supports were most commonly reported (U)		
Appraisal and instrumental support were also exchanged (U)		
Mentor–mentor connection (U)	Preferences for intervention components	
Mentor training (U)		
Facilitator to Participation: Support from study staff (U)		
Delivery: All participants, including those who had one or more telephone meetings, felt that a face-to-face element was essential. (U)		
PALS Manual: Participants spoke variably of the manual and resources, with some liking the information provided, some using the manual as a step-by-step guide, and some not using it at all. (U)		
All participants were unequivocal about the need for a peer support programme for individuals with EIA. (U)		

Key: U=unequivocal, C=credible, PALS=Peer support in Aberdeenshire for Long-term condition Self-management, EIA=Early Inflammatory Arthritis, PSVs=peer support volunteers, PAP=peer-led pain management programme, PSI=peer support intervention

Category 8: Sharing ideas on self-management

This category combined two unequivocal findings (Kohut, Sara Ahola et al. 2017; Matthias, Marianne S. et al. 2016a) to show that PSVs provided advice on pain management strategies and some discussed specific life transitions and accommodations that can be requested (high school to university). One PSV stated his favourite part of working with participants was sharing concrete ideas about self-management, not just abstract principles (Matthias, Marianne S. et al. 2016a). He was able to share specific strategies that both of his participants implemented in their own lives. Several participants expressed a willingness to try new coping strategies or methods of pacing.

> *"…figuring out ways to cope with my pain or learning tricks to ease the pain, [my peer coach] just sharing information that he found out with me, you know all the tips and tricks were very beneficial. Because I'm in pain, I don't think it's going to hurt to try something new (chuckles)." (Veteran 215)* (Matthias, Marianne S. et al. 2016a)

Category 9: Types of support and discussion topics

Five unequivocal findings (Matthias, Marianne S. et al. 2016a; Sandhu, Sharron et al. 2013) revealed that emotional, informational, appraisal and instrumental support were all provided by PSVs. Emotional and informational support appeared to be the most commonly reported forms and frequent discussion topics included exercise, activity pacing and navigating health care resources. Informational support included both program resources and mentors' experiential knowledge. After incorporating more activity into their routines, at least one participant was able to reduce his use of pain medication and also noted improved sleep quality (Matthias, Marianne S. et al. 2016a). PSVs also shared information about coping strategies or preventative measures to take to reduce pain. PSVs shared their experiences oftentimes to model what could work like walking with a friend or keeping weights nearby while they are watching TV and trying to incorporate small exercises during commercials (Matthias, Marianne S., Kukla, Bair and McGuire 2016).

> *"I would ask her when she encountered bad weather, how were her joints? What did she do about that? …Can I do something prior to, when you know the weather is coming." (EIA3)* (Sandhu, Sharron et al. 2013)

At least one PSV went beyond discussing techniques and agreed to engage in the same self-management routine as his assigned participant.

> *"I told them up front, Look I'm gonna do these with you, so if you agree to do them over the next two weeks, I will do them for two weeks and I'll even document the days that I do 'em." (Peer Coach 106)* (Matthias, Marianne S. et al. 2016a)

Category 10: Preferences for intervention components

Six unequivocal findings (Cooper, Kay et al. 2020; Kohut, Sara Ahola et al. 2017; Matthias, Marianne S. et al. 2016b; Sandhu, Sharron et al. 2013) were combined to form this category, showing preferences for a range of intervention components. Both participants and PSVs stressed the need for PSIs; participants describing them as “critical” and PSVs wishing that a similar intervention had been available earlier in their diagnosis (Sandhu, Sharron et al. 2013). Regarding the delivery of the intervention, both parties preferred at least one face-to-face interaction, often with additional phone interactions.

> *“Both [face-to-face & telephone] were good…just as easy over the phone…but it’s vital to see a face, you couldn’t do them all by phone” [52, Male]* (Cooper, Kay et al. 2020)

PSVs appreciated the training provided to them, particularly how to use their story in a constructive way (Kohut, Sara Ahola et al. 2017). In an intervention where a manual was provided, PSVs varied in their use of said manual, some citing it as helpful if participants went off track during a session as they could use the manual to direct the conversation back to the topic for the session (Cooper, Kay et al. 2020) Some PSVs noted the manual was helpful but there was far too much content; it could be halved. Finally, one intervention provided support to PSVs via regular group conference calls with other PSVs, supervised by the psychologist, as well as individual phone calls from the psychologist who provided supervision (Matthias, Marianne S., Kukla, McGuire, Damush, Gill and Bair 2016). PSVs agreed that this support was crucial as a main facilitator to participation.

2.8.4 Synthesised finding #4

A number of physical, logistical and interpersonal barriers to successful implementation of peer support for chronic pain have been reported; ways of overcoming these barriers should be considered when developing future PSIs.

PSVs noted physical challenges such as enduring the length of the therapy sessions during a pain flare and struggling to physically assist frail participants during an exercise portion. Logistical challenges included difficulties with scheduling, access to technology or transportation, and time commitment. PSVs discussed interpersonal challenges such as ascertaining and providing an appropriate level of engagement with their peer. PSVs and participants both commented on some negative interactions relating to difficulty building rapport due to differences in disease stage, gender, sexuality or political views. This synthesised finding summarizes four categories comprised of 12 findings (Table 2.9).

Category 11: Physical barriers to leading intervention

Two findings (one unequivocal (Tse, Mimi Mun Yee et al. 2019) and one credible (Arnstein, P. et al. 2002)) showed that PSVs experienced some challenges with leading an intervention. In one intervention, PSVs led a brief (20 minute) exercise period with participants; PSVs reported some difficulty with providing assistance to particularly frail participants (Tse, Mimi Mun Yee et al. 2019).

> *"Some nursing home residents were too frail and required more (Tse, Mimi Mun Yee, Ng, Bai, Lee, Lo, Cheung, Cheung and Yeung 2019 p. 7)*

In another intervention, PSVs similarly noted the physical challenges of enduring the duration of the therapy sessions along with transportation to the clinic, particularly during their own pain flares (Arnstein, P. et al. 2002).

Table 2.9 Synthesised Finding #4

Finding	Category	Synthesised Finding
Barriers encountered in leading the PAP (U)	Physical Barriers to leading intervention	A number of physical, logistical and interpersonal barriers to successful implementation of peer support for chronic pain have been reported; ways of overcoming these barriers should be considered when developing future PSIs.
Physical Challenges (C)		
Scheduling issues (U)	Logistical barriers to participation	
Technological issues (U)		
Barriers to Participation: Logistical Challenges (U)		
Programmatic issues (U)		
Protocol-related challenges (C)		
Barriers to Participation: Challenges to motivation and engagement (U)	Difficulties with correct level of engagement from PSV	
Psychosocial challenges (C)		
Two patients stood out in expressing some negative feelings about the interaction. (U)	Challenges/negative interactions between PSV and participant	
A few mentors experienced challenges (C)		
Four participants faced challenges building rapport due to differences in gender, sexuality, political views and disease stage (U)		

Key: U=unequivocal, C=credible, PSVs=peer support volunteers, PAP=peer-led pain management programme, PSI=peer support intervention

Category 12: Logistical barriers to participation

This category combined five findings (four (Kohut, Sara Ahola, Stinson, Luca, Forgeron, Harris and Ahola Kohut 2017; Matthias, Marianne S., Kukla, McGuire, Damush, Gill and Bair 2016) and one credible (Arnstein, P. et al. 2002) revealing a number of logistical barriers related to technology, time commitment and finances. PSVs noted internet connectivity as an occasional disruption to video calls but stated the overall quality of the calls was never compromised. PSVs also discussed barriers such as scheduling challenges and finding time to meet with their assigned participants. Time commitment was also highlighted as a substantial consideration; with one particular study requiring three to seven hours per week, along with paperwork (Arnstein, P. et al. 2002). Some PSVs struggled to establish an initial contact with participants if not done in person, and others noted challenges with properly connecting with participants if there was an interruption to their meeting schedule. Participants discussed transport expenses when weighing how to meet, with some deciding on phone calls as a lower cost option.

> *"I told [my peer coach], I got to ride the bus to get [to the medical center to meet]. I said that's four bucks. I said I have to look at that money because I'm on a fixed income. I said I know it's a lot of gas for you, and gas at that time was almost $4 a gallon. That's why we decided to do the phone calls." (Veteran 210)* (Matthias, Marianne S. et al. 2016b)

Category 13: Difficulties with correct level of engagement from PSV

Two findings (one unequivocal (Matthias, Marianne S. et al. 2016b) and one credible (Arnstein, P. et al. 2002) indicated that some PSVs experienced the psychosocial challenge of determining and executing the correct level of engagement with their assigned participants. PSVs reported an eagerness to get overly involved and had to scale back their efforts when their desire to help actually exceeded what they could feasibly achieve. PSVs also spoke of their own challenges with engagement when they themselves were fatigued or not in the right headspace to mentor.

> *"Sometimes I was also weak. I didn't call or nothing because I was spaced out. My disabilities were taking over, and I just would come into the house and just sit in the corner in my chair…and watch TV." (Peer 109)* (Matthias, Marianne S. et al. 2016b)

Category 14: Challenges/negative interactions between PSV and participant

Three findings (two unequivocal (Sandhu, Sharron et al. 2013; Kumar et al. 2011b) and one credible (Sandhu, Sharron et al. 2013) were combined to form this category, where some participants noted fear or disbelief when meeting PSVs with reduced mobility as they reflected on that possibility of disease progression in their own lives.

> *"When I first saw her I felt very afraid. For a whole week I was upset, I was thinking, gosh... will I be like this in another 10 years time? Then I tried to make myself understand that, no, I will not end up like that because I have been treated reasonably early. Then I thought that it could be that some people have different disease and patterns." (45 years old, disease duration three years)* (Kumar et al. 2011b)

One participant found herself disassociating from her PSV who was a wheelchair user (Sandhu, Sharron et al. 2013). PSVs also relayed difficulties in building rapport due to differences in gender, sexuality, political views or disease stage. Finally, PSVs reported a few specific incidents such as a participant who was reluctant to stop consuming alcohol in order to take methotrexate (Sandhu, Sharron et al. 2013). Another incident involved a PSV struggling to advise a participant who had problems returning to work after being on long-term disability (Sandhu, Sharron et al. 2013).

2.9 Discussion

This is the first systematic review to synthesize the available qualitative evidence on the experience of participating in a PSI for adults with chronic non-cancer pain. One of the main findings is the lack of research in this field. These studies represented four countries; the US, UK, China and Canada. Generalizability must be considered not only between these countries, but also from these countries to other parts of the world as they represent different healthcare systems, cultures and societies. In addition, the organization and funding of health and social care also varies widely between countries. The results present the experiences of people from high income settings and may not be contextualized to low- and middle-income countries, this warrants further research to be conducted in the latter countries. Other literature on peer support for adults with diabetes has noted varying peer support strategies and preferences for different ethnic and racial groups (Pérez-Escamilla et al. 2008; Sarkar et al. 2007). Additionally, the impact of peer support may be influenced by contextual factors such as culture and social environment (Zhang, Xuxi et al. 2016). Therefore, these factors may need to be considered for the population of adults with chronic non-cancer pain.

The four synthesised findings have provided an understanding of the unique relationship formed between peers, the benefits for both parties, essential intervention components, and barriers to implementation. ConQual (Munn, Z. et al. 2014) was utilized to determine the confidence of the evidence for the four synthesised findings, which resulted in two high ratings and two low ratings. These findings will now be discussed in relation to each of the review questions.

2.9.1 *What are the perceptions of adults with chronic non-cancer pain regarding the format, delivery, role and training of PSVs and duration of the PSI?*

This review illuminated findings on delivery and PSV training, but no evidence was found on the remaining intervention components, namely the format, role of the PSV, length of intervention and frequency of contact between PSVs and participants. In the realm of PSIs, delivery can vary from a face-to-face interaction, (Tse, Mimi et al. 2020a) audio call, (Shadick et al. 2018) video call, (Jeffrey et al. 2020) social media platform, (Young et al. 2018) online discussion forum, (Gavin et al. 2014) or a combination of two or more of these interaction types (Cooper, Kay et al. 2020). This review elucidated only one finding regarding participants' perceptions of delivery modes (Cooper, Kay, Schofield, Smith and Klein 2020) which reported that all participants deemed a face-to-face element to be essential, including participants who had one or more telephone meetings. This preference for a face-to-face element is an important consideration in light of the increasing number of studies that are incorporating virtual components to interventions. The cause of this increase could be twofold, as access to smart devices is expanding (Poushter 2016) and owing to ongoing concerns relating to Covid-19. With only one finding exposed in this review, further research is required to determine if this was simply an outlier or a function of other studies not reporting on preferences of delivery mode. Furthermore, as this finding was from a study completed before the global outbreak of Covid-19, it would also be important to consider how participant and PSV preferences may be impacted by ongoing concerns relating to Covid-19. Evidently there is still a need for further research to gain a more comprehensive understanding of participant and PSV perceptions of this component.

Another component is PSV training, and two findings were related to this topic. Training can range from as little as three (Matthias, Marianne S. et al. 2016a) to 12 hours, (Cooper, Kay et al. 2020) as demonstrated by the studies included in this review. One PSV noted training was valuable in terms of learning how to mentor and use his story in a constructive way (Kohut, Sara Ahola et al. 2017). Another intervention provided manuals to PSVs to use throughout the PSI, and PSVs had variable opinions on the usefulness of the manuals (Cooper, Kay et al. 2020). For the purpose of this review, some amount of training was required for PSVs in order to be included in the chosen definition of peer support, but it should be noted that many PSIs are implemented without any training being provided to PSVs. A future review could be conducted to evaluate and synthesize and/or compare PSIs with or without training for PSVs.

This review did not find any evidence on the remaining intervention components, these include the format, role of the PSV, length of intervention and frequency of contact between PSVs and participants. Further research is warranted on these topics in order to address this prominent gap in the evidence base. The format of PSIs can vary from a one-to-one interaction, (Matthias, Marianne S. et al. 2016a) a group (Tse, Mimi et al. 2020a) or a hybrid (Shadick et al. 2018). With peer support in critical care, one-to-one interactions have demonstrated more significant improvements in certain health outcomes (Haines et al. 2018) compared to group interactions. These include reductions in anxiety and depression and increases in perceived social support and self-efficacy (Haines et al. 2018). Depending on the parameters of the intervention, if a group is gathered, the composition can also vary from homogenous to mixed disease type and several other demographics. It is important to consider the impact this could have on group dynamics and the level of shared experiences. With any PSI, the most beneficial design will depend on the preferences of the individuals and any unique circumstances or challenges associated with a particular diagnosis.

The role of the PSV can also vary based on the design of the intervention. All interventions included in this review designated PSVs who received training and were matched either with an individual or helped lead a group of participants, all of whom desired some kind of support. While the interventions are termed "peer support," this type of partnership does reveal a slight hierarchy. The PSVs are usually chosen due to their experience at managing their condition well, thus they take on somewhat of a mentorship role towards the participant. This contrasts other interventions which construct partnerships that are reciprocal in nature; all participants complete the same training and have the opportunity to both offer and receive support (Heisler 2010).

The length of a PSI can range from as little as a singular interaction (Kumar et al. 2011b) to two years (Johansson et al. 2017). The frequency of meetings can vary, again from a singular interaction, (Kumar et al. 2011b) although most are weekly, (Tse, Mimi Mun Yee et al. 2019) every two weeks (Cooper, Kay et al. 2020) or a hybrid of one-to-one meetings weekly and groups meetings monthly (Johansson et al. 2017).

2.9.2 *What are the perceptions of adults with chronic non-cancer pain regarding the strengths and limitations of PSIs?*

This review mainly found strengths and instead of limitations found barriers, which will be discussed in detail in the next section. Both PSVs and participants identified several strengths of PSIs. These pertained to the benefits they received from taking part in the interventions, including developing a greater sense of purpose, feeling optimistic about the future, and an overall improvement in skills such as communication, confidence and knowledge. Similar benefits have been reported with the use of PSIs with other conditions. With regard to diabetes, peer support increased scores for patients in the areas of self-efficacy, self-management and quality of life (Peimani et al. 2018) Patients with cancer have also expressed high satisfaction and acceptance of PSIs, along with improvements in the areas of emotional distress, decision-making skills, communication, and psychological adjustment (Meyer, Coroiu and Korner 2015).

There were no findings specifically on limitations of PSIs, but barriers to implementation of PSIs are explored in the next section, which heavily relates to limitations as well.

2.9.3 *What do adults with chronic non-cancer pain perceive to be the barriers and facilitators to implementation of PSIs?*

This review found barriers to implementation of PSIs could be categorized into physical, logistical, and interpersonal barriers. PSVs noted the physical challenge of assisting frail participants, (Tse, Mimi Mun Yee et al. 2019) along with enduring the length of the exercise portion of the intervention (Arnstein, P. et al. 2002).

Logistical barriers included technological difficulties such as internet connectivity, (Kohut, Sara Ahola et al. 2017) challenges with time commitment, (Kohut, Sara Ahola et al. 2017; Arnstein, P. et al. 2002) and travel costs (Matthias, Marianne S. et al. 2016b). Studies on peer support with adults with diabetes have also found that poor attendance rates can potentially impair the effects of peer support (Smith et al. 2011b). For those who design and deliver future interventions, it is important to mitigate against these logistical barriers. Shue, McGuire and Matthias (Shue, McGuire and Matthias 2019) also identified adequate time and space as potential barriers, coming from clinicians' (or implementers') perspectives. This included time for the initial training of PSVs and ongoing supervision, along with securing physical space to meet. Evidently, interventions that are held virtually would not have to address the barrier of securing physical space, although implementers of these interventions would have to consider access to smart devices and internet connectivity. A systematic review on peer support in mental health reported barriers such as the absence of training for PSVs, unclear role definition for PSVs and a lack of support from staff/implementers of the intervention (Ibrahim, Nashwa et al. 2019).

Interpersonal barriers included negative interactions between peers. PSVs commented on challenges in building rapport with some participants due to differences in gender, sexuality, political views or disease stage (Sandhu, Sharron et al. 2013). In the interventions, the connection between peers and thus the potential benefits are largely based on good rapport, built from similarities or shared experiential knowledge of the condition. These benefits could be hindered if peers have a difficult time building rapport due to differences.

Another barrier was the challenge noted by PSVs to avoid the tendency to get overly involved in the lives of the participants and dealing with frustration when their desire to help exceeded their ability to help (Arnstein, P. et al. 2002). PSVs also commented on their own challenges with engagement when they themselves were fatigued or not in the right headspace to mentor. This points to a larger limitation of peer support in general, which is that it relies on the active participation of both PSVs and additionally participants that are motivated towards behavioural change, yet not all peers will possess these attributes.

We intended to explore facilitators to intervention implementation, however we instead found facilitators to patient participation, in an intervention from one study on veterans with chronic pain (Matthias, Marianne S. et al. 2016b). While the literature did not directly answer our original question, this information is still valuable. This study established the significance of participants sharing a common identity as veterans, along with the shared experience of living with chronic pain. It was evident that the veterans had struggled to share their experience with non-veterans and valued having a space to meet with other veterans. Similarly, the experience of living with chronic pain was also difficult to express and the veterans valued meeting with others with experiential knowledge of their circumstances. Our findings concur with those of Kong et al., (Kong, Ling-Na et al. 2019) who stressed the integral role that PSVs play and how their experiences, competency and extent of involvement could impact outcomes for participants with diabetes. Kong et al.'s 2019 review found that the selection criteria and training of PSVs is widely varied and could also impact the effects of peer support. Finally, the PSVs in this intervention stated that having support from the study staff also was a great benefit and facilitator to their participation. Another systematic review on peer support in mental health has also identified support for PSV wellbeing and access to their own peer network as facilitators (Ibrahim, Nashwa et al. 2019). This same review also found that providing adequate training and supervision to PSVs was essential.

2.9.4 *Strengths and Limitations of this Review*

The strengths of this review include a comprehensive, multi-language search strategy, the use of two independent reviewers throughout the review, which helped to reduce bias, and the assessment of the quality of evidence in the included studies. The search strategy was developed in consultation with a research librarian and relevant search terms were congruent with recent systematic reviews, (Berkanish, Patricia et al. 2022; Levy, Ben B. et al. 2019) including a large umbrella review (Thompson, Dean M. et al. 2022). We are confident that our comprehensive search strategy identified most relevant studies, although it is possible some studies were not discoverable due to the range of terms for "peer support" used by different researchers. However, we used all the terms related to peer support commonly cited in the literature and used in previous systematic review searches, including "peer group," "peer counsel*," "peer mentor*," "peer coach*" and "social support." It is always possible that studies have been missed, but we are confident that the search strategy was comprehensive, identifying 3,894 unique records. Studies retrievable via non-English databases may also have been missed as the searches were only conducted using English databases. Human error may have been possible in the screening of the titles and abstracts, however high reliability was achieved between the 25% screened by two independent reviewers. There was an included study authored by one of the reviewers (KC). Inclusion of this study and the subsequent risk of author bias was unavoidable as this author had done previous research in the area of chronic pain and peer support, but steps were taken to mitigate the risk of author bias. These steps comprised of excluding KC from any decisions regarding inclusion, critical appraisal or data extraction related to her study. These steps were in line with recent suggestions from a 2022 JBI editorial on this issue (Aromataris 2022).

Additionally, there were concerns around the methodological quality of some of the included reports. None of the included reports clearly stated a philosophical perspective, as such none scored a "yes" to the criterion assessing congruity between the stated philosophical perspective and the research methodology. Only one of the reports had a statement locating the researcher culturally or theoretically and just three of the reports addressed the potential influence of the researcher on the researched. These limitations may have impacted the researcher's influence on the results, although are unlikely to have influenced the findings and illustrations.

2.10 Conclusion

There is limited qualitative research exploring the experience of participating in a PSI for adults with chronic pain. Most of the seven included studies were qualitative descriptive, which is a common design used in healthcare research due to its simplicity, flexibility and utility in healthcare contexts (Doyle et al. 2020). The findings can be used to inform the development and delivery of PSIs, and direct future research in this important area of practice. The peer-peer relationship is perceived as unique by those giving and receiving peer support, and important components included communication, a shared understanding, and an ability to connect on a personal level. These components should be considered when matching participants with PSVs. PSVs and participants perceive a number of benefits from taking part in PSIs including developing a greater sense of purpose, feeling optimistic about the future, and an overall improvement in skills such as communication, knowledge and confidence. These benefits should be considered when developing and recruiting to future PSIs. People developing or implementing PSIs should be cognizant of elements that are deemed essential by PSVs and participants, which include specific discussion topics, a sharing of ideas and individual preferences. A number of physical, logistical and interpersonal barriers to successful implementation of peer support for chronic pain have been reported; ways of overcoming these barriers should be considered when developing future PSIs.

2.10.1 Recommendations for practice

Based on the evidence displayed in the Summary of Findings table (Table *2.5*), the overall findings in this review provide evidence to guide practice for organizations involved with developing and implementing PSIs for adults with chronic non-cancer pain. The summary of findings presents the overall ratings of confidence in our findings. Recommendations for practice are rated according to the JBI Grades of Recommendation, which is a system to help establish the importance of the evidence (The Joanna Briggs Institute Levels of Evidence and Grades of Recommendation Working Party 2014). Findings are given either a Grade A or Grade

B rating, Grade A referring to “a ‘strong’ recommendation for a certain health management strategy where (1) it is clear that desirable effects outweigh undesirable effects of the strategy; (2) where there is evidence of adequate quality supporting its use; (3) there is a benefit or no impact on resource use, and (4) values, preferences and the patient experience have been taken into account” (The Joanna Briggs Institute Levels of Evidence and Grades of Recommendation Working Party 2014). Grade B refers to “a ‘weak’ recommendation for a certain health management strategy where (1) desirable effects appear to outweigh undesirable effects of the strategy, although this is not as clear; (2) where there is evidence supporting its use, although this may not be of high quality; (3) there is a benefit, no impact or minimal impact on resource use, and (4) values, preferences and the patient experience may or may not have been taken into account” (The Joanna Briggs Institute Levels of Evidence and Grades of Recommendation Working Party 2014).

i. Individuals and organizations involved in developing and running PSIs for people with chronic pain should ensure that PSVs possess the relevant lived experience, personal attributes and communication skills in order to provide effective peer support. A screening process could be used to determine suitability and/or to help target necessary training to be provided to PSVs. (Grade B)
ii. This review found several benefits for both participants and PSVs, which could be used during recruitment to future PSIs to inform interested parties of potential benefits. These findings can also be used to develop feasible, acceptable and effective interventions. (Grade B)
iii. Participants and PSVs deemed a few essential elements to PSIs such as specific discussion topics like pain management and an open environment to share ideas. People developing or implementing PSIs should be cognizant of these elements and consider these topics for PSV training. (Grade B)

2.10.2 Recommendations for research

This systematic review paves the way for future research to purposefully assess patient preferences regarding the many components of peer support. Most notably, no evidence was found in the areas of intervention format, length of intervention and frequency of contact between PSVs and participants. As such, these areas require investigation. Further research is also required in other geographical locations and healthcare contexts in order for the findings to be generalized more widely. Additionally, future research can combine the findings of this review with evidence of effectiveness and cost-effectiveness of peer support in order to make more informed recommendations to policy-makers.

3 CHAPTER 3: METHODOLOGY AND METHODS

3.1 Introduction

The previous chapter reviewed the literature on the experiences and perceptions of participating in a PSI for adults with chronic pain and concluded that there is limited qualitative research on this topic. Therefore, this chapter will discuss the rationale for the study, introduce the aim and research objectives and present the methodology and methods. Justification will be provided for the chosen methodology and other strategies will be reviewed.

3.2 Rationale for this study

Globally, healthcare systems have been highlighting the importance of person-centred care in recent years, which means treating patients as unique individuals and partnering with them on their health journey (Santana et al. 2018). Person-centred care is intended to be empowering, bespoke and coordinated. People should be seen not as passive recipients of care or victims of a disease but as active contributors with skills and knowledge to help improve their own health. In order to best equip those wanting to improve their health, healthcare systems should aim to provide the necessary information and tools for them to be successful. Alternatively, it has been shown that overly directive approaches in healthcare actually reduce patient engagement; creating dependency and undermining a person's confidence in managing their own care (Coulter 2012). As such, it can be seen why the 2012 NHS Mandate stated anyone with a long-term condition must be involved in a tailored care plan that reflected their preferences and agreed decisions (Department of Health and Social Care 2014).

Peer support interventions have the potential to provide proactive support and play a vital role in the management of chronic pain. Research has been conducted on the effectiveness of peer support interventions for adults with chronic pain (Tse, M. et al. 2020; Matthias, M. S. et al. 2015; Cooper, K., Kirkpatrick and Wilcock 2014), although there has not been a study to assess the preferences of adults with chronic pain or healthcare professionals regarding intervention components. The author's systematic review (Chapter 2) examined the existing literature on adults with chronic non-cancer pain and their experiences of participating in peer support interventions (Arnott, Park and Cooper 2021). This review demonstrated there are critical gaps in the research that must be addressed. These included understanding the perceptions of those that develop and participate in peer support interventions. This information is crucial for healthcare services, charities and community groups to be able to develop and implement interventions that are both feasible and optimally beneficial for those involved. Interventions can vary in a myriad of ways, including the format which could be a one-to-one interaction, (Matthias, Marianne S. et al. 2016a) a group (Tse, Mimi et al. 2020a) or a hybrid of the two (Shadick et al. 2018). Another variation includes delivery, which can range from a face-to-face interaction, (Tse, Mimi et al. 2020a) audio call, (Shadick et al. 2018) video call, (Jeffrey et al. 2020) social media platform, (Young et al. 2018) online discussion forum, (Gavin et al. 2014) or a combination of two or more of these interaction types (Cooper, Kay et al. 2020). The length of a PSI can also vary from as little as a singular interaction (Kumar et al. 2011b) to two years (Johansson et al. 2017). Another important component is the role and training of the peer support volunteer (PSV), as formal interventions may provide extensive training (Cooper, Kay et al. 2020) while less formal interventions may provide no training whatsoever (Young and Heinzerling 2017). All of these variables need to be taken into consideration with regard to the preferences of stakeholders.

3.3 Aim and research objectives

The aim of this study was to explore the preferences of stakeholders surrounding peer support interventions in order to make recommendations for the design and development of peer support interventions tailored to adults with chronic non-cancer pain. Stakeholders included adults with chronic non-cancer pain and individuals with experience of managing chronic pain or delivering peer support interventions.

The objectives were to:

1. Explore the perceptions of adults with chronic non-cancer pain regarding potential intervention ingredients and modes of delivery for a peer support intervention,

including preferences and barriers and facilitators to engaging with the proposed intervention,

2. Explore the perceptions of individuals with experience of managing chronic pain or delivering peer support interventions regarding potential intervention ingredients and modes of delivery for a peer support intervention, including preferences and barriers and facilitators to engaging with the proposed intervention,
3. Make recommendations for the design and delivery of a peer support intervention that can be tested in a future study.

3.4 The Research Onion

"Health research is a systematic and principled way of obtaining evidence (data or information) for solving health care problems and investigating health issues" (Polgar and Thomas 2020). Research is systematic as there is a sequential process that researchers follow and principled as research is typically conducted following explicit rules (Polgar and Thomas 2020). The primary research conducted by the author did aim to obtain evidence from participants regarding their perceptions of PSIs and aid in offering a solution to how PSIs could be designed and implemented. However, there were multiple options for how this research could have been conducted, and a multitude of decisions made by the author with regard to philosophy, methodology and methods.

The Research Onion developed by Saunders in 2007 is a useful tool for describing the different decisions necessary when holistically developing a research methodology. Pictured below in Figure 3.1, the Research Onion provides an overview of how philosophy, methodology and methods all relate to one another. Beginning from the outside and working inwards, decisions range from high-level and philosophical to more practical in nature. Each of these layers will be discussed in turn, with an exploration of the options available at each layer and justification provided for the author's decision for each component.

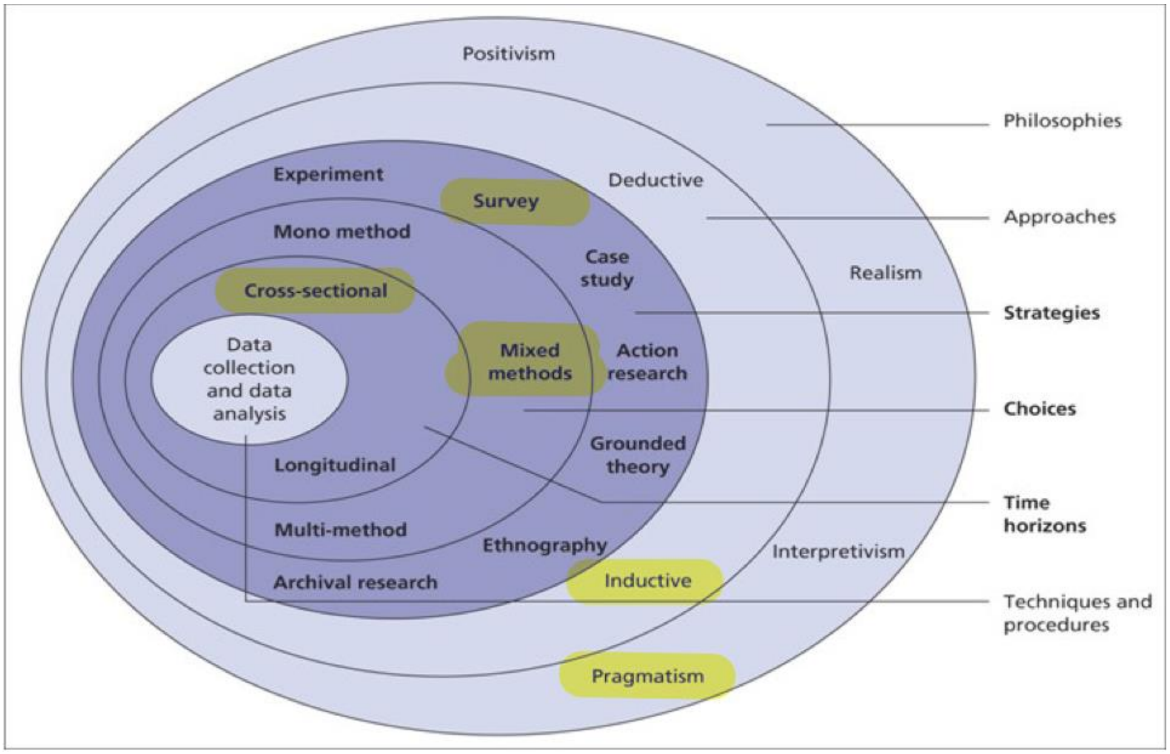


Figure 3.1 The Research Onion *(Saunders, Lewis and Thornhill 2011)* used with permission

3.4.1 Research philosophies

This section will begin with a discussion of the various research philosophies and justification for the chosen philosophy of pragmatism. Research philosophy refers to the foundational set of beliefs upon which a study is built (Doyle, Brady and Byrne 2016).

3.4.1.1 Positivism

This philosophy is typically associated with quantitative research and aims to identify causal relationships through objective measurement (Doyle, Brady and Byrne 2016). Reality is seen as singular, tangible and measurable (Cleland 2015) and is therefore independent of personal views and social contexts (Polgar and Thomas 2020).

3.4.1.2 Interpretivism

This philosophy is oftentimes associated with qualitative research and emerged as an alternative to positivism as researchers strived to examine the human experience (Denzin and Lincoln 2005). Interpretivism is also known as constructivism or naturalistic inquiry (Doyle, Brady and Byrne 2016). Reality is seen as socially constructed through an individual's unique experience or phenomena and is thus subjective (Polgar and Thomas 2020). If a group of people are experiencing something, there could be multiple realities and different interpretations of those realities. Within research underpinned by this philosophy, a certain degree of interpretation is required to understand social phenomena and human behaviour (Silverman 2013).

3.4.1.3 Pragmatism

Pragmatism is typically associated with mixed methods research. Instead of using a singular approach to address the research objectives, this philosophy guides the researcher to employ a variety of methods in order to optimally fulfil the research objectives (Doyle, Brady and Byrne 2016). The author of this research chose to adhere to pragmatism. This research examined and compared the perceptions of multiple participant groups. Using only qualitative or quantitative choices would have failed to fully address these issues, thus a pragmatist perspective allowed a mixing of these choices to optimally examine these perceptions.

3.4.2 Ontology – Realism and Idealism

Ontology is the study of reality and how we view the world (Allmark and Machaczek 2018). There are two distinct ontological positions which are realism and idealism. Realism claims a single, external reality exists, independent of what people may think or understand it to be (Ritchie et al. 2014). Idealism asserts that multiple realities exist since the reality of a human experience is only knowable through the human mind and through our socially constructed meaning around that experience (Ritchie et al. 2014). Furthermore, idealism states there is no external reality beyond an individual's own beliefs and understandings (Ritchie et al. 2014). In other words, realism claims reality exists as a single objective entity, while idealism claims reality is different for each person so multiple realities can exist. The author's ontological position was idealism as the aim of the research was to explore the realities of each participant's own unique experiences and perceptions of peer support. The author was interested in seeking participants' socially constructed meaning around their experiences. Thus there was not only one reality to explore, but multiple.

3.4.3 Research Approaches – Inductive and Deductive

Epistemology is the study of knowledge and how we come to acquire it and understand the world around us (Allmark and Machaczek 2018). It can be explored either inductively or deductively. The main difference between these two approaches is that the goal of an inductive approach is to develop a theory while the goal of a deductive approach is to test an existing theory (Creswell, John W. and Plano Clark 2011). The inductive approach begins with observation, proceeds through detecting any patterns and ends with developing a theory, in this way the knowledge is built from the 'bottom-up' (Creswell, John W. and Plano Clark 2011). In contrast, the deductive approach builds knowledge from the 'top-down' as it starts with an existing theory, forms a hypothesis, tests the hypothesis and analyses the results to determine whether to reject or support said hypothesis (Creswell, John W. and Plano Clark 2011).

The author took the inductive approach, as the knowledge in this study was built from the 'bottom-up.' The author surveyed and interviewed participants to collect their own observations and perceptions of their experiences. The author then analysed all the data to detect patterns and finally developed a theory or recommendation for the design of a PSI.

3.4.4 Research Strategies

A research strategy is a plan of how a researcher may go about addressing his or her research objectives (Saunders, Lewis and Thornhill 2011). The strategy provides a link between the philosophical underpinning and the choice of methods for data collection and analysis (Denzin and Lincoln 2005). The previous layers of the onion have addressed conceptual aspects of research planning, but this section on strategies will now examine more practical considerations of how the actual research can be conducted. A brief examination of each strategy is provided, with a justification for the chosen strategy delivered at the end of this section.

3.4.4.1 Experiment

The goal of an experiment is to manipulate the independent variable and observe any potential change in the dependent variable (Saunders, Lewis and Thornhill 2011). The researcher predicts the outcome of the experiment or the ultimate relationship between the variables, and this is reflected in the hypothesis. This strategy has its roots in natural science and laboratory-based research and requires precision in order to conduct an experiment, therefore this strategy is oftentimes viewed as the 'gold standard' by which the rigour of other strategies is measured (Saunders, Lewis and Thornhill 2011).

Experiments are typically conducted in laboratories instead of out in the field, but not all research questions can be answered within a laboratory. The nature of the research question will determine whether an experiment is appropriate, such as a researcher wanting to test an anticipated relationship between variables. Conducting research in a laboratory provides more control over sample selection and the research environment, this improves the internal validity of an experiment, but can decrease the external validity of results. Additionally, this strategy uses predictive hypotheses instead of open research questions, illustrating it is not appropriate for exploratory research.

3.4.4.2 Survey

The survey strategy is most commonly used to answer 'who', 'what', 'where', 'how much', or 'how many' questions (Saunders, Lewis and Thornhill 2011). This strategy is oftentimes used for exploratory or descriptive research (Saunders, Lewis and Thornhill 2011). Surveys using online questionnaires have the strength of gathering standardized data from a population in an economical way, providing easy comparison (Saunders, Lewis and Thornhill 2011). Things to consider when using surveys are the time spent: ensuring a sample is representative, designing and piloting a data collection instrument and garnering a good response rate. The survey strategy can be used to collect quantitative data to analyse with descriptive statistics. Other data collection methods include structured observation and structured interviews.

3.4.4.3 Case Study

The goal of a case study is to obtain an in-depth understanding of a single subject, be it a person, institution or event (Denzin and Lincoln 2005). The objective is for thorough comprehension of the subject within the context of the study, and not necessarily to generalise the findings (Denzin and Lincoln 2005). It is important to consider the cultural and societal context of the researched subject, therefor this strategy is typically associated with qualitative research (Denzin and Lincoln 2005).

3.4.4.4 Action research

Researchers aim to examine interactions in the real world, as such, this style of research is typically associated with the social sciences and with qualitative studies (Ritchie et al. 2014). In contrast to experimental research held in a laboratory, action research is conducted in practical settings such as a hospital, workspace or school (Ritchie et al. 2014). Participatory Action Research or 'PAR' falls under this strategy and was developed as a way to enhance the role of the participant and create more collaborative research opportunities between the researcher and the participant (Ritchie et al. 2014).

3.4.4.5 Grounded theory

Ideally summarized by Ritchie et al., grounded theory "aims to generate theories that explain social processes or action through analysis of data from participants who have experienced them" (2014). In other words, the newly developed theory is 'grounded' in the data. This strategy can be useful for delving into issues that are under researched or completely new.

3.4.4.6 Ethnography

Another good summary is provided, this time from Creswell, "Ethnographers study the meaning of the behaviour, the language, and the interaction among members of the culture-sharing group" (2013). The aim of ethnography is to observe participants in their natural environment and gather their subjective experiences.

3.4.4.7 Archival research

This strategy turns to administrative records and documents as the main sources of data. Research questions can be exploratory, explanatory or descriptive in nature but inevitably focus on the past and examine changes over time (Saunders, Lewis and Thornhill 2011).

3.4.4.8 Justification for the chosen strategy – survey

The author chose to use the survey strategy. This was in line with the research objective, which is summarized as: 'to explore the perceptions of stakeholders regarding potential intervention ingredients for a PSI.' The research objective was seeking to answer the question of, '**What** are the perceptions of the participants?' Surveys are most commonly used to answer questions beginning with 'what,' (Saunders, Lewis and Thornhill 2011) so this strategy was deemed suitable by the author. Surveys are oftentimes used in descriptive and exploratory research (Saunders, Lewis and Thornhill 2011), both of which describe this research. This research was descriptive in nature as the aim was to describe participants' perceptions, and both questionnaires and interviews are helpful for describing participants' views.

One shortcoming of the research onion is that is does not include more qualitative descriptive strategies such as interviews. As this was a mixed methods study, an online questionnaire was chosen for the quantitative phase of the research and semi-structured interviews chosen for the qualitative phase. This research was also exploratory as the topic had not been studied before.

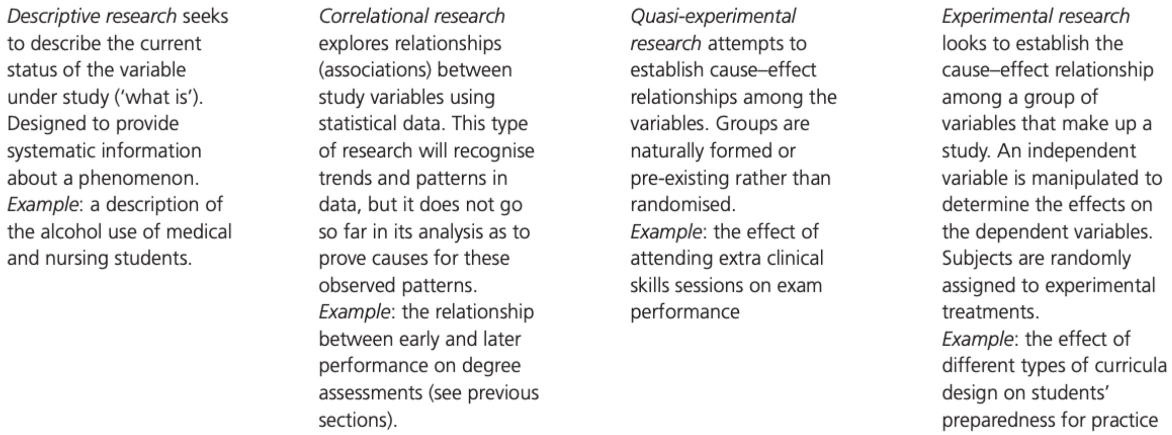
3.4.5 Methodological Choices – Mono method, Mixed methods and Multi-method

Methodological choices refer to how many data types (quantitative or qualitative) are used in the research (Saunders, Lewis and Thornhill 2011). Mono method refers to using just one type of data, mixed methods use both types and multi-method uses more than just one quantitative or qualitative data type (Saunders, Lewis and Thornhill 2011). This section will first provide an explanation of quantitative and qualitative data types, which vary in many ways such as study design, data collection methods and position of the researcher (Cleland 2015). The chosen methodological choice will then be discussed and justified.

3.4.5.1 Quantitative

Quantitative research comes from the traditions of the natural sciences such as biology and physics, (Polgar and Thomas 2020) thus it typically seeks to validate a theory or idea by carrying out an experiment and numerically analysing the results (Cleland 2015). Types of study designs include descriptive, correlational, experimental and quasi-experimental and are further explained in Table *3.1*. Quantitative data is measured and observed under controlled conditions and data is then presented in numerical form using statistical analysis (Polgar and Thomas 2020). Data collection methods can include surveys, numerical observations or measurements. In quantitative research the position of the researcher is objective since observation is detached and variables are measured more precisely than in qualitative research (Polgar and Thomas 2020).

Table 3.1 Types of quantitative design (Cleland 2015, used with permission)



Descriptive research seeks to describe the current status of the variable under study ('what is'). Designed to provide systematic information about a phenomenon. *Example*: a description of the alcohol use of medical and nursing students.	*Correlational research* explores relationships (associations) between study variables using statistical data. This type of research will recognise trends and patterns in data, but it does not go so far in its analysis as to prove causes for these observed patterns. *Example*: the relationship between early and later performance on degree assessments (see previous sections).	*Quasi-experimental research* attempts to establish cause–effect relationships among the variables. Groups are naturally formed or pre-existing rather than randomised. *Example*: the effect of attending extra clinical skills sessions on exam performance	*Experimental research* looks to establish the cause–effect relationship among a group of variables that make up a study. An independent variable is manipulated to determine the effects on the dependent variables. Subjects are randomly assigned to experimental treatments. *Example*: the effect of different types of curricula design on students' preparedness for practice

3.4.5.2 Qualitative

Qualitative research differs on a number of fronts compared to quantitative research. It stems from different disciplines, mainly the social sciences and philosophy (Polgar and Thomas 2020). While quantitative research is focused on hypothesis testing and confirmation, qualitative research is concentrated on hypothesis generation and understanding through describing phenomena in a natural setting (Cleland 2015). Qualitative study design is largely determined by the research question(s) being asked and data collection methods can include interviews or detailed observations of people and events with the goal to understand a particular phenomenon in a natural setting (Cleland 2015). As the researcher has a more personal interaction with participants, the researcher's position is subjective (Polgar and Thomas 2020).

3.4.5.3 Mixed methods

Now that both quantitative and qualitative data types have been explored, a mixing of both can be considered. Mixed methods research requires an integration of research components such as study design, methods and analysis (Fetters, Curry and Creswell 2013b). This type of research is philosophically guided by pragmatism, which enables the mixing of methods in order to best answer the research question(s) (Creswell, John W. and Plano Clark 2011). There are several advantages to mixing methods. These include triangulation from both sets of findings, which increases the overall validity and credibility of the results (Creswell, John W. and Plano Clark 2011). Using both methods can also provide a more comprehensive picture of a particular phenomenon. Different research questions can be answered by each method. Each set of data can be useful for explaining the other set, for example in the case of unusual or unanticipated findings from a survey; follow up questions could be asked in an interview (O'Cathain, Murphy and Nicholl 2010). Finally, a hypothesis could be generated in one phase and then tested in the next (O'Cathain, Murphy and Nicholl 2010). It is also worth noting the limitations of mixing methods. The incompatibility thesis states that methods cannot be mixed in a single study due to differences in ontology and epistemology (Teddlie and Tashakkori 2012). Additionally, practicalities such as timelines must be considered as it may be difficult for one researcher to conduct concurrent phases, likewise sequential phases could also take considerable time and resources.

The mixing of methods can occur in three different ways and is dependent on how the researcher aims to best integrate study design, methods, interpretation and reporting (Fetters, Curry and Creswell 2013a). The three ways of integrating are known as explanatory sequential, exploratory sequential or convergent. An explanatory sequential study begins with a researcher collecting and analysing quantitative data, the results of which inform qualitative data collection and analysis (Fetters, Curry and Creswell 2013a). Alternatively, an exploratory study starts with collection and analysis of qualitative data and the researcher then proceeds to use these findings to inform quantitative data collection (Fetters, Curry and Creswell 2013a). Finally, a convergent study has the researcher collect and analyse quantitative and qualitative during a similar timeframe (Fetters, Curry and Creswell 2013a).

3.4.6 Justification for selecting mixed methods

Directed by the pragmatism driving this research and in order to optimally address the research objectives stated above, the author chose to mix methods in a sequential explanatory study. The quantitative phase (survey) could then provide direction for areas to explore more in depth in the qualitative phase (interviews); in turn the qualitative results could help explain the quantitative results. Several of the above-stated advantages could also be employed, such as triangulation to increase the validity and credibility of the results and the provision of more comprehensive insight into the experience and perceptions of participants.

3.4.7 Time horizons - Cross-sectional and Longitudinal

A time horizon refers to how long the research will last and how many points there will be for data collection (Ritchie et al. 2014). Data collected over multiple points in time is referred to as longitudinal and is useful for studying progressions and changes over time (Ritchie et al. 2014). Data collected at a certain point in time is called cross-sectional and is utilised to study a snapshot in time (Ritchie et al. 2014). When choosing a particular time horizon, consideration must be given to deadlines, funding, resources available and the window of opportunity for accessing participants. For this research, the author chose a cross-sectional time horizon as there was indeed a deadline for the doctoral thesis to be completed within 18 months. A longitudinal time horizon would not have been feasible for the 18-month timeline. Additionally, the aim of the research was to obtain the perceptions of participants during one timeframe, which was between June and August of 2022. As this was an unfunded study, funding was not a consideration.

3.4.8 Techniques and Procedures

At the centre of the research onion are techniques and procedures or the data collection methods and data analysis. Data collection methods for this research included an online questionnaire and virtual semi-structured interviews. The questionnaire provided quantitative data and the interviews delivered qualitative data. The quantitative data was analysed with descriptive statistics using Microsoft Excel and the qualitative data was analysed using framework analysis via Microsoft Word, Microsoft Excel and NVivo 12, (QSR International Pty Ltd 2018) a qualitative analysis software. The Methods section (p. 73) will provide greater depth for each component of the data collection methods and data analysis.

3.5 Ethical Considerations

As this research recruited human participants, it was essential to consider the Belmont Report, which identifies basic ethical principles and guidelines for researchers (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 1979). The main ethical principles discussed in the Belmont Report are respect for persons, beneficence and justice (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 1979). Each of these will be addressed in the following sections as the main ethical considerations for this research related to recruitment, informed consent and confidentiality and data protection.

3.5.1 Recruitment

A multipronged strategy was implemented to recruit both participant groups. The aim was to effectively recruit diverse samples to allow for meaningful data analysis and determine how PSIs could be tailored to a wide range of people and thus generalise the results further. Gatekeepers were used in order to minimise the contact between the researcher and the participants and thus eliminate any sense of coercion. Within the health board of NHS Grampian, NHS physiotherapy outpatient departments (in Aberdeen city and one community hospital in Aberdeenshire), and the NHS Grampian Pain Management Service were involved with recruitment. NHS physiotherapy outpatient departments and the NHS Grampian Pain

Management Service contacted adults with chronic non-cancer pain virtually through email. Recruitment materials included a participant information sheet (Appendix V) with details and the purpose of the study, a letter of invitation (Appendix VI) and a flyer (Appendix VII). Participants could choose to opt in by contacting the research team by phone or email or following a provided link to the online survey. Participants were treated as autonomous individuals and were provided with appropriate information about the research in an understandable manner in order to uphold the ethical principle of respect for persons (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 1979).

Healthcare professionals were contacted via line managers of NHS physiotherapy outpatient departments (Aberdeen city departments and Turriff Community Hospital) and the NHS Grampian Pain Management Service. Line managers sent an email on behalf of the research team which included a participant information sheet (Appendix VIII) and a flyer (Appendix IX). Interested participants could opt in by following a provided link to the online survey or contacting the research team by email.

Additionally, both participant groups were also recruited via charities and community groups, including the Physiotherapy Pain Association, Pain Association Scotland, Pain UK, Flippin Pain, Pain Concern and the Interactive Chartered Society of Physiotherapy. These organisations shared study information with members via email and/or on social media platforms. Interested participants could again follow a provided link to the online survey or contact the research team by email.

Finally, the social media accounts of Robert Gordon University, NHS Grampian and the personal accounts of the research team were utilised to share study information with the public and interested participants could follow a provided link to the online survey or contact the research team by email.

At the conclusion of the survey, participants were asked whether they would like to be contacted for an interview or be included in a focus group.

In addition to being used as a recruitment material, the Participant Information Sheets were also provided at the start of the survey and sent to all interviewed participants. This was to uphold the ethical principles of beneficence (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 1979). With regard to beneficence, efforts were made to secure the wellbeing of participants by informing them of the potential disadvantages of the study (loss of time and/or potential emotional distress from discussing experience of pain). In order to mitigate the previously mentioned disadvantages, the participant information sheet included signposting to mental health organizations.

3.5.2 *Informed Consent*

With the online survey, participants were initially taken to a landing page explaining the purpose of the study, how their information would be used, the estimated time to complete the survey, and a space to provide electronic consent for participation in the study. This was to uphold the ethical principle of respect for persons via informed consent which states that research participants should be provided with appropriate information about the research in an understandable manner (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 1979).

Interview consent was obtained in two different ways, dependent on the participant group. Adults with chronic pain provided verbal consent (Appendix X) on Microsoft Teams and individuals with experience of managing chronic pain or delivering PSIs provided a signed consent form (Appendix XI) prior to the scheduled interview. This difference was due to the fact that the second participant group was initially intended to gather in focus groups, but due to scheduling conflicts, these participants were all interviewed individually. Signed consent sent directly to the author prior to the scheduled interview was intended to save time and to ensure patient confidentiality for other demographic questions also asked at the time.

3.5.3 Confidentiality and data protection

One of the key ethical concerns in this study was maintaining participant privacy, data management and data security. It was crucial to ensure participant privacy as violation of this had potential risks for the participants such as loss of privacy, strained relationships, career damage or shame (Karen Kaiser 2016). The author aimed to uphold the convention of confidentiality which is “a means to protect the privacy of all persons, to build trust and rapport with study participants, and to maintain ethical standards and the integrity of the research process” (Kaiser 2009). It was important to consider confidentiality during research planning, data collection, data cleaning and dissemination of research results (Kaiser 2009).

All study data was stored on password protected and encrypted university servers (Sharepoint). Upon entering the study, participants were given anonymised study identification numbers which were used for all data collection and participants were referred to with their number in analysis. Any personal or identifying data that was collected was stored in a password protected file on a secure network folder at the university.

Other data was accessible by the doctoral student and supervisors using Microsoft Teams Sharepoint service where data is held in compliance with General Data Protection Regulation (GDPR). Participants completing the survey were asked for consent to contact them for the interview. If consent was given, they were asked to provide their email address and a contact telephone number. This was stored separately to data used for processing and analysis which was labelled by a unique ID only. Direct quotes from participants used in the findings were anonymised using unique codes. The lead author ensured that all quotes were non-attributable and details that were reported were presented in such a way that individual sources cannot be identified. Participants were asked for consent to interviews being audio-recorded.

3.6 Ethical Approval

This study was conducted in accordance with the UK policy framework for health and social care research (NHS Health Research Authority 2017). This study collected data from completed participant surveys and recorded and transcribed statements from interviews. All data collected was recorded, anonymised, handled and stored appropriately and confidentially in accordance with the GDPR (UK Government 2018) and findings will be accessible upon completion of the study through Open Air, Robert Gordon University’s open access institutional repository. Study data was only accessible to members of the research team. Personal identifiable data, including audio recordings will be safely destroyed when the main results of the study are published. Anonymised study data will be retained for 10 years following the publication of the final study report. Both participant groups were fully informed of the aim of the study and that participation was voluntary and could be withdrawn at any point without reason. Participants were afforded respect and autonomy; this was especially important during the semi-structured interviews as individuals were sharing their perceptions and experiences. Robert Gordon University sponsored the study. Ethical approval was obtained from the North East - Tyne & Wear South Research Ethics Committee (Appendix XII), and NHS Grampian Research and Development provided local approval (Appendix XIII).

3.7 Methods

This research was a mixed methods sequential explanatory study with two phases. Both phases were conducted with two participant groups: 1) adults with chronic non-cancer pain and 2) individuals with experience of treating chronic pain or delivering peer support interventions. The first phase consisted of an online survey and subsequent analysis with descriptive statistics to determine participant preferences regarding intervention components. The second phase consisted of qualitative semi-structured interviews with framework analysis. This aided in exploring these preferences in greater depth and determining any common similarities or differences amongst and within the participant groups.

Overall, this research formed part of intervention development and it was essential to consider the MRC framework for developing a complex intervention. Complex intervention research is not solely focussed on determining whether an intervention is successful with regard to achieving its intended outcome (Skivington et al. 2021). Broader questions must be asked such as considering the wider impact of the intervention, ascertaining its value relative to the required resources and theorising how it works (Skivington et al. 2021). The author considered these questions in relation to her research, and this will be further explored in the discussion.

When developing a complex intervention, theory is an essential consideration. In lieu of selecting a singular theory to underpin an intervention, a combined approach such as the behaviour change wheel can be utilised. The behaviour change wheel (pictured below in Figure 3.2) was developed from the synthesis of 19 behaviour change frameworks across a variety of disciplines (Michie, van Stralen and West 2011). It functions as a toolkit for intervention developers that equips them with an understanding of the nature of the behaviour to be changed and how best to incorporate this knowledge into intervention design. Most notably, the wheel includes a behaviour change system which states that behaviours are a function of capability, opportunity and motivation, or the COM-B system (Michie, van Stralen and West 2011). A benefit of using the behaviour change wheel is it highlights the importance of considering the target behaviour and the theoretically predicted mechanisms of action (Michie, van Stralen and West 2011). Considering a complex intervention, a singular guiding theory is unlikely to account for the full range of possible influences on behaviour and would thus exclude significant variables. For example, the theory of planned behaviour does not address the impact of habit, self-control, impulsivity, associative learning or emotional processing (Davies, Walker and Grimshaw 2010). The behaviour change wheel can be used to practically inform an intervention; developers can consider how to provide opportunities to modify capability, opportunity and motivation, and select appropriate behaviour change techniques for the appropriate functions (Michie et al. 2013).

3.7.1 Phase One: Quantitative Survey

The first phase consisted of a survey with closed and open questions. Upon completion of the survey, participants were asked if they were willing to take part in an interview and had an opportunity to provide contact details separately from their survey responses to ensure anonymity.

3.7.1.1 Survey development

Currently there is a lack of studies exploring patient preferences with regard to peer support, therefore a survey was designed by the author specifically for this study. Topics and questions for the survey were informed by the evidence base and the author’s systematic review, as

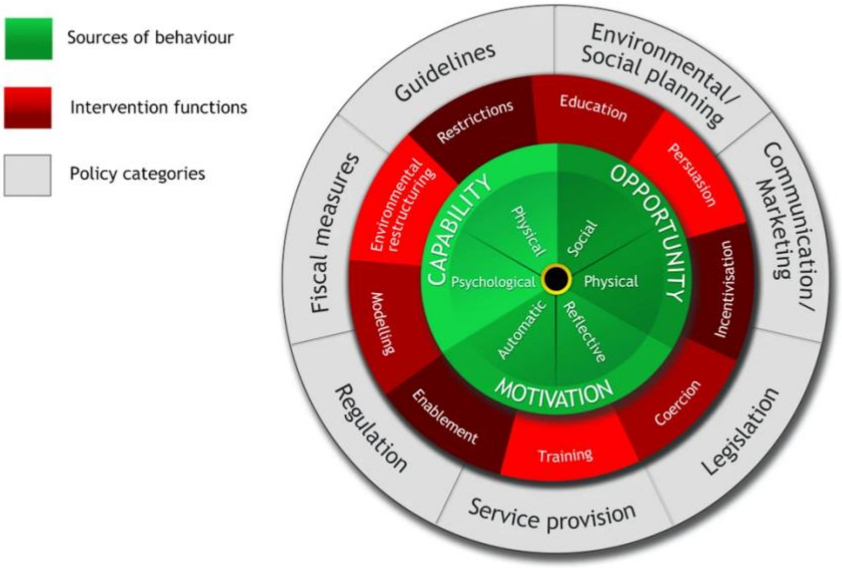


Figure 3.2 The Behaviour Change Wheel (used with permission, (Michie, van Stralen and West 2011))

discussed in Chapter Two. The systematic review found limited research had been conducted on assessing patient preferences regarding the components of peer support; specifically no evidence was found in the areas of intervention format, length of intervention and frequency of contact between PSVs and participants. As such, survey questions were developed on these topics. The design and development of the survey was also informed by the author’s supervisory team which included an academic with experience in chronic pain (Victoria Park), a researcher with peer support expertise (Kay Cooper) and the Scottish lead for chronic pain (Nicola Rhind).

When developing a measurement instrument, it is significant to evaluate psychometric properties, which help ascertain the quality of a measurement instrument. There are several psychometric properties, which are listed below in Figure 3.3.

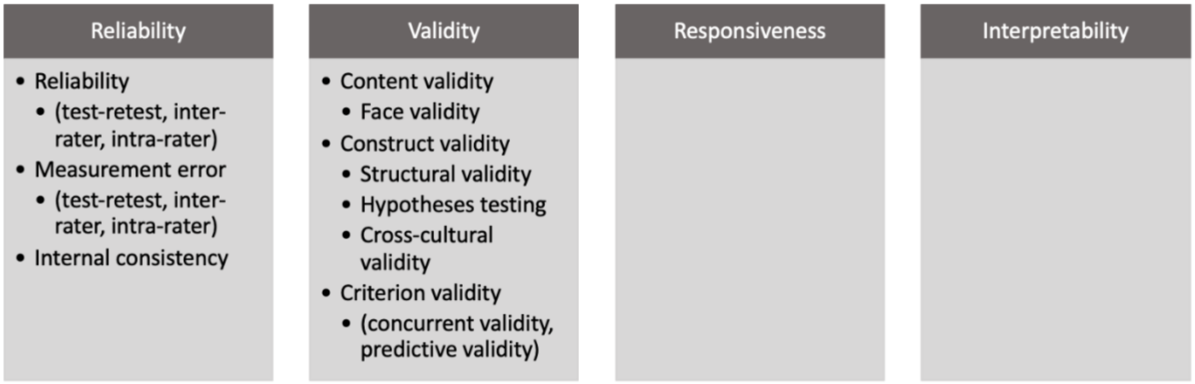


Figure 3.3 Measurement Properties of Outcome Measurement Instruments (adapted from Mokkink et al. 2010)

When developing a survey in particular, validity and reliability are important considerations. Validity is a holistic consideration which examines whether a survey is useful, appropriate, meaningful and accurate in measuring an intended construct (DeVellis 2016), each of these terms are explored in more depth below:

- Useful – does the survey measure what it's intended to measure? (construct validity)
- Appropriate – is the survey asking appropriate questions to suit it's aims? (face validity)
- Meaningful – is the survey fully representative of what it intends to measure? (content validity)
- Accuracy – do the results accurately measure what they are intended to measure? (criterion validity)

Face validity refers to whether the questions in a survey are appropriate and construct validity refers to whether the survey is useful in measuring the intended topic (DeVellis 2016). In the case of this research, the question is whether this survey had appropriate questions to actually measure the preferences of stakeholders regarding PSI components. The author developed the survey questions with her supervisory team and conducted piloting with the target population (two adults with chronic pain) in an effort to ensure face validity. The survey had face validity but there was not adequate time or resources to consider all psychometric properties as this was an unfunded doctorate study. Developing a survey for a particular study is not unusual in survey research (Gohel et al. 2021; Carroll et al. 2020; Saggers et al. 2019) as validated tools are not always available. There are of course limitations with this as a validated tool would have a greater level of validity, but it was deemed the most appropriate option as a previously validated survey did not exist at the time the author was conducting the study.

The reliability of a survey refers to its ability to produce consistent and reproducible results (DeVellis 2016). The survey was delivered online and thus the questions were delivered in a consistent way that could be reproduced.

Survey topics included intervention components such as format, delivery, length of programme, frequency of contact with a PSV and the amount of training provided to the PSV. Two surveys were designed, one for each of the participant groups. Questions regarding intervention components were similar, with variations in the demographic questions posed to each group. Full surveys are included in Appendix XIV and Appendix XV and an overview of the questions is included below in Box 3.1.

The survey was piloted by two adults with chronic pain (aged 30 and 68) who provided feedback on the content of the survey. These adults stated the content was appropriate, relevant and topical to areas they believed deserved more research. Two children (both aged 11) also piloted the survey and provided feedback on the readability of the survey. The children reported the survey was readable and did not recommend any changes. Health Education England recommends piloting health information with 11–14-year-olds as this is the average reading level for the majority of adults in the UK (NHS Health Education England 2020). Piloting a survey is important in order to ensure questions are clearly articulated and response options are relevant (Ruel, Wagner and Gillespie 2015). Piloting also helps to confirm that researchers and respondents are interpreting questions in the same way (Ruel, Wagner and Gillespie 2015). Finally, piloting allowed the author to determine the response latency or the amount of time needed to complete the survey, which was then be reported in the introduction to the survey (Ruel, Wagner and Gillespie 2015).

Box 3.1 Overview of survey questions

1. Have you ever participated in a peer support intervention? / Have you ever been involved with the design or delivery of a peer support intervention?
2. What topics do you think are important to include in a peer support intervention for chronic pain?
3. How do you think a peer support intervention for adults with chronic pain should be delivered? (face-to-face, phone call, video call, etc.)
4. What kind of format do you think should be used in a peer support intervention? (one-to-one, group, combination)
5. How long do you think a peer support intervention for chronic pain should last?
6. How often do you think peers should meet together?
7. Consider an adult with chronic pain being matched with a peer support volunteer. How important do you think it is for the two people to have the same: gender, age group, chronic condition, interests, personality, politics, race, or sexuality.
8. Do you think peer support volunteers should receive training?
9. How much training do you think peer support volunteers should receive?
10. What do you think would prevent someone from participating in a peer support intervention?
11. What do you think would help someone participate in a peer support intervention?
12. Overall, what is your opinion of peer support for chronic pain?

3.7.1.2 Participants

This research considered 1) adults with all types of chronic pain except for cancer-related pain and 2) people with experience of treating chronic pain or delivering PSIs. Table 3.2 has details of inclusion and exclusion criteria.

Regarding the first participant group, adults with cancer pain were excluded due to the unique experience and management, which typically differs from other types of pain and circumstances (Howell, D. et al. 2017). The WHO recognizes pharmacological interventions as the “mainstay” of cancer pain management, (World Health Organization 2018) while other types of chronic pain utilize a variety of management techniques. Individuals under the age of 18 were excluded due to differences in management strategies and particular guidelines for children compared with adults (Scottish Government 2018b). There was no upper age limit as chronic pain can impact adults of all ages. As this was an unfunded study, translation services were unavailable, so participants were required to understand both written and spoken English.

Concerning the second participant group, it was deemed significant to include not only health professionals but also those with experience designing or implementing a PSI as this could include someone working for a charity or in the third sector that may not necessarily hold a medical certification but would still have valuable insight on PSIs. A list of several potential healthcare professionals is listed, which included professionals commonly involved in the management of chronic pain. While student healthcare professionals can be valuable adjuncts in clinical areas, they were excluded from this study due to a lack of familiarity with the population and subject area.

3.7.1.1 Sample Size

After the multipronged recruitment strategy was active, convenience sampling was used to accept all participants who were available and fulfilled the inclusion criteria (Ritchie et al. 2014). The aim was to recruit 30 participants from each group, as this is a suitable number to conduct descriptive statistics and is supported by the Central Limit Theorem (Chang, Huang and Wu 2006). This theorem requires a sample size to be sufficiently large in order for the sample to be representative of a population (Chang, Huang and Wu 2006).

3.7.1.1 Location

The survey was administered online through Jisc online surveys© which is compliant with the GDPR. The strengths of an online survey include: cost effectiveness, ease of delivery, standardization and greater access to participants who may otherwise have geographical limitations (Nayak and Narayan 2019). An additional benefit was accessibility for any participants with ongoing concerns related to COVID-19. The limitations of an online survey are potential79l exclusion of participants with limited access to the internet or a necessary device, (laptop, tablet or smart phone) and those who are not at ease with using such devices (Nayak and Narayan 2019). This was remedied by offering the survey in paper format or a structured telephone interview on request, neither options were requested by any participants.

Table 3.2 Participant Inclusion and Exclusion Criteria

	Inclusion	**Exclusion**
Adults with chronic non-cancer pain	• Aged 18+ • Experience of chronic non-cancer pain (can include but not limited to arthritis, low back pain, chronic headaches, fibromyalgia) • Able to understand written and spoken English	• Aged <18 • Diagnosis of cancer • Unable to understand written or spoken English • Unable or unwilling to provide informed consent
Adults with experience of treating chronic pain or implementing a peer support intervention	• Individuals with experience of delivering care to adults with chronic pain or implementing a peer support intervention • Including but not limited to physiotherapists, psychologists, nurses, healthcare support workers, consultant and specialist doctors in anaesthesia	• Student healthcare professionals

3.7.1.2 Data collection and analysis

Survey results were exported to Microsoft Excel® and cleaned (i.e. checked for missing/wrong values, none of which were found) and anonymised. Survey results were analysed with descriptive statistics.

3.7.2 Phase Two: Qualitative Interviews

The second phase consisted of semi-structured interviews which were conducted with a sub-sample of participants. Semi-structured interviews can be beneficial for ascertaining the independent thoughts of each individual in a study, as participants may not be candid if sitting with peers in a focus group (Hatry, Newcomer and Wholey 2015). The nature of open-ended questioning can also allow for extended probing into topic areas that may not have been considered. Disadvantages of semi-structured interviews include the intensity of time and labour and requirement of a sophisticated interviewer (Hatry, Newcomer and Wholey 2015). Focus groups were intended for individuals with experience of treating chronic pain or delivering PSIs as they would already be familiar with the subject area and with discussing professional practice with one another. Focus groups are well suited to helping ideas emerge and build in a group (Krueger and Casey 2015). In actuality, all participants were interviewed individually due to scheduling conflicts; none of the participants from the second group were available at the same time for a focus group to occur. In keeping with the flexible nature of qualitative research and to be inclusive, individual interviews were conducted.

3.7.2.1 Participants

This phase used the same inclusion criteria as the first phase. All participants were self-selected, meaning they chose to take part in the study of their own accord and approached the author, rather than being approached by the author directly (Sharma 2017). An advantage of self-selection is that participants typically have an inherent interest in the topic of study and may be more committed and willing to share their views to provide insight into the phenomenon (Sharma 2017). Alternatively, disadvantages include the potential for self-selection bias if certain participants have a characteristic trait motivating them to share their opinion (i.e., wanting to share about a negative experience in the NHS). Another disadvantage is the potential for findings to be exaggerated.

While the inclusion criteria were the same for this phase as the earlier phase, a third group emerged which was adults with chronic non-cancer pain who also had experience of treating people with chronic pain or delivering PSIs. This group included three HCPs and one non-HCP participant with experience of leading a PSI. Two physiotherapists worked in musculoskeletal practice, one with 20 years of chronic low back pain and the other with 20+ years of musculoskeletal pain. There was also an occupational therapist working in the community with eight years of fibromyalgia pain. The non-HCP participant had 30 years of back, neck and hip pain and had led her PSI for the past eight years.

This third group was seen as separate from the two other groups and therefore analysed separately. The author did consider whether to attempt a separation of data as some participants initially answered questions separately from their two viewpoints as a person with chronic pain and then as an HCP or PSI lead, but this separation of data was challenging as some of the data from their unique viewpoint could not be separated and resulted in duplication. The author decided to instead include this group as entirely separate due to the importance of capturing the unique viewpoint of this group. The strengths of separating this group include gaining a holistic view of both sides of the phenomenon of both having chronic pain and working as an HCP or delivering a PSI. Concerning limitations, three out of four participants in this group were HCPs and thus had medical training, knowledge and skills which differed from the one participant without a medical background. This singular participant had experience delivering a PSI. An important consideration is whether the participants with a medical background had different experience and views on the PSI components compared to the one non-HCP participant. During data analysis the responses of the non-HCP participant were broadly similar to the HCPs, suggesting this difference in background did not bias the results.

3.7.2.2 Sample size

Convenience sampling was used across the two participant groups. With the aim of reaching data saturation, the target for the initial analysis sample was ten participants per group and the stopping criterion was three additional participants. If analysis of the additional interviews did not reveal any new themes or ideas, data saturation would be considered to be reached and no further interviews would be necessary (Francis et al. 2010).

3.7.2.3 Location

The interviews were held on Microsoft Teams as it is GDPR compliant (Microsoft 2021) or via telephone. The strengths and limitations of online offerings were covered in 3.7.1.1 Location.

3.7.2.4 Interview Procedure

Interviews can be structured, semi-structured or unstructured and the chosen type is dependent on the philosophy underpinning the research. As this study was guided by pragmatism, semi-structured interviews were conducted. A list of questions guided each interview but there was room for flexibility and further probing if the occasion arose (i.e. a participant expressly verbalized a new or related topic or the author noted any verbal or non-verbal cues and probed further). Semi-structured interviews can be powerful tools to comprehend the thoughts, beliefs and experiences of a population; although it is important for the interviewer to establish good rapport to ensure the participant is open to sharing his or her views (DeJonckheere and Vaughn 2019).

Interviews were conducted by the author from June to August 2022. At the start of each interview, the author reviewed the purpose of the study with the participant and discussed what to expect during the interview. The author also provided a reminder regarding confidentiality and anonymity and addressed any questions the participant had. The participant was informed the interview would be audio recorded with an external recording device. Verbal consent and demographic information was taken for participant group one, and this audio recording was saved separately to the interview. Electronic consent and demographic information was already received from participant group two. The interview then proceeded and the schedule and prompt questions can be viewed in Appendix XVI and Appendix XVII. The questions were developed from the survey results as areas were identified to explore further.

Once each interview was complete, the audio recording was uploaded to a secure server at Robert Gordon University, accessible only to the research team. Otter.ai© was used for transcription and the lead author also reviewed transcripts for accuracy, anonymisation and addition of any emotive facial expressions or body language. Verbatim or 'word-for-word' transcription was used as this can aid in providing rich data over other transcription types such as intelligent verbatim (where paralanguage is removed) or edited transcription (transcriber edits for grammar) (Immy and Kathleen 2016).

This review of the transcription assisted the author in understanding the variety of viewpoints and began the process of familiarisation within framework analysis (Ritchie et al. 2014). Both digital recordings and accurate transcriptions aid in providing credibility and dependability in qualitative research as the interviewer and research team have reference points to help determine the truth of each participant (Green and Thorogood 2018). Indeed, the author utilized the digital recordings to clarify certain phrases that the transcription software struggled to identify.

3.7.2.5 Data analysis

The five stages to general qualitative data analysis include: familiarization, identifying a thematic framework, indexing/coding, charting/summarizing and mapping and interpretation (Ritchie et al. 2014). Framework analysis was chosen to thematically analyse the interview data. Framework analysis is comparable to other thematic analysis methods as it includes indexing/coding, but its distinctive feature lies in the matrices used for data summary and display (Ritchie et al. 2014). This allows for comparisons across themes and cases (Ritchie et al. 2014).

Other qualitative data analysis methods include content analysis, narrative analysis, grounded theory analysis and discourse analysis. Many of these methods are associated with specific disciplines and underpinned by different philosophies which will shape the process of analysis (Gale et al. 2013). Each method approaches the data differently and choosing an appropriate method is dependent on the research aims and underpinning philosophy. A method such as grounded theory is helpful for generating theories during analysis, but the author's research was focused on describing the experiences of participants, thus making framework analysis a more appropriate method. Indeed, framework analysis was a suitable choice as it is most commonly used for the thematic analysis of semi-structured interview transcripts, in addition to its wide use in health research (Gale et al. 2013). Framework analysis was beneficial as the stages of data analysis were transparent and thus auditable, which is important for proving rigorous qualitative analysis (Green and Thorogood 2018). Utilizing framework analysis was a strength as it provided systematic and comprehensive coverage of the data, meaning every unit of analysis (interview excerpt) was given the same standardized 'treatment.'

The five stages of general qualitative analysis were provided above; in framework analysis these stages are further expanded (Ritchie et al. 2014):

Data management:

1. Familiarisation
2. Constructing an initial thematic framework
3. Indexing and sorting
4. Reviewing data extracts
5. Data summary and display

Abstraction and interpretation

6. Description: developing categories
7. Description: mapping linkages
8. Explanation: accounting for patterns

Regarding software and applications, Microsoft Word was used for the first two stages of data management and then interview transcripts were uploaded to NVivo 12 (QSR International Pty Ltd 2018) a qualitative analysis software that assisted with the framework analysis, particularly coding. Microsoft Excel was also used for the final stages of the analysis. Any data outside of NVivo was saved on a secure server at Robert Gordon University.

To begin, familiarisation consisted of the author immersing herself with the data (19 interview transcripts) which she had transcribed herself. The author read the transcripts multiple times in the transcription process to ensure accuracy and consider any emerging themes.

Next, the author constructed an initial thematic framework by considering both the themes that emerged from the process of familiarisation and the interview questions as a topic guide. The initial thematic framework for participants with chronic pain is provided below in Box 3.2.

As there were three participant groups, the author created three different thematic frameworks in order to enable coding of these groups separately. The thematic frameworks were largely the same with a few exceptions, details of which will be explored further in the results section. The thematic framework went through several iterations as some participants offered unique insights that were not always touched on by other participants. The author went through multiple stages of revision to create a framework that encompassed all the themes across the 19 interviews, whilst keeping the size of the framework manageable by grouping together similar themes.

Box 3.2 Initial thematic framework - adults with chronic pain

Peer Support (PS)

- What is PS?
- Purpose
- Individual needs/preferences
- Previous experience of PS
- Ambivalence
- Positive
- Negative

Ideal PSP design

- Flexible
- Aims
- Content
- Delivery
- Format
- PSV Role and Training
- Peer or group matching

- PSP Frequency
- PSP Duration
- Organizers of PSP

Barriers

- Pain flare
- Unrealistic expectations
- Physical cost
- Mental or emotional cost
- Financial cost
- Travel
- Time commitment
- Technology

Facilitators

- Accessible
- Consistency
- Follow up
- Tea and coffee
- Timing of access
- Committed attendees
- Information
- Psychosocial
- Recognition of condition
- Location
- Setting
- Awareness/promotion of programme
- Obligation

Covid

- Impact of Covid on communication/meeting
- Impact of Covid on healthcare services

Other

The next stage of data management was indexing and sorting. The author took the themes collated in the framework and applied these themes to each transcript in a process known as qualitative coding.

Data extracts were then reviewed by the author which provided the opportunity for further refinement of the thematic framework. As the author read through the coded material, some labels were amended in order to create better cohesion for topics that were related.

In the final stage of data management, the author wrote data summaries in order to more succinctly show what each participant was saying for every theme. The author worked across the whole set of data, theme by theme and created brief summaries of the raw excerpts (quotes) from participants. This was a time-consuming process but provided the advantage of "deep immersion in the subject matter and enables the analyst to get a more refined understanding of its content and variation" (Ritchie et al. 2014). Some quotes were kept when they demonstrated a concept particularly well or were short enough that writing a new summary would not be worthwhile. The data summaries and quotes were displayed in a matrix showing each participant's contribution to every theme.

Moving onto abstraction and interpretation, this consisted of developing categories, mapping linkages and accounting for patterns in the data. The author first developed categories, which consisted of elements and dimensions. The author viewed each data summary or quote and pulled out the elements of each. Ritchie et al. (2014) states that there are two features of qualitative data that are vital to consider during the description of categories:

> *"The first is language – the actual words used by study participants. It is these that portray how a phenomenon is conceived, how important it is and the richness or 'colour it holds. Second, the substantive content of people's accounts, in terms of both descriptive coverage and assigned meaning, forms the nucleus of qualitative evidence in thematic analysis. This needs to be sensitively reviewed and captured so that the fineness of detail in different perspectives or descriptions is understood."* (Ritchie et al. 2014 p. 310)

With this in mind, the author aimed to accurately reflect the meaning of participants' quotes by using participants' own words and phrases in elements when possible.

For example, here is a quote from the theme psychosocial barriers:

> *"There is an element of risk, as a person with pain you're opening yourself up to risk with every new experience. And if you may be caught in that cycle of fear avoidance, or you don't want other people knowing what's wrong with you." (HCP 1- 54-year-old female, PT, 12 years managing chronic pain)*

The elements from this quote included: hesitant of new experience, cycle of fear avoidance and unwilling to be vulnerable with others. The author worked through all the data and created categories and summarized information in order to move towards broader synthesised findings, which are explored in detail in the results section.

3.7.3 Research Rigour

As this was a mixed methods study, the rigour of the research was considered for both the quantitative and qualitative phases. Table 3.3 illustrates the author's efforts to conduct a study that upheld the standard of rigour both quantitatively and qualitatively. Regarding the survey, it was available online during the course of recruitment and can be requested from the author afterwards in order to provide the transparency required of reliability. The survey was also piloted to assess the appropriateness, clarity and comprehensibility of questions for face validity. The author conducted a multipronged recruitment strategy which aimed to recruit a representative sample of adults with chronic pain and HCPs so that results can be generalisable to the wider population. And the final consideration for survey was objectivity and the author both administered and analysed the survey objectively.

Moving onto the interviews, the author aimed to conduct the research in a transparent and auditable way by having the interview schedule available upon request and working closely with her research supervisor to review study processes and decisions. Multiple analysts were involved in all the study phases to produce credible findings. Purposeful sampling was used so that findings could be transferable to other contexts. And finally, the author used direct quotations from participants in order to uphold confirmability and reflect the participants' narratives.

Table 3.3 Research rigour and means to support survey and interview phases (adapted from Tuckett 2005)

	Reliability Research must be conducted in a transparent way that can be audited and replicated	**Validity** Findings reflect an accurate interpretation of the data	**Generalisability** Findings can be applied to similar population outside the study	**Objectivity** Awareness and mitigation of the researcher's position and influence
Survey	-Was publicly available online and is available from author on request -Replicable	-Piloted for face validity	-Aimed to recruit a sample that was representative of adults with CP and HCPs	-Survey was administered and analysed objectively
	Dependability Research was conducted in a transparent way that can be audited and replicated	**Credibility** Findings are correct and accurate	**Transferability** Findings can be applied to other contexts	**Confirmability** Confidence that the findings reflect the participants' narratives and not the researcher's bias
Interviews	-Interview schedules included the same set of base questions for participants -Interview schedule is available from author on request -Regular research meetings were held with the author's supervisory team to review study process and decisions -Author kept a record of processes and decisions available for external audit	-Author's supervisor acted as the second analysis in all study phases -Any coding differences were resolved through discussion and consensus -Author strived to ensure participants were comfortable to share views	-Purposeful sampling	-Author used direct quotations from participants in presentation of findings

3.8 Summary of Chapter 3

This chapter discussed the rationale for the study, introduced the aim and research objectives and presented the methodology and methods. Justification was provided for the chosen methodology and other strategies were reviewed. The next chapter will present the results of both phases of the mixed methods study.

4 CHAPTER 4: RESULTS

4.1 Introduction to the chapter

This chapter presents both the quantitative and qualitative results of this mixed methods study in relation to the research questions, which are stated in the previous chapter, section 3.3. For each phase of the study, participant demographics are described first, followed by the results.

4.2 Quantitative survey results

4.2.1 Participant demographics

Illustrated in Table 4.1 and Table 4.2, a total of 65 participants completed the two bespoke surveys, comprising 44 adults with chronic pain and 21 HCPs or those with experience of either delivering care to adults with chronic pain or implementing a PSI. Concerning the latter participant group, it was deemed significant to include not only HCPs but also those with experience designing or implementing a PSI as this could include someone working for a charity or in the third sector. This person may not necessarily hold a medical certification but would still have valuable insight on PSIs. HCPs commonly involved in the management of chronic pain could include but was not limited to physiotherapists, psychologists, nurses, healthcare support workers, and consultant and specialist doctors in anaesthesia. For simplicity, this group of HCPs or those with experience of implementing a PSI is henceforth referred to as “HCPs.” Percentages are provided below in the overview of participants; raw numbers can be viewed in Table 4.1 and Table 4.2.

For the participant group of adults with chronic pain, most were female (86%), although a variety of ages, educational levels and areas demarcated by the Scottish and English Indices of Multiple Deprivation (IMD) were represented in the sample. Forty-one percent of participants were employed either full time (28%), part time (11%) or were self-employed (2%). A further 36% were permanently sick or disabled, five percent were homemakers, five percent were in further/higher education, and the remaining 13% were not working. The most common chronic

Table 4.1 Survey demographics (Adults with chronic pain) N=44 reported as n (%)

Gender		Age		Education	
Female	38 (86%)	18-24	2 (5%)	Higher/A-level	15 (34%)
Male	6 (14%)	25-34	6 (14%)	Degree level; BSc, BA	12 (26%)
		35-44	7 (16%)	National 5/O-level	6 (14%)
		45-54	18 (41%)	No formal qualification	3 (7%)
		55-64	7 (16%)	Master's Degree level	3 (7%)
		65+	4 (8%)	Other	3 (7%)
				Doctorate	2 (5%)

IMD Decile		Working Status	
10	8 (18%)	Permanently sick/disabled	16 (36%)
2	7 (16%)	Employed full-time	12 (28%)
9	4 (9%)	Employed part-time	5 (11%)
7	4 (9%)	Permanently retired	5 (11%)
6	4 (9%)	Looking after the home or family	2 (5%)
4	4 (9%)	In further/higher education	2 (5%)
3	4 (9%)	Self-employed	1 (2%)
8	3 (7%)	Unable to work due to short-term illness or injury	1 (2%)
1	3 (7%)	Other	0 (0%)
N/R	2 (5%)	Unemployed and seeking work	0 (0%)
5	1 (2%)	At school	0 (0%)
		Government work or training scheme	0 (0%)

CP Condition		Treatments for CP included		PMH	
Low back pain	30 (68%)	Anti-inflammatories	37 (84%)	Anxiety	24 (55%)
Nerve pain	23 (52%)	Physiotherapy	34 (77%)	Depression	23 (53%)
Arthritis	20 (45%)	Paracetamol	32 (73%)	Other	10 (14%)
Fibromyalgia	20 (45%)	Antidepressants	32 (73%)	High blood pressure	6 (23%)
Headaches or migraines	15 (34%)	Exercise	27 (61%)	Diabetes	6 (23%)
Other	15 (34%)	Weak opioids	26 (59%)	Cardiovascular disease	3 (7%)
Chronic fatigue syndrome	10 (23%)	Gabapentinoids	26 (59%)	High cholesterol	2 (5%)
Post-surgical pain	6 (14%)	Acupuncture	21 (48%)		
CRPS	3 (7%)	Strong opioids	19 (43%)	Other included: Adrenal Insufficiency, asthma, cardiac conditions, thyroid conditions, GI conditions, restless leg syndrome, seizures, osteoarthritis, Reynaud's, osteopenia, other mental health conditions	
Long Covid	1 (2%)	Steroid injections	15 (34%)		
Ankylosing Spondylitis	1 (2%)	Talking therapies	13 (30%)		
Lupus (SLE)	1 (2%)	Other	8 (18%)		
		Chiropractic	6 (14%)		
Other included: Hypermobility, MSK, sciatica, Sjogren's, history of fractures, Chiari malformation, cerebral palsy, Perthes Disease, erythromelalgia		Support to improve sleep	6 (14%)		
		Osteopathy	4 (9%)		
		None of these	0 (0%)		
		Other included: Reflexology, denervation, TENS, medicated patches, methotrexate HRT, vitamin D supplement, Beta blockers			

Key: BSc=Bachelor of Science, BA=Bachelor of Art, IMD=Indices of multiple deprivation, N/R= not reported, CP=chronic pain, CRPS=Chronic Regional Pain Syndrome, SLE=Systemic Lupus Erythematosus, MSK=Musculoskeletal, TENS=transcutaneous electrical nerve stimulation, HRT=hormone replacement therapy, PMH=past medical history, GI=gastrointestinal

Table 4.2 Survey demographics (healthcare professionals) N=21 presented as n (%)*

Gender (N=21)		**Age (N=21)**		**Education (N=21)**	
Female	16 (76%)	18-24	0 (0%)	Undergraduate	7 (33%)
Male	5 (24%)	25-34	3 (14%)	Postgraduate	9 (43%)
		35-44	10 (48%)	PhD	1 (5%)
		45-54	5 (24%)	Diploma	3 (14%)
		55-64	2 (10%)	Other	1 (5%)
		65+	1 (5%)	None	0 (0%)
				Prefer not to say	0 (0%)

Professional Background (N=20)		**Clinical Specialty (N=18)**		**Band level (N=14)**	
Physiotherapist	15 (75%)	MSK	7 (39%)	1-4.	0 (0%)
Medical Doctor	3 (15%)	Chronic pain	6 (33%)	5	1 (7%)
Pain Specialist	1 (5%)	General practice	4 (22%)	6	4 (29%)
Psychologist	1 5%)	Acute medical	1 (6%)	7	5 (36%)
Nurse	0 (0%)			8	4 (29%)
HCSW	0 (0%)				
OT	0 (0%)				
Other	0 (0%)				

		Experience managing CP or involved with PSI		
Work location (N=21)		**Years**	**Managing CP (N=21)**	**Involved with PSI (N=13)**
Scotland	9 (43%)	N/A	0 (0%)	8 (62%)
England: West Midlands	3 (14%)	0-5	5 (24%)	3 (23%)
England: London	3 (14%)	6-10	4 (19%)	1 (8%)
Wales	1 (5%)	11-20	8 (38%)	1 (8%)
England: NE	1 (5%)	21+	4 (19%)	0 (0%)
England: NW	1 (5%)			
England: East	1 (5%)			
England: SE	1 (5%)			
England: SW	1 (5%)			
N. Ireland	0 (0%)			
England: Yorkshire and the Humber	0 (0%)			
England: East Midlands	0 (0%)			

Key: HCSW= Healthcare Support Worker, OT=Occupational Therapist, MSK=Musculoskeletal, NE=Northeast, NW=Northwest, SE=Southeast, SW=Southwest, N. Ireland= Northern Ireland, CP=Chronic pain, PSI=Peer support intervention

*Number of respondents for each question varied as questions were optional

pain conditions were low back pain (21%) and nerve pain (16%). A wide range of treatments had been experienced by participants, including anti-inflammatories, physiotherapy and paracetamol. Anxiety (32%) and depression (31%) were the most prevalent conditions provided in participants' past medical history.

The group of HCPs was mostly female (76%), and all except one were of working age, with almost 50 percent aged 35-44 (48%). Most participants were at least degree qualified (81%), with three (14%) having a diploma and one stating 'other.' Most participants were physiotherapists (75%), a further 15% were medical doctors, one was a pain specialist (no further details provided) and one a psychologist. Clinical specialties included musculoskeletal (39%), chronic pain (33%), general practice (22%) and acute medicine (6%). Geographically, 52% of participants were from various regions of England and another 43% were from Scotland with the final 5% from Wales. Participants had a range of years of experience managing chronic pain, however only 24% had any previous involvement with a peer support intervention.

4.3 Survey findings

4.3.1 Meeting format

Participants were asked to order their preferred meeting format from one being least desired to three being most desired. It can be seen (Figure 4.1) that both participant groups expressed a clear preference for a mixture (i.e., one-to-one and group meetings in the same PSI).

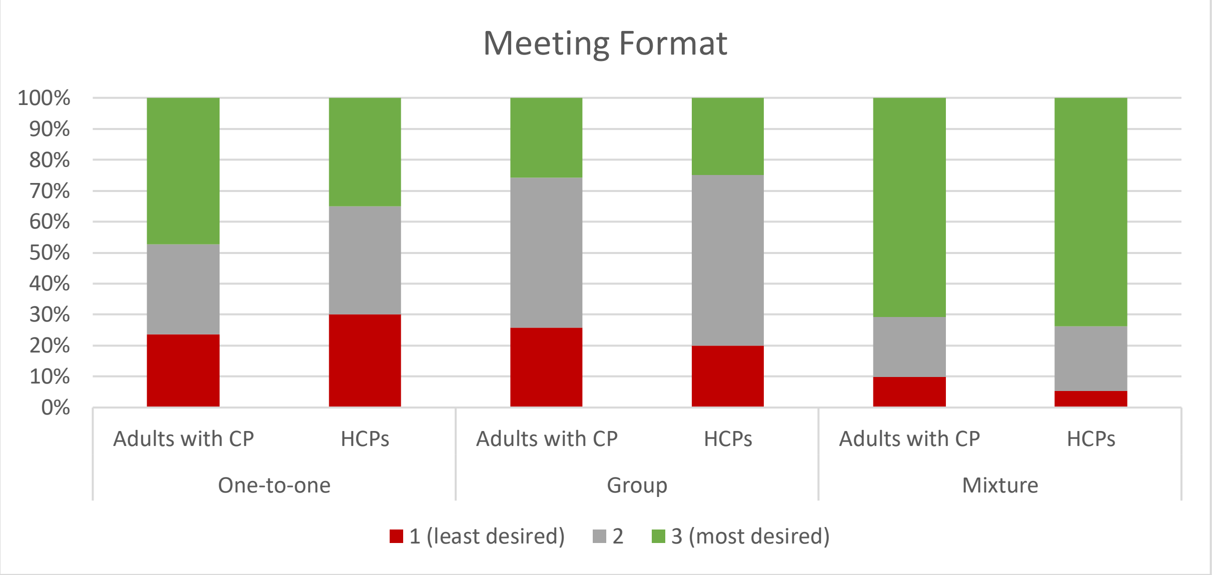


Figure 4.1 Meeting Format

Key: CP=chronic pain, HCPs=healthcare professionals

4.3.2 Mode of delivery

Participants were asked to order their preferred mode of delivery from one being least desired to six being most desired. Two figures are provided for this component as there was a level of variability in what participants preferred across the six delivery modes. The results have been dichotomised and can be viewed in Figure 4.2 and the full results are also provided in Figure 4.3. In both figures, it can be seen that face-to-face and hybrid delivery options were highly desired by both participant groups. Alternatively, social media was selected as the least desired delivery mode by both participant groups, and messaging and email were the second least desired. Participants expressed mixed views on telephone or video calls.

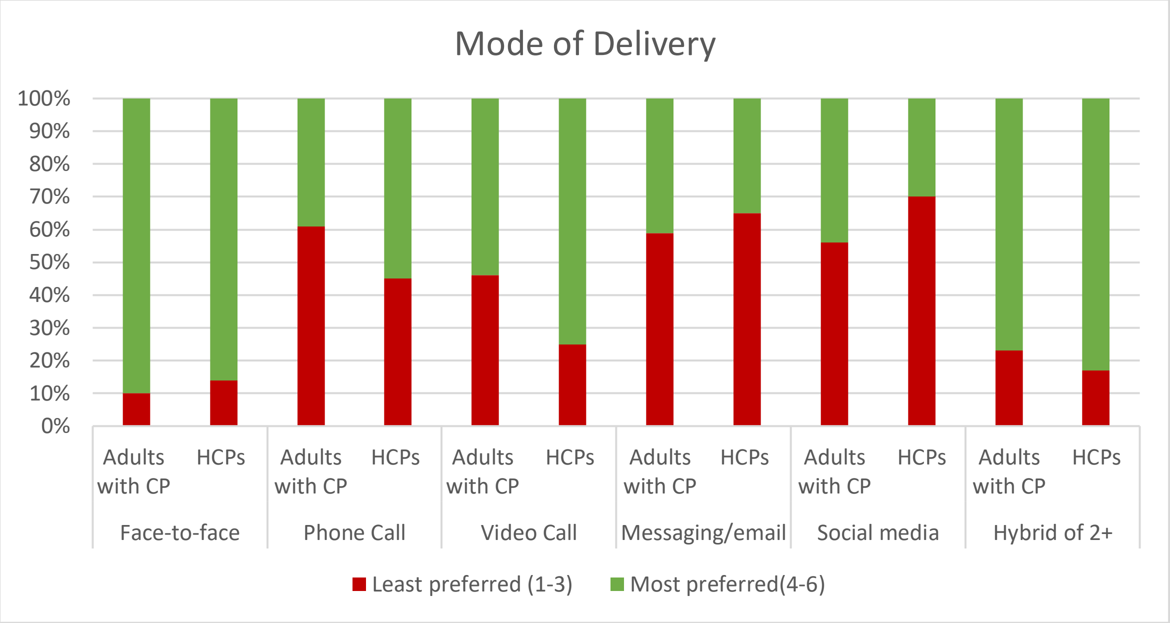


Figure 4.2 Mode of Delivery - Dichotomised Results

Key: CP=chronic pain, HCPs=healthcare professionals

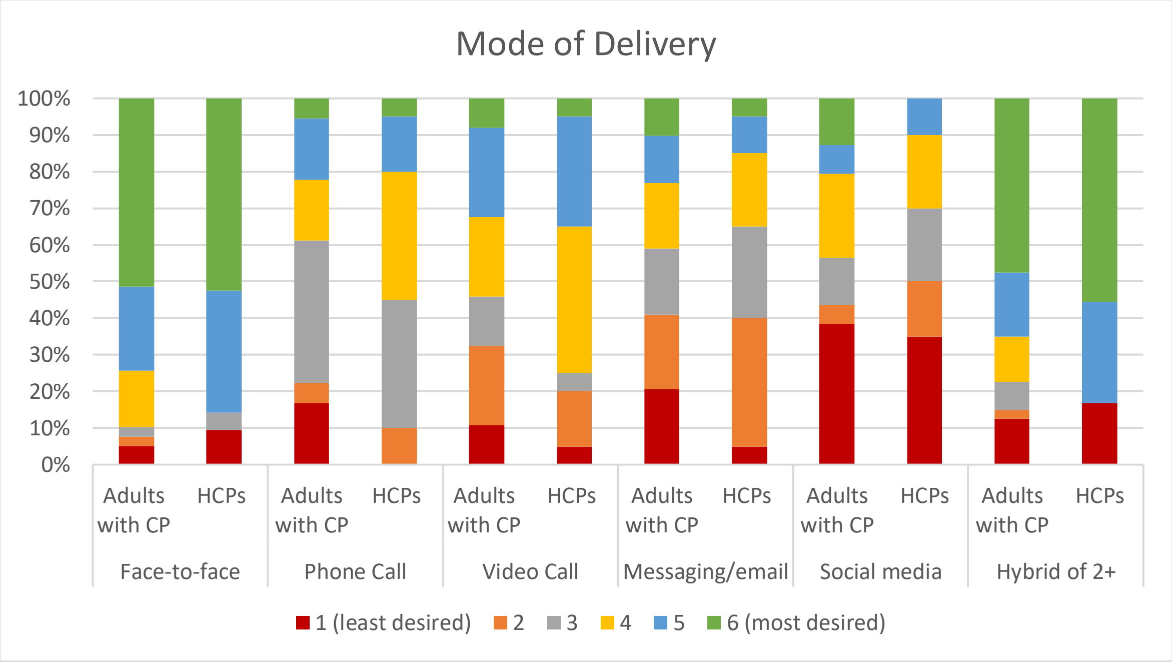


Figure 4.3 Mode of Delivery – Full Results

Key: CP=chronic pain, HCPs=healthcare professionals

4.3.3 Dosage

Both participant groups were asked how long they thought a PSI should last. Figure 4.4 illustrates that 43% of adults with chronic pain thought the PSI should last longer than six months and 29% of HCPs thought the PSI should last six months. The second most selected option for adults with chronic pain was "other" and common responses included "individual preference," "dependent on nature of pain," and "start with 3 months with option to extend or withdraw." Both participant groups agreed less than six weeks was least preferred (adults with chronic pain 2%; HCPs 0%).

All participants were asked how often they thought peers should meet. Figure 4.5 shows the results for frequency of meeting, illustrating that once every two-weeks was most popular (adults with chronic pain 46%; HCPs 43%) and once per week least popular (adults with chronic pain 11%; HCPs 14%).

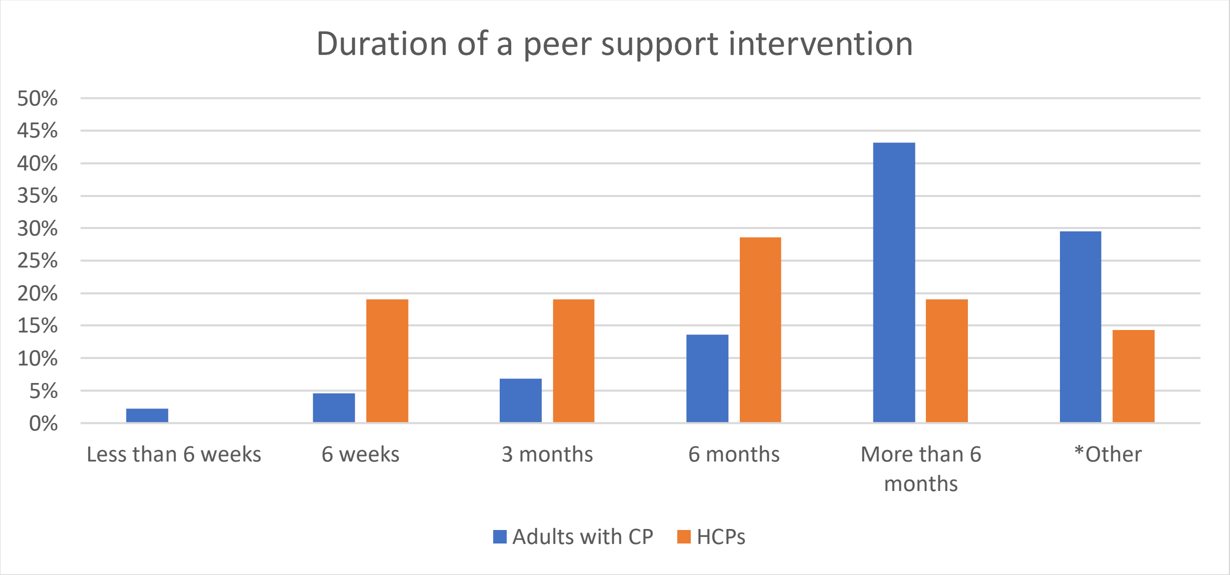


Figure 4.4 Duration of a peer support intervention

Key: CP=chronic pain, HCPs=healthcare professionals

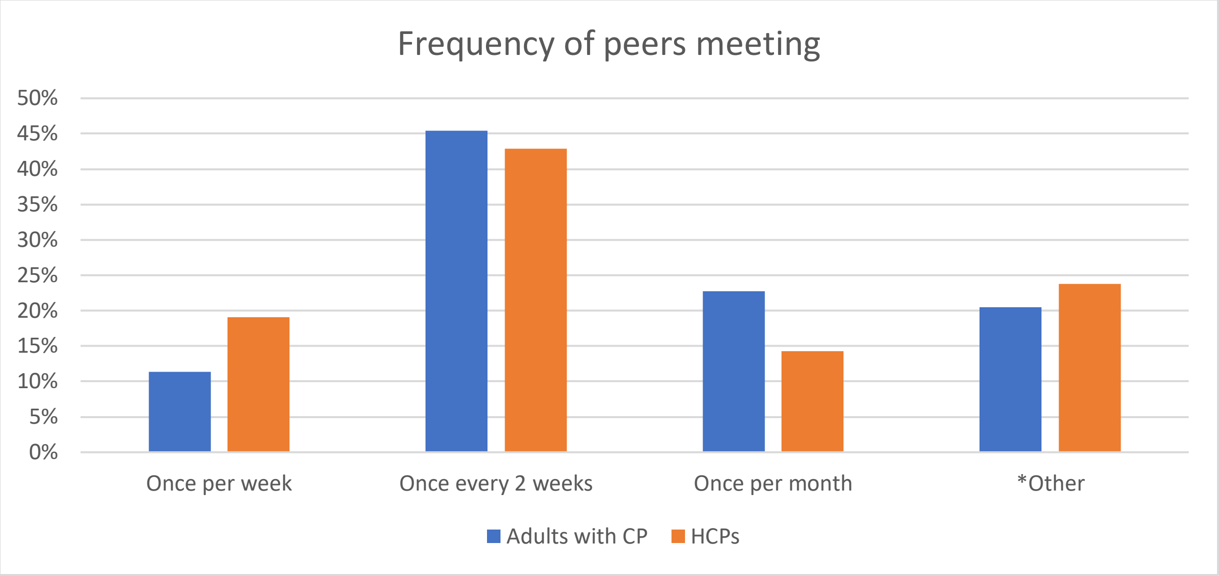


Figure 4.5 Frequency of peers meeting

Key: PSI=peer support intervention, CP=chronic pain, HCPs=healthcare professionals

*Other responses included:

- Adults with CP: individually tailored, people should be able to attend as they feel necessary, activity dependent, consider seasonal changes
- HCPS: individual preference, some may want more initially, group sessions monthly and flexible individual meetings outside of that, weekly but consider whether adding too much to burden of pain

4.3.4 Topics

Participants were asked what topics should be included in a PSI, referring to what content they would like covered. Participants were allowed to choose as many options as they liked. Figure 4.6 illustrates there was generally agreement between participant groups, with the exception of goal setting, which was selected by 15% of HCPs and only 10% of adults with chronic pain. "Other" responses for adults with chronic pain included nutrition, hydration, social support, mental health, HIV and realistic expectations of pain. "Other" responses for HCPs included nutrition, sleep hygiene, mental health, self-care, behaviour change, work resources and acceptance.

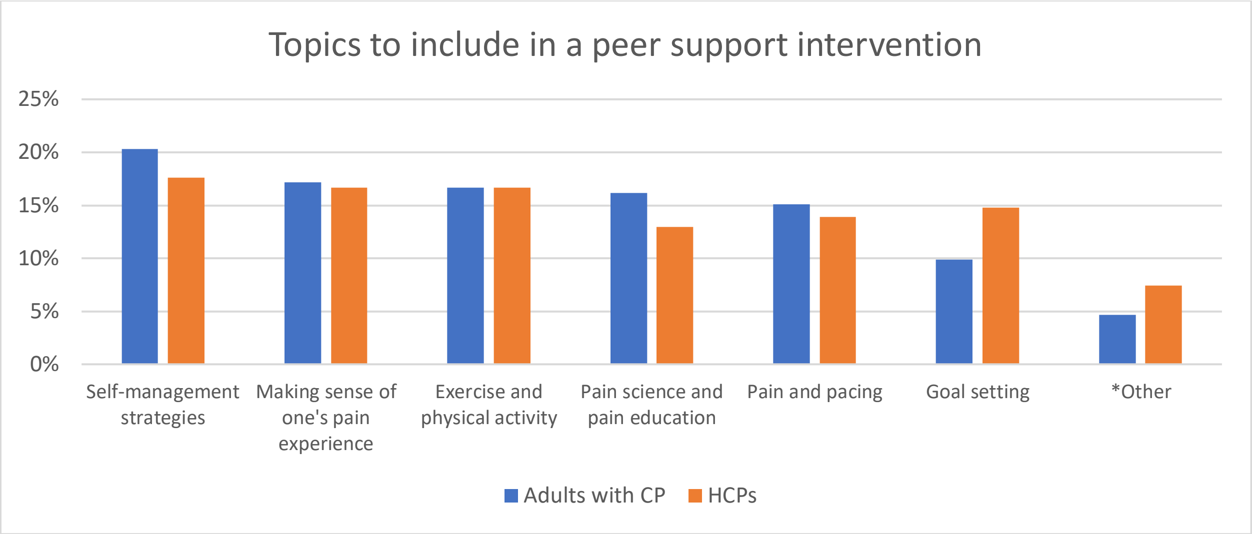


Figure 4.6 Topics to include in a peer support intervention
Key: CP=chronic pain, HCPs=healthcare professionals

4.3.5 Matching characteristics

Participants were asked to consider an adult with chronic pain being matched with a PSV and then rate how important it was for the two people to share the characteristics listed below. Demonstrated in Figure 4.7, political views, race and sexuality were all deemed unimportant by over 60% of participants from both groups. Chronic condition was the most important (adults with chronic pain 77%; HCPs 65%), closely followed by age group, interests and personality. (over 45% of both groups). Both groups had mixed opinions on gender.

4.3.6 Peer Support Volunteer Training

Participants were first asked whether PSVs should receive training and the majority of both groups chose yes (adults with chronic pain 93%; HCPs 90%). Participants were then asked how much training PSVs should receive, with results presented in Figure 4.8. Both participant groups most preferred 8+ hours of training, with over 40% of respondents choosing this option. Participants were finally asked what topics training should include and were allowed to provide free text responses. The author conducted a brief content analysis and summarized the responses into categories, presented below in Table 4.3. Both participant groups agreed on several topics such as safeguarding, communication, pain science, mental health and exercise. Novel topics identified by each group are also presented below.

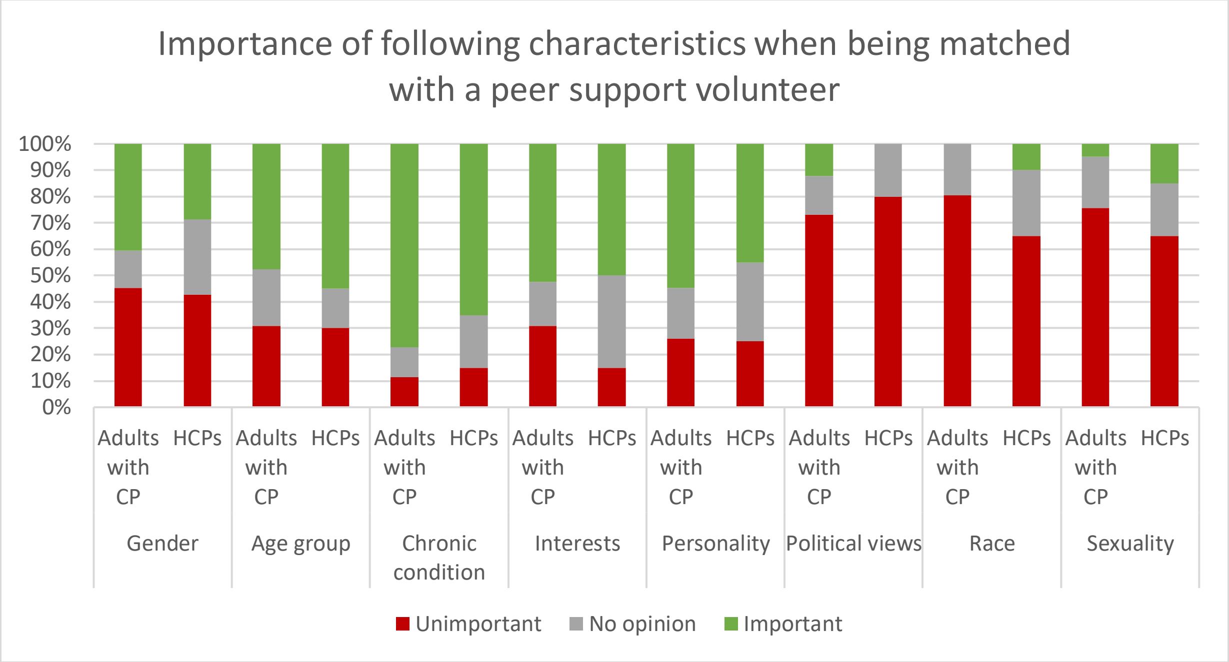


Figure 4.7 Importance of following characteristics when being matched with a peer support volunteer

Key: CP=chronic pain, HCPs=healthcare professionals

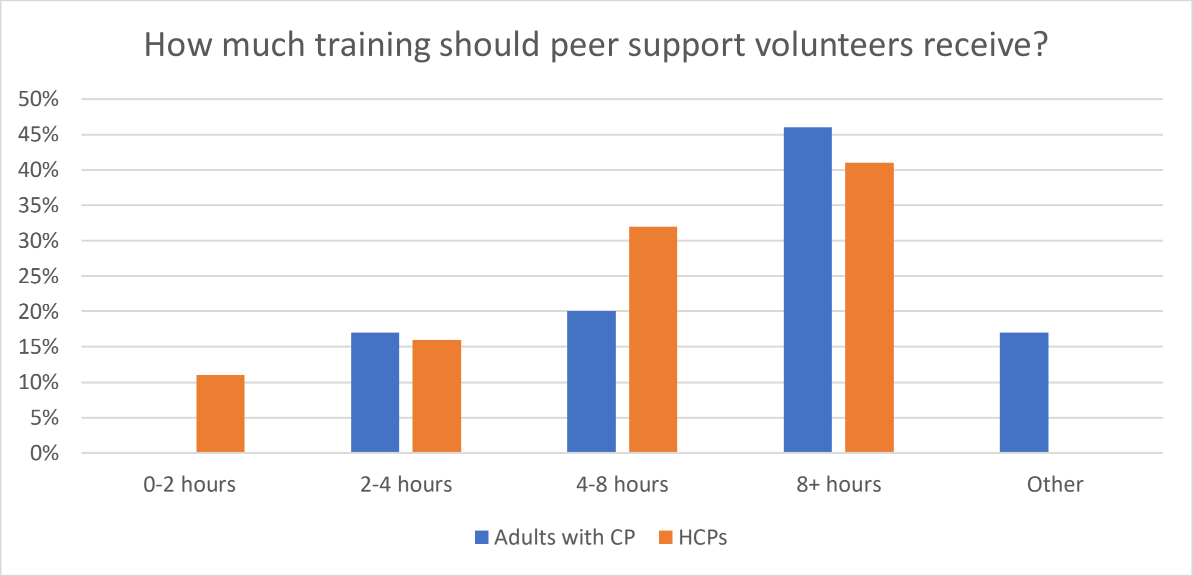


Figure 4.8 How much training should peer support volunteers receive?

Key: CP=chronic pain, HCPs=healthcare professionals

*Other responses included: dependent on experience and background, initial training and continued support/training, one+ week of training, 24+ hours of training-CP is very complex and patient needs to feel truly believed and supported

Table 4.3 Peer support volunteer training topics

Both groups	Adults with chronic pain (36 responses)	HCPs (18 responses)
Safeguarding	Knowledge of painful conditions	Acceptance
Communication	Pain management	Goal setting
Pain science		Coping with stress
Mental health		How to emotionally contain a group
Exercise and physical activity		Self-care
		Motivational interviewing

Key: HCPs=healthcare professionals

4.3.7 Barriers and Facilitators

Participants were asked what they thought would prevent someone from participating in a PSI and were allowed to tick all that applied. Figure 4.9 displays the results for barriers to participating in a PSI. There is general agreement between both participant groups on the barriers asked about in the survey. However, both groups made further suggestions such as pain flares and competing demands or schedules. Some barriers were uniquely identified by each participant group such as mental health and inaccessible venues (adults with chronic pain) and finances or no capacity to support others (HCPs).

Participants were then asked what would help someone participate in a PSI and again were allowed to tick all that applied; results are presented in Figure 4.10. The first three options were all rated highly, with 24-30% of participants selecting the options which were: “facilitators of the meeting are helpful and friendly,” “meeting with another person you can relate to” and “meeting is held in a convenient location.” The fourth option, “meeting is held online” had slightly lower percentage with 14-15% of participants.

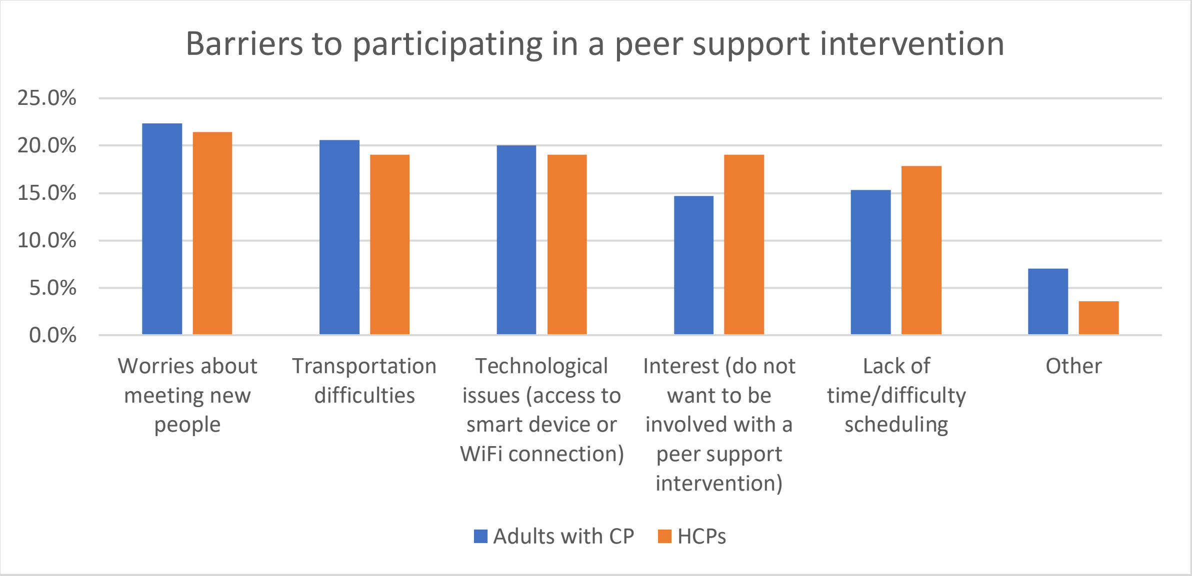


Figure 4.9 Barriers to participating in a peer support intervention

Key: CP=chronic pain, HCPs=healthcare professionals

*Other responses included:

- Adults with CP: Pain limiting attendance, work commitments, mental health, inaccessible venues
- HCPs: Finances, competing demands, pain flares, no capacity to support others

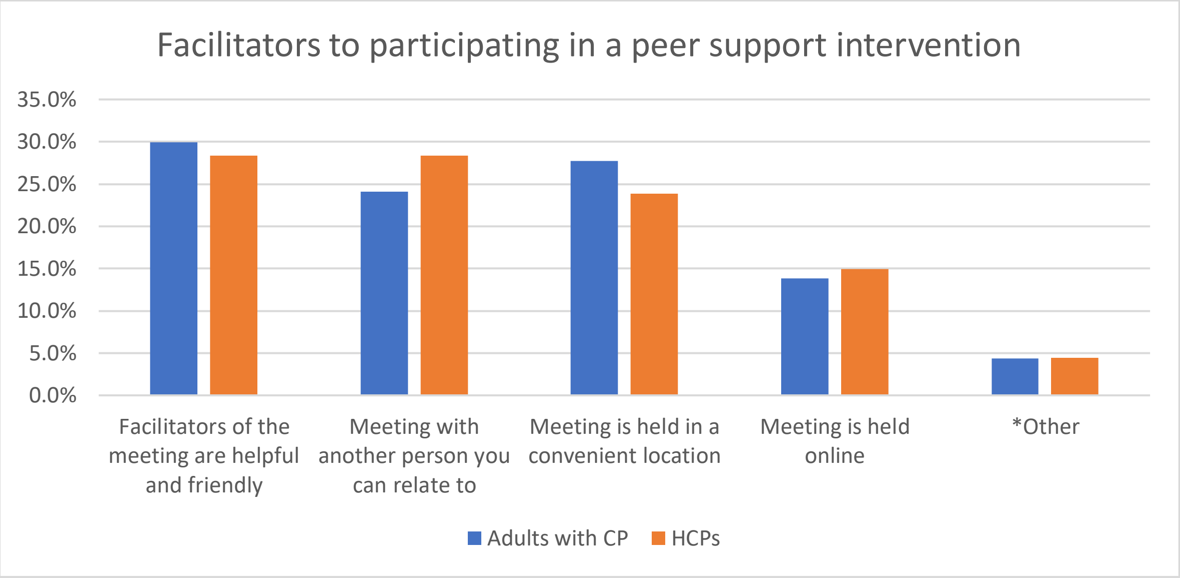


Figure 4.10 Facilitators to participating in a peer support intervention

Key: CP=chronic pain, HCPs=healthcare professionals

*Other responses included:

- Adults with CP: Convenient time, flexible programme, relevant topics, meeting PSV or group leader before attending
- HCPs: accessible in multiple formats, rapport with organizers

4.3.8 Summary of PSI Components

A summary of participant views on PSI components can be viewed below in Table 4.4.

Table 4.4 - Summary of PSI Components

PSI Component	Preference*
Format	Mixture of one-to-one and group
Delivery	Face-to-face and hybrid (least preferred: social media)
Dosage	Duration: adults with CP: 6+ months, HCPs: 6 months Frequency: once every 2 weeks
Topics	Self-management strategies (high interest in all topics provided)
Matching characteristics	Chronic condition, also age group and interests (unimportant: political views, race and sexuality)
PSV training	Yes/no: Yes Amount: 8+ hours
Barriers and Facilitators	**Barriers:** worries about meeting new people (also high responses for all offered barrier options) **Facilitators:** "facilitators of the meeting are helpful and friendly," "meeting with another person you can relate to" and "meeting is held in a convenient location"

*unless otherwise noted, all preferences reflect the views of both participant groups

Key: CP=chronic pain, HCPs=healthcare professionals

4.3.9 Overall opinion of peer support

The final questions of the survey asked participants about their overall opinion of peer support (Table 4.5) and they were provided with the option to provide free text responses (Table 4.6). Both groups had overall positive views of peer support, describing it as "valuable," "important" and "helpful." Final comments on peer support were also overall positive, with both groups suggesting it reduces isolation and several providing suggestions on how it should be run (i.e. "needs to highlight mental and emotional aspects of living with pain," "shouldn't just focus on discussing medication," "needs to be cost effective").

Table 4.5 Overall opinion of peer support

Both groups	Adults with chronic pain (42 responses)	HCPs (21 responses)
Valuable	has to be run and organized well	significant for patient to be at the right stage and ready to engage,
Important	good to exchange coping mechanisms	important for patient to be accessing other services such as one-to-one physio if needed or psychology
Helpful	should focus on lived experience	Potential for participants to exacerbate each other's symptoms
Could help reduce loneliness and isolation	important to be evidence-based	Compensation should be provided to PSVs

Key: HCPs=healthcare professionals, PSVs=peer support volunteers

Table 4.6 Final comments on peer support

Both groups	Adults with chronic pain (19 responses)	HCPs (9 responses)
Helps reduce isolation	Should be offered locally	Validating
	may need to look different in urban vs rural areas	Needs to be cost effective
	Not always helpful depending on background	Codesign with patients
	valuable to gather with others with a shared understanding	
	Needs to be a biopsychosocial approach to living with pain	
	Should not fixate on medication	
	Avoid competition in being unwell	

Key: HCPs=healthcare professionals, PSVs=peer support volunteers

4.3.10 Direction for qualitative interviews

The quantitative findings provided an overview of participants' views and preferences on many PSI components. Agreement was found for what participants most preferred for many PSI components and can be viewed in Table 4.4. Some questions on PSI components revealed greater variety in viewpoints and thus provided direction for further investigation and discussion in the interview phase. These areas included mode of delivery and mixed views on phone or video calls and PSI duration.

The author used a similar template for the interview questions. In order to provide a comprehensive picture of stakeholders' views, the exploratory nature of interviews allowed for investigation into why participants expressed certain preferences. The author was keen to investigate further into some of the more complex components such as matching characteristics.

4.4 Qualitative Interview Results

4.4.1 Participant Demographics

Illustrated in Table 4.7 (adults with chronic pain, n=11), Table 4.8 (HCPs, n=4), and Table 4.9 (mixed, n=4), a total of 19 participants were interviewed. Initially two participant groups were

Table 4.7 Interview Demographics (Adults with Chronic Pain)

Participants (Adults with CP)	Age	Gender	Education	IMD Decile	Notes on pain experience	PMH	Previous treatments	Working status
PwCP 1	44	M	BSc	9	23 years CLBP	None	Physiotherapy Chiropractic Acupuncture Medications Exercise Massage	FT
PwCP 2	25	M	BSc	N/R	10 years CLBP Neck pain	Ehlers-Danlos Syndrome	Physiotherapy Orthotics medication Pain management Counselling	Student
PwCP 3	45	F	A-levels	4	20 years Hip pain Fibromyalgia	None	Medication Meditation Heat Rest	FT
PwCP 4	58	F	BSc	N/R	20+ years Fibromyalgia	Diabetic Cancer Quadruple heart bypass	Chiropractic Medication	Looking after home
PwCP 5	53	F	A-levels	4	8 years CLBP MSK pain	High cholesterol	Physiotherapy Exercise Medication Meditation	PT
PwCP 6	49	F	A-levels	7	31 years CLBP MSK pain Sciatica	None	Exercise CBT Meditation "Alternative therapies"	FT

Participants (Adults with CP)	Age	Gender	Education	IMD Decile	Notes on pain experience	PMH	Previous treatments	Working status
PwCP 7	65	F	BSc	5	20+ years Arthritis Thoracic pain MSK	HTN High cholesterol Hypothyroidism	Physiotherapy Medication	Retired
PwCP 8	39	F	BSc	3	3.5 years CLBP	None	Physiotherapy Chiropractic Acupuncture Epidural Medications Currently on waiting list for spinal cord stimulator	Disabled
PwCP 9	52	F	MSc	6	Lifelong (52 years) Cerebral palsy Perthes disease	None	Physiotherapy Exercise Medications Surgical	Retired
PwCP 10	71	F	BSc	10	46 years RA	Petit mal epilepsy	Physiotherapy Orthotics Acupuncture Medication Surgical	Retired
PwCP 11	77	F	No formal qual	10	10 years Back pain Leg pain Sciatica	Heart stent	Physiotherapy Acupuncture Medication	Retired

Key: PwCP=Participant with chronic pain, CP=chronic pain, IMD=Indices of Multiple Deprivation, PMH=past medical history, M=male, F=female, BSc=Bachelor of Science, MSc=Master of Science, N/R=not reported, CLBP=chronic low back pain, RA=rheumatoid arthritis, HTN=hypertension, FT=full-time, PT=part-time, N/A=not applicable, MSK=musculoskeletal, CBT=cognitive behavioural therapy

Table 4.8 Interview Demographics (HCPs)

HCP	Age	Clinical Area	Education	Gender	IMD Decile (work location)	Involvement with PSI	Profession	Working status	Years managing chronic pain
HCP 1	54	Chronic Pain	MSc	F	1	Several programmes over 12 years, face-to-face, online, hybrid, group, 1-to-1, education, activities	Physiotherapist	FT	12
HCP 2	48	Chronic Pain	BSc	M	7	10+ years experience, general chronic pain groups face-to-face and online	Physiotherapist	FT	16
HCP 3	41	Rheumatology	PhD	F	4 and 10	Fibromyalgia, 6-weeks, face-to-face, group, education on self-management	Physiotherapist	FT	8
HCP 4	38	MSK	MSc	F	2	Arthritis, face-to-face, group, 6-week program, meets 2x per week, education on self-management	Physiotherapist	FT	2

Key: HCP=healthcare professional, MSc=Master of Science, BSc=Bachelor of Science, PhD=Doctor of Philosophy, F=female, M=male, FT=full-time

Table 4.9 Interview Demographics (Mixed)

Mixed	Age	Gender	Education	Profession	Clinical Area	Working status	IMD Decile	Notes on pain experience	Treatment
Mixed 1	34	F	BSc	Physiotherapist	MSK	Self employed	9	20 years CLBP, joint pain	Physiotherapy, exercise, medication, hydrotherapy, acupuncture, hypnotherapy
Mixed 2	52	F	A-levels	voluntarily leads independent PSI	N/R	Disabled	1	30 years back, neck, hips	Physiotherapy, acupuncture, nerve ablation, exercise, medication, injections
Mixed 3	47	F	BSc	Occupational therapist	Community	FT	8	8 years back, neck, fibromyalgia	Physiotherapy, herbal remedies, acupuncture, exercise, medication,
Mixed 4	57	F	Masters	Physiotherapist	MSK	Retired	3	20+ years, joint, MSK, bowel and abdominal	Exercise, medication, surgical

Key: F=female, BSc=Bachelor of Science, MSK=musculoskeletal, N/R=not reported, FT=full-time, CLBP=chronic low back pain targeted which were (1) adults with chronic pain, and (2) HCPs or those with experience of either managing those with chronic pain or designing or delivering a PSI. However, a third group emerged during data collection; (3) a mixed group which included people who fulfilled both criteria.

For the participant group of adults with chronic pain, 82% were female, and the mean age was 53 years old (SD 15 years). Fifty-five percent of participants had back pain, making it the most common type of chronic pain. Other types of chronic pain included arthritis (18%), fibromyalgia (18%), and cerebral palsy (9%). With regards to education, ten out of 11 participants had completed A levels or higher.

The HCP group was 75% female with a mean age of 45 (SD seven years). All participants were physiotherapists who came from the clinical areas of chronic pain (50%), rheumatology (25%) and musculoskeletal (25%). They had 2-16 years of experience of managing people with chronic pain.

The mixed group was all female, and the mean age was 48 years (SD ten years). The professional background of participants included physiotherapists (50%), an occupational therapist (25%) and an organizer of a PSI (25%). Seventy-five percent of participants had back pain and 25% had joint and musculoskeletal pain.

4.5 Higher order classifications, classifications and categories

This section presents results from the 19 interviews conducted with the three different participant groups. Framework analysis produced an abundance of dimensions which were organized into 64 categories and then into a further 19 classifications which were finally synthesised into four higher level classifications, all of which are displayed in Table 4.10. Each higher order classification is now presented in turn. ‘Participants’ refers to the individuals interviewed for this study, ‘attendees’ refers to hypothetical participants in a PSI. Where appropriate, the dimensions for some classifications are displayed in tables to illustrate common dimensions and agreement amongst the three participant groups and also show when a participant group contributed a novel dimension. As a note, a short demographic summary is

Table 4.10 Categories, classifications, and higher order classifications

Categories	*Classifications*	Higher order classifications
What is PS	*What is PS*	**1. Peer Support: definition, recommended content, design and delivery**
Information is clear and accurate	*Information*	
Content related to pain management	*Content*	
Content unrelated to pain		
Advantages of virtual and hybrid delivery	*Mode of delivery: virtual, F2F, hybrid*	
Disadvantages of virtual delivery options		
Advantages of F2F delivery		
Disadvantages of 1:1 format	*Meeting format: 1:1, group, mixture*	
Advantages of 1:1 format		
Advantages of group format		
Disadvantages of group		
Advantages of mixed format		
Disadvantages of mixed format		
Group composition - considerations	*Group composition*	
Group composition - Advantages of similar age and gender		
Group composition - Advantages of mixed age		
Group composition – Advantages of similar condition or ability		
Group composition – Advantages of generic groups		
Group composition – Advantages of generic and similar condition groups		
Organization of PSI – HCP involvement	*Organization of PSI and roles*	
Organization of PSI – participant involvement		
Organization of PSI – leader characteristics		
PSV should be self-managing well, mentally stable and able to set good boundaries		
Peer matching is complicated	*Peer matching*	
Peer matching – no age or gender preference		
Peer matching – preference for similar age and gender		
Peer matching - Individual preference and considerations for age and gender		
Peer matching – preference for similar condition		
Peer matching – switching and personal characteristics		

Both PSI frequency and duration dependent on funding, participant schedules and overall success of programme	*Dosage*	
Valuable to have consistent and ongoing PSIs		
PSI Frequency could vary between weekly to monthly		
PSI duration – other considerations		
PSVs should be compensated, but limited by funding	*PSV requirements: support and training*	
PSVs require emotional, logistical and safeguarding support		
PSV training is necessary and should include mental health first aid, pain science and communication		
Different needs for PS	*Individual needs and preferences*	
Importance of determining participant preferences		
Condition-related barriers to participating in a PSI	*Barriers*	**2. Barriers and facilitators to participating and organizing a PSI for CP**
Logistical barriers to participating and organizing a PSI		
Personal (both inter and intra) barriers		
Logistical facilitators: location, accessibility, consistency		
Logistical facilitator: adequate promotion of PSI	*Facilitators*	
Logistical facilitator: timely access to PSI		
Socio personal facilitators		
Benefits of PSI: positive outlook	*Benefits of PSI*	**3. Consequences of PSIs**
Benefits of PSI: practical support or advice		
Benefits of PSI: social support		
Benefits of PSI: Reduced loneliness		
Benefits of PSI: sense of purpose		
Benefits of PSI: importance of community and shared experience		
Benefits of PSI: educational		
Benefits of PSI for HCPS		
Disadvantages of PSI: burden on PSV or poor dynamics	*Disadvantages of PSI*	
Disadvantages of PSI: fear of worsening condition		
Disadvantages of PSI: fixation on pain or pessimism		
Disadvantages of PSI: inaccurate information or harmful advice		
Ambivalent view on PSI	*Ambivalence*	
Lack of services and support for CP and need for PS	*Need for PS*	**4. Broader views on PSIs**
Need for educational resources on CP		
Impact of Covid on PSIs and healthcare	*Impact of Covid*	

Benefits of dual perspective Challenges of dual roles Disadvantages of current HCP training programmes	*Views from mixed participants*	

Key: PS=peer support, F2F=face-to-face, PSI=peer support intervention, HCP=healthcare professional, PSV=peer support volunteer, CP=chronic pain provided for the speaker of each quote, in the case of all the HCPs and three out of four participants (mixed), these participants were physiotherapists and this has been abbreviated to "PT."

4.5.1 Peer Support: definition, recommended content, design and delivery

Eleven classifications consisting of 38 categories contributed to this higher order classification. This section is presented in four parts, exploring each of the subsections of peer support: definition, recommended content, design and delivery.

4.5.2 Definition of peer support

Dimensions within this category were wide ranging and can be viewed in Table 4.11, but there was common ground found amongst the participant groups as all felt peer support was educational, supportive and included an element of reciprocal helping:

> *"An opportunity for people living with same or similar long-term conditions to support each other." (HCP 1 54-year-old female, PT, 12 years managing chronic pain)*

The first column shows where multiple participant groups expressed similar views when describing peer support. These groups were in agreement and the numbers following each dimension refer to the following groups: (1) Adults with chronic pain, (2) HCPs and (3) Mixed. For example, the first dimension of "Educational (1,2,3)" means that all three groups agreed peer support is educational. The fourth dimension listed is "Community (1,2)" which represents that just adults with chronic pain (1) and HCPs (2) contributed to this dimension. The second column shows where each group had novel views that were not represented by any other group.

Table 4.11 Dimensions for "What is peer support"

Agreement	Novel		
Multiple participant groups	**Adults with CP (1)**	**HCPs (2)**	**Mixed (3)**
• Educational (1,2,3) • Supportive (1,2,3) • Reciprocal helping (1,2,3) • Community (1,2) • Shared understanding (1,3) • Permission to talk about pain (1,3)	• Family • Work colleagues • Informal • Social media • Activity driven	• Inclusive	• Social

Key: CP=chronic pain, HCPs=healthcare professionals

Several dimensions were detected exclusively by adults with chronic pain and included who could be identified as a peer supporter such as family members or work colleagues. Adults with chronic pain also suggested that peer support could be informal; not arranged by any organization but simply meeting with friends or connecting with others on social media and feeling emotionally supported. Finally, adults with chronic pain particularly liked gatherings that were activity-driven, such as singing or drawing. Both adults with chronic pain and participants (mixed) thought of peer support as a place for people with a shared understanding of living with chronic pain, and this was greatly valued as participants struggled to find others with experiential knowledge of their condition. These two participant groups also felt peer support gave them permission to talk about their pain and enjoyed the social element of peer support.

4.5.3 Recommended content

4.5.3.1 Information

Both adults with chronic pain and HCPs contributed to this category and expressed a need for clarity on aims and intended benefits of a PSI, along with managing the expectations of what a group is capable of accomplishing. For example, an adult with chronic pain wanted any information provided by the PSI to be accurate and evidence based:

> *"I think aims are really important, I think to be very clear about what those are and decide what those are." (PwCP 9: 52-year-old female, 52 years cerebral palsy, Perthes disease)*

4.5.3.2 Content

Participants discussed content that was both related and unrelated to pain management. All three participant groups contributed to this finding. Participants expressed a desire for relevant topics to be discussed at each meeting, including topics related to pain and coping such as potential treatments or solutions. Participants were also keen to have informative talks from various HCPs, including from physiotherapists on topics such as exercise and from dieticians on healthy eating:

> *"…having a dietitian come in and saying, here's what you should and shouldn't eat, because if you can't exercise much because of your condition, you're gonna get diabetes, for example." (PwCP 2: 25-year-old male, 10 years CLBP & neck pain)*

> *"maybe there were some, you know, chronic fatigue tips" (Mixed 3: 47-year-old female, 8 years CLBP & neck pain & FM, OT)*

Participants also wanted content unrelated to pain management, since there was strong commonality across the three participant groups that activities can be useful distractions from pain. Participants suggested that activities could include arts or crafts, knitting, a book club, baking, and outdoor activities such as bee keeping. However, one participant (mixed) observed that certain activities like crafting or knitting might actually cause more pain and as such, they felt that these activities should not be offered in isolation. Beyond activities, participants also wanted topics and discussions to expand beyond just pain management to include overall wellbeing and local resources and events:

> *"So having something like activities that people join in which we know are good as distractions." (PwCP 6: 49-year-old female, 31 years CLBP & MSK pain)*

> *"You know, how some reassurance now that how can they still be independent at home, for example, or they might want to know about your local job centre and what services they offer." (HCP 1: 54-year-old female, PT, 12 years managing chronic pain)*

4.5.4 Delivery

The components of how a PSI is delivered includes the meeting format (group, one-to-one or a mixture), the mode of delivery (virtual, face-to-face or hybrid) and the dosage (frequency of meetings and entire duration of PSI). The findings related to each of these components will now be explored.

4.5.4.1 Meeting format: Group, one-to-one or mixture

This classification was comprised of several categories related to the advantages and disadvantages of each meeting format and the dimensions can be viewed in

Table 4.12. All three participant groups contributed, but only one dimension had agreement between the groups which was a preference for the mixture of formats. This table is in a similar format to Table 4.11 with two columns to illustrate which dimensions were agreed upon by multiple groups and which dimensions were novel contributions from a single

group. This table has the addition of highlighted text which pertains to advantages (highlighted in green) and disadvantages (highlighted in red) to each delivery mode.

Other preferences related to the mixture format included the idea for attendees to start in a one-to-one format and then ease into the group format when they felt ready. Adults with chronic pain and participants (mixed) shared how groups can be overwhelming for some people and it would be good to have a one-to-one option initially so the attendee can then make the transition to the group when s/he is ready. Another advantage of the mixture format suggested by adults with chronic pain was that it was good to have the option to develop deeper friendships outside of a group setting. HCPs agreed that it was good to provide options to attendees, but this was also a disadvantage as it does complicate the design of a PSI:

Table 4.12 Dimensions for "Meeting format: 1:1, group or mixture"

	Agreement	Novel		
	Multiple participant groups	**Adults with CP (1)**	**HCPs (2)**	**Mixed (3)**
1:1 A&Ds	-Prefers 1:1 (1,3)	-Dislikes 1:1	-Overdependence -Unfair obligation -Difficult to manage -Poor match	-Easier to talk
Group A&Ds	-Can be overwhelming (1,3)	-Prefers group	-Greater benefit from groups	-Shared experience helps people open up
		-Greater chance of connection with others	-Groups don't always work	-Dislikes groups
Mixture A&Ds	-Prefers mixture (1,2,3)	-Option to develop deeper friendship outside of group	-Options are good	
	-Start with 1:1 then ease into group (1,3)		-Complicates design	

Key: A&Ds=Advantages and Disadvantages, CP=chronic pain, HCPs=healthcare professionals

> *"You know, I think if you set up a social media type group or something that you could allow members to use, and then be able to check in. Say, for example, you met somebody at the group that you felt really friendly with, then you could type a message back and forth and see how they're getting on in that period, between the meetings." (PwCP 4: 58-year-old female, 20 years FM)*

Moving on to the group format, adults with chronic pain proposed a preference for groups as they felt there was a greater chance of connecting with others. HCPs thought groups were safer than one-to-one formats due to safeguarding concerns. A participant (mixed) proposed a group setting can provide positive peer pressure:

> *"…being in a group, I find in some situations, people spur each other on and motivate each other to perhaps do more than they might have if they hadn't been there." (Mixed 4: 57-year-old female, 20 years MSK & bowel and abdominal pain, PT)*

In contrast, another participant (mixed) reported a dislike for group formats due to feeling overwhelmed and drained of energy.

The final format option of one-to-one had some adults with chronic pain express a preference for this format and others who disliked it. HCPs discussed several disadvantages which included multiple risks for the PSV such as the participant becoming overly dependent, the PSV feeling an unfair obligation to the organizer of the PSI and an overall difficulty managing the relationship.

> *"Because I always worry that they become overly dependent or demanding on each other. And if we just let them go without any support, I think it can be difficult for some people to curtail the interaction or keep the interaction to a level that doesn't disrupt their life. If that makes sense, I think in some cases, there might be, they might feel responsible towards the pain service, because they put us in touch." (HCP 1: 54-year-old female, PT, 12 years managing chronic pain)*

The same HCP also suggested some matches are simply not successful and the dynamic can become unhelpful. However, one participant (mixed) did feel the one-to-one format was helpful as it would be easier to talk about her experiences with just one person, rather than a whole group:

> *"Yeah so I'm not sure, as much as I am happy to talk about my experiences with people sort of on a one to one basis. I don't know how I would feel in a larger group." (Mixed 3: 47-year-old female, 8 years CLBP & neck pain & FM, OT)*

4.5.4.2 Mode of delivery: virtual, face-to-face or hybrid

Findings pertained to the advantages and disadvantages of virtual and hybrid delivery and advantages of face-to-face delivery, with all three participant groups contributing. Dimensions can be viewed in Table 4.13.

Table 4.13 Dimensions for “Mode of delivery: face-to-face, virtual or hybrid”

	Agreement	Novel		
	Multiple participant groups	**Adults with CP (1)**	**HCPs (2)**	**Mixed (3)**
Advantages of virtual and hybrid	-Prefers hybrid (1,2,3)	-Flexible structure is important		-Easier to access from home
	-Flexible choices are important (1,2,3)	-Social media is positive and helpful		-Prefers social media
	-Prefers virtual (1,2,3)	-Likes casual nature of interactions		
	-Easier to access from home (1,2,3)	-No obligation with Facebook		
	-Easy to access and connect (1,3)			
Disadvantages of virtual options	-Dislikes impersonal nature of virtual interactions (1,2)	-Consider tech accessibility	-Screens trigger migraines	
		-Negative and competition in being unwell		
		-Unkind remarks		
		-Inaccurate information		
		-Difficult to live separate to pain with constant access (1)		
		-Some messages come with expectation		
		-Needs to limit social media usage		
		-Participant fatigue impacts focus		
Advantages of F2F	-Prefers F2F (1,3)	-Easier than navigating online meetings	-Benefit more from F2F	
	-Human connection is important (1,3)	-Minimum of 1 F2F		

Key: F2F=face-to-face, CP=chronic pain, HCPs=healthcare professionals, Advantages, Disadvantages

When asked about preferred virtual options, participants discussed audio or video calls or messaging via social media platforms like Facebook, Twitter or WhatsApp. One mixed participant suggested a platform similar to Tinder but for finding friends. She was keen to find others with her diagnosis and shared interests. Across all three participant groups, there was representation of an overall preference for virtual or hybrid delivery, compared to exclusively face-to-face delivery. The advantages of virtual and hybrid delivery focused strongly on the importance of flexibility as the reality of living with chronic pain resulted in a frequent need to change prearranged plans. The need for flexibility was also associated with living in a post-COVID world and participants felt that it would be helpful to offer multiple delivery options:

> *“Because it's post COVID now, so I guess the more flexibly you could deliver it. Or the different, and various formats, I think would be quite helpful.” (HCP 3: 41-year-old female, PT, 8 years managing chronic pain)*

Having the possibility of attending a group virtually provided the advantage of easier access along with the ability to initially engage with the group at a distance and then decide whether to become a committed attendee. Facebook in particular was associated with reduced obligation to attend a formal meeting and a preferable casual nature of interaction:

> *“So it's kind of nice to have that Facebook group where if you're feeling you need to connect with someone you can but yeah, it's not. It's not any kind of pressure or a scheduled thing that you have to attend. You'd rather just use it when you need it.” (PwCP 5: 53-year-old female, 8 years CLBP & MSK pain)*
>
> *“So you know, that might be an option as well. Maybe some people are a bit shy about joining in and would want to hear what's being said and what's going on. So there's the option to just watch I guess.” (Mixed 4: 57-year-old female, 20 years MSK & bowel and abdominal pain, PT)*

Disadvantages of virtual delivery options were identified by both adults with chronic pain and HCPs. Many of the disadvantages related to a general dislike for the impersonal nature of virtual interactions, along with observations that inaccurate information and negativity spread more easily on the internet. Some participants indicated they needed to limit their social media usage as the constant access made it difficult to live a life separate to their pain. Logistically, participants reflected that not everyone has access to smart devices or internet access. Physically, participants commented that screens can trigger migraines and also impact overall participant fatigue.

> *“Facebook and that, nah, wouldn't go to it. It's not face to face, and people just type a load of rubbish on Facebook (*laughs). Yeah, it's not personalized. So people feel they can put things down.” (PwCP 7: 65-year-old female, 20 years arthritis & MSK pain)*

All three participant groups reported advantages of face-to-face delivery, which included valuing human connection and experiencing overall greater benefits from the PSI. Some participants did express a preference for a face-to-face PSI as they were easier to access than navigating online meetings. Other participants also favoured a minimum of at least one face-to-face meeting throughout the duration of a PSI.

> *"…but for me, personally, sitting in a room, being able to talk to people face to face is definitely preferable." (Mixed 4: 57-year-old female, 20 years MSK & bowel and abdominal pain, PT)*

4.5.4.3 Dosage

This category brought together findings related to the frequency and duration of a PSI. All three participant groups agreed it would be valuable to have consistent and ongoing PSIs available, ideally meeting weekly, although some adults with chronic pain and HCPs preferred meeting monthly. Certain dimensions were detected exclusively by adults with chronic pain such as observing the dosage would be dependent on funding and the overall success of the PSI (or whether attendees were continuing to benefit from it). One adult with chronic pain also felt the frequency would depend on whether the format was group or one-to-one, as she would not want to attend a group every week but would like a one-to-one meeting weekly. Another adult with chronic pain thought one-off events were still valuable. Both adults with chronic pain and mixed participants commented the dosage would be dependent on participant schedules and organizers should consider working individuals.

> *"But again, that I think perhaps if it is a group session to have a couple of sessions to start with, and then again, asking people, because different groups will have different dynamics, and some groups will want to meet every week, or the groups might just want to meet every month, you know, it might be that you've got a group of people that are working." (PwCP 3: 45-year-old female, 20 years hip pain, FM)*

Finally, HCPs and participants (mixed) also observed organizers should consider the attention span of users, especially for online meetings as not all attendees may have the concentration to sit for longer than an hour:

> *"Again, people's attention as a group online is probably…in my experience, probably no more, definitely no more than an hour. Again, screens can be triggering for some people, you know, people with migraines, and so you're probably 45 minutes 40 to 45 minutes." (HCP 2: 48-year-old male, PT, 16 years managing chronic pain)*

4.5.5 Design

The components of how a PSI is designed include peer matching, group composition, organization and roles, PSV requirements and individual needs and preferences. The findings related to each of these components will now be explored.

4.5.5.1 Peer matching and group composition

These findings pertained to all the considerations involved in matching a PSV with a participant in a one-to-one PSI, along with the overall composition of a group PSI. There were several similarities across the findings for these two design features. The findings included a variety of preferences, as participants expressed their thoughts around whether they preferred peers with a similar age, gender, condition and other characteristics. Across the three participant groups, preferences were voiced on both sides of all the characteristics, for example some participants preferred meeting with peers of a similar age or gender and others preferred mixed ages and/or genders. Those who did prefer a similar age talked about the importance for younger people to meet together. One HCP suggested that some older people may have learned unhelpful strategies, which would not be ideal to pass onto younger people. She also spoke of the potential to impact more life choices and directions in young people. A participant (mixed) also felt any suggestions from a retired person may be difficult to implement for a working person. Several participants suggested that they would like a peer with shared interests or in a similar life stage (such as a working adult or a parent). Regarding age, one adult with chronic pain shared that she would prefer the same gender, as her pain changed during her monthly cycle:

> *"But I think gender is more relevant. I know for me that with my pain, it's definitely worse at certain points during my monthly cycle. And obviously, if I'm talking to a man about that, they're not necessarily going to understand that in the same way than a woman might." (PwCP 3: 45-year-old female, 20 years hip pain, FM)*

Those who did prefer a mix of ages thought some attendees could benefit from seeing how others have managed their condition over a lifespan. Others felt there were better discussions with mixed ages and genders, suggesting that groups that are overly similar tend to complain about the same things repeatedly.

Moving onto similarity of condition, groups can vary from being tailored to a single condition such as arthritis or fibromyalgia, or a group can be more generic and open to anyone experiencing any kind of chronic pain. Participants reported advantages for single condition groups such as an HCP observing that attendees found it most helpful to obtain information that was bespoke to their condition:

> *"For example, we work like, just let's say it's fibromyalgia versus chronic pain, pelvic pain versus hypermobility and Ehlers Danlos Syndrome. I know that the content to the outside, I would say that all looks pretty similar information and obvious, but the nuances specific to the condition, actually are what people find really helpful." (HCP 2: 48-year-old male, PT, 16 years managing chronic pain)*

The same HCP also discussed the challenges of running single condition groups:

> *"…to get enough people with a specific condition into the same place at the same time isn't easy. So that's why we end up doing general programs." (HCP 2: 48-year-old male, PT, 16 years managing chronic pain)*

Continuing with the challenges of running single condition groups, a participant (mixed) felt these groups can be isolating as they exclude people if they do not fall under the criteria of a certain condition. An HCP also supported this finding, stating single condition groups can be limiting as many people have multiple conditions. Other HCPs and participants (mixed) identified advantages to generic chronic pain groups, such as more beneficial discussions that are not solely focused on the specifics of medication and treatments:

> *"'Cause some people just want to talk about medication and focus on like, oh, this drug or this or something like that. Where as if it's kind of multi-condition, you're talking more about how it affects you like the fatigue or the pain, or the you know, what other things that you've tried, you know, you're...rather than, cause everybody just wants to know what medication you're on and what works for you and what the latest treatments are, and do you know what I mean? Rather than, actually, when I'm having that really bad day. It's not that pill that's gonna get me out a bed. It's my attitude, and what I'm going to do to make myself get there and do what I have to do." (Mixed 3: 47-year-old female, 8 years CLBP & neck pain & FM, OT)*

Several participants contributed towards an overarching category, which was that peer matching and group composition is complicated, and it is important to determine the preferences of potential attendees. HCPs contributed several dimensions to this category such as noting the importance of ensuring a good peer match to successfully encourage self-management behaviours, although not all matches are successful:

> *"Often, especially if you're trying to encourage people to change their behaviours, how to self-manage their persistent pain, and to learn how to live well with it and change things that they do. (*laughs) Then it becomes you have to have somebody who's the match in terms of their, almost like almost like a dating app, isn't it? Like you have to kind of match them up. But then we know that those don't work*

> *sometimes too though…" (HCP 3: 41-year-old female, PT, 8 years managing chronic pain)*

Another HCP observed how some people are adaptable and can get on with many types of people, while others are not. The same HCP observed even a good matching system can fail:

> *"Well it could be that you could work out a really good system, but the chances are, there's a chance that it might not work as well." (HCP 3: 41-year-old female, PT, 8 years managing chronic pain)*

When matches fail or participants simply are not benefiting from a match, both adults with chronic pain and HCPs felt it would be helpful to have the option for participants to switch and be matched with a different peer.

Adults with chronic pain shared a few personal characteristics they deemed important in a peer. These included being optimistic, outgoing, trustworthy and approachable. One adult with chronic pain suggested similarity of condition was less important as long as the PSV was managing his or her condition well:

> *"…you're going to find some people won't be overly concerned. But then there will be the ones that will be quite stringent on the fact that they don't want certain individuals or certain ages." (PwCP 1: 44-year-old male, 23 years CLBP)*

4.5.5.2 Organization and roles

Views were wide-ranging on the best way to organize a PSI, mainly surrounding how much involvement should come from HCPs versus people with lived experience of chronic pain. Regarding HCP involvement, adults with chronic pain were unique in stating HCPs should be involved periodically to deliver educational sessions, but the overall organization and ongoing leadership should come from those with lived experience of pain. Adults with chronic pain felt HCPs did not understand the lived experience of pain and valued having leaders with this experience. Alternatively, HCPs did feel it was important to have participant input on the overall design and aims of a PSI but preferred to have HCPs in the position of organizing and leading the PSI. One HCP spoke of the logistics of organizing a group and in her experience, groups tended to fold once they were passed from clinical leadership to those with lived experience:

> *"And obviously, they have a life to live as well. So the peer support group and the setting up of the peer support group and the leading it and, you know, all the little nitty gritty of chasing people, booking a venue, making sure everything is ready, all that kind of stuff can tip them over the edge. So they might do it for a short period of time, and then they can't cope with it any longer." (HCP 1: 54-year-old female, PT, 12 years managing chronic pain)*
>
> *"Once we handed them over, for the reasons I said before, people run out of steam, life happens, they can't keep up with the commitment, becomes too much for them. They tended to fold." (HCP 1: 54-year-old female, PT, 12 years managing chronic pain)*

The same HCP identified funding as a limiting factor in providing ongoing clinical support.

Beyond the professional background of the organizers of a PSI, adults with chronic pain also shared several characteristics they deemed important for the leader of a PSI. They stated the leader should be skilled with communication, organization and fundraising. One participant also felt it would be beneficial to have a team of leaders in order to avoid burnout.

Now that the leadership of a PSI has been discussed, the focus will be shifted towards the role of the PSV. Both adults with chronic pain and HCPs stated an ideal PSV was someone who was successfully self-managing their condition and good at encouraging others. Adults with chronic pain added the PSV should be adept with setting good boundaries. HCPs commented the PSV should be mentally and emotionally balanced. One HCP clarified having a mental health condition should not exclude anyone, but it should be confirmed that the condition is stable and well-managed.

Regarding the role of the PSV, some participants preferred a reciprocal relationship, being able to both give and receive advice:

> *"peer support...I don't really mean balance of power, but I can't think of another phrase. It's gonna vary, isn't it? Like, for me, if I had peer support, I actually want somebody who is currently in a very similar situation to me. And it would be very much a kind of two way thing, I might have something that would help them, they might have something that would help me. There are other people who will be looking for somebody who was...they primarily wanted advice from that person. And for me, that would be a different kind of balance." (PwCP 9: 52-year-old female, 52 years cerebral palsy, Perthes disease)*

4.5.5.3 PSV requirements: training and support

All three participant groups agreed that PSV training was necessary and should equip PSVs with training for mental health first aid and teach them how to share their experience in a helpful way. Adults with chronic pain added PSVs should be taught how to emotionally support others in a healthy way and DBS (Disclosure and Barring) checks should be conducted. HCPs and participants (mixed) thought training should provide PSVs with the basics of pain science and general exercise recommendations. HCPs also observed training would be funding dependent.

In addition to receiving training before acting as a PSV, HCPs and adults with chronic pain further insisted on PSVs obtaining emotional, logistical and safeguarding support while acting as a PSV. Logistical support was discussed in relation to information, resources and content to go through in peer meetings. Safeguarding included instruction on red flags and policy for escalation in the case of severe mental health.

Both adults with chronic pain and HCPs discussed the need for compensation for PSVs, one adult with chronic pain questioned the fairness of treating PSVs as volunteers. She also commented on the number of people with chronic pain that are on benefits and she felt it was then problematic to ask them to give up their time and energy without any form of compensation:

> *“...to ask people to volunteer, if you if they need a lot of training to do the job you're asking them to do, you have to question is it fair for them to be a volunteer? Truthfully, because so often, people want to use your lived experience. And don't count that as being expertise. Whereas if they spoke to a professional, they would pay them for their time. Because they...people study and their book learning is seen as expertise, whereas lived experience is often not seen in the same light.” (PwCP 3: 45-year-old female, 20 years hip pain, FM)*

> *“…if people are being expected to give up a number of hours or a number of, you know, especially when you have chronic pain, and you often can't work, so you're often people are often on benefits, people are often on the breadline, to then also ask them to give up their time is problematic for me, and that- I feel that people's lived experience ought to be recognized more than it currently is, and to do it with just with volunteers. Yeah, it just feels wrong somehow, especially if you're, if your program wouldn't run well, without them, then they're integral and ought to be*

> *treated as such. You know, so it's, it's important to make sure that everyone is valued for the work that they do, even if traditionally, that's been a volunteer role, you have to ask, well, if it wouldn't run without them, should they have some? You know, should there be something that we can do here?" (PwCP 3: 45-year-old female, 20 years hip pain, FM)*

Another HCP echoed similar comments on fairness and believed there should be compensation but acknowledged the limitations of funding.

4.5.5.4 Individual needs and preferences

This classification pertained to the different needs people have for peer support and the importance of determining attendee preferences. All three participant groups concurred that not everyone with chronic pain wants or needs formalized peer support. Indeed, some participants preferred informal peer support (or simply speaking with friends or family members), others preferred to meet one-on-one with an HCP, still others did not want to share their experience in a group setting or with strangers at all. Furthermore, an adult with chronic pain thought a person's mental health would impact what they need from peer support:

> *"So I think someone's mental, mental health as well as going probably affect it as well. You're already in a low mood, and you've got this, then you're going to be in a completely different place with your chronic pain to someone that is mentally stronger at that time." (PwCP 1: 44-year-old male, 23 years CLBP)*

For those who would be interested in peer support, adults with chronic pain observed one programme would not suit everyone's needs or preferences, and particularly indicated attendees would have varying preferences on how much they want to share or engage. HCPs and participants (mixed) discussed the significance of determining attendee preferences with relation to many of the previously explored intervention components related to delivery and design (format, delivery, dosage, peer matching):

> *"My first thought is getting access to people and, and having them fill out surveys, you know, directly just directly asking people, but do you want in a peer support and is peer support appropriate?" (HCP 4: 38-year-old female, PT, 2 years managing chronic pain)*

4.5.6 Barriers and facilitators to participating and organizing a PSI for CP

Two classifications consisting of seven categories contributed to this higher order classification.

4.5.6.1 Barriers

All three participant groups contributed to this classification, which comprised of barriers that were condition-related, logistical and personal (both inter and intra). Condition-related barriers included physical difficult traveling, which was impacted by pain flares, fatigue or specific pain related to being in a seated position in a car for an extended period of time. Other condition-related barriers included limited focus or energy, which was discussed in relation to both face-to-face and virtual PSIs. Finally, participants voiced the difficulty in attending a PSI consistently due to fluctuating pain levels:

> *"…because obviously people in pain have to get to a location and if they're in pain, they might not be able to." (PwCP 6: 49-year-old female, 31 years CLBP & MSK pain)*

Concerning logistics, all three participant groups identified funding, access and familiarity with smart devices and internet, and poor awareness or promotion of PSIs as substantial barriers. Participants discussed funding in terms of associated costs to the organizers of the PSI, such as booking a meeting space, and providing clinical support and food and drinks. Additionally, costs were related to attendees and included travel cost and potential contributions towards food and drinks. Participants spoke at length about a lack of awareness for what PSIs or other resources for chronic pain are available. Participants felt many people did not know where to go for help. One HCP suggested both people with chronic pain and GPs were not always adequately informed of other treatment options beyond a prescription; and felt PSIs can be a valuable tool:

> *"…people just don't know they have other options apart from a prescription. I think you used the phrase 'options' earlier on, which I think that is the biggest thing that people say is that I don't know how I have any other options, I just have to live with taking pills every day. And they don't like that. And the GPs will say, Well, I don't have any other options apart from prescribing. And we are your other option." (HCP 2: 48-year-old male, PT, 16 years managing chronic pain)*

Another logistical barrier included lack of transport as a face-to-face PSI would require a car for some people. Scheduling was also discussed, particularly for working attendees. Finally, low attendance or engagement was also discussed by HCPs and the mixed group.

Personal barriers were also discussed by all three participant groups. An interpersonal barrier was having to rely on others such as a partner, family member or friend to assist with transport to and from a PSI. Intrapersonal barriers included a hesitancy to new people and situations or being vulnerable with others:

> *"I think the main barriers will be people who are a bit shy and don't like, like getting involved with new people, new situations." (Mixed 4: 57-year-old female, 20 years MSK & bowel and abdominal pain, PT)*

Some participants also expressed concern for the emotional toll of listening to others' problems:

> *"I think the problem is sometimes with these sort of things is that you're feeling the weight of other people's problems and I guess...although it's a shared thing, there's always going to be someone that's in a worse place." (PwCP 8: 39-year-old female, 3.5 years CLBP)*

4.5.6.2 Facilitators

All three participant groups contributed to this classification which included multiple logistical facilitators such as location, promotion and timely access to a PSI, along with socio personal facilitators. The first group of logistical facilitators pertained to location, accessibility, and consistency. All three participant groups agreed that the location of a face-to-face PSI should be physically accessible for all mobility aids; alternatively, some participants also commented that virtual options were beneficial as they would be accessible to those who were more homebound. One HCP reported the content should be accessible to those with learning disabilities. Concerning location, many participants were vocal about the benefits of a central location, particularly with other shops around in order to make the journey out of the house worthwhile:

> *"And there's other things around. Like I find that really useful. Because, like I say, if I'm going to the effort of like hair wash, hair dried, dress, suffering through the journey, I always like to make a bit more of it while I'm out." (PwCP 8: 39-year-old female, 3.5 years CLBP)*

Regarding the setting and environment of a face-to-face PSI, multiple adults with chronic pain commented on the benefits of meeting in a non-clinical environment such as a community centre, church hall or café, in order to avoid pre-existing negative associations with clinical environments. One adult with chronic pain specifically commented on furniture, noting particular discomfort in hard, waiting room chairs and a preference for comfortable chairs that would not exacerbate back pain. Multiple participants also shared how they enjoyed refreshments such as tea and coffee whilst socializing.

Both adults with chronic pain and HCPs felt it was important to have committed attendees that were engaged with the PSI. Adults with chronic pain did indicate it can be challenging for those with chronic pain to attend a group regularly, but it is helpful to know a group is offered consistently so they can attend when able.

The next group of logistical facilitators related to adequate promotion of PSIs. Participants discussed multiple modes of promotion should be utilized such as social media, newsletters, and word of mouth. Participants also observed many people with chronic pain do not have access to pain services, as such they felt it was important to promote PSIs outside of the pain related sector. Participants identified other HCPs such as GPs, AHPs, along with mental health organisations, all of which they would like to be involved with promotion of PSIs. One HCP also identified carers and third sector organisations as important avenues to provide information as well:

> *"But I think probably coming from GP services, and also carers in the community. So people that do home visits, that look after people, anyone with disabilities, or the elderly should have information on how to access those programs. Because sometimes the carers are the only social interaction they have where that patient might benefit from getting access to those things. So already in the third sector, they should be aware of those programs and finding out from those people, the best way for them to get access." (HCP 4: 38-year-old female, PT, 2 years managing chronic pain)*

The final group of logistical facilitators concerned timely access to PSIs. Participants stated it would be beneficial to have a wait list of no longer than one to two months in order to access a PSI. One HCP also reported it would be ideal for patients to self-refer and access peer support when they are feeling challenged and require additional support. Participants believed it was important that any potential attendees of a PSI have access to a GP and pain services prior to joining a PSI. Participants felt medical advice (particularly instruction on pain science) and preliminary support should be provided by HCPs first, or else expectations of the PSI would be too high, and it could fail:

> *"I wonder whether it's a group of people who may well have not had much support. And then if it's the first bit of support they're offered, then there's quite, there's quite a high expectation there. I think. So I don't particularly like the phrase managing expectations. But I think that's...it's probably important. I think it's I think they can actually, ironically, they could actually fail because they're needed too much." (PwCP 9: 52-year-old female, 52 years cerebral palsy, Perthes disease)*

Several adults with chronic pain also commented on the danger of PSIs plugging a gap as people with chronic pain may be on a long wait list to access an HCP. These participants observed that a PSI is not an equivalent to meeting one-on-one with an HCP.

Another group of facilitators pertained to socio personal factors. All three participant groups valued a social period in order to meet others, build friendships and share personal experiences. Many participants also highlighted the PSI should be welcoming and promote open and honest discussions where people can share without fear of being judged. Participants wanted a space where their concerns were validated, they could learn from others and they felt normal amongst their peers. A few participants voiced the difficulty of discussing issues related to pain with other friends or family members as it was a challenge to feel understood. As such, both adults with chronic pain and HCPs identified an important facilitator of having a space where attendees were heard and felt valued.

Adults with chronic pain observed there can be a lot of heavy topics around chronic pain, and reported it was important to have transparent discussions, while also maintaining an overall positive tone. One participant suggested reserving a time to share achievements, what has worked well or stories of encouragement:

> *"You've got to try and find a way through I think maybe just talking about things, achievements, or things that have worked out well, or, you know, I, I don't know, I did a four mile walk the other day, and I've not walked that far for four years. And we sort of almost like celebrate those things. So having a space for kind of positive affirmation, stories of encouragement or just funny, a light-hearted period." (PwCP 8: 39-year-old female, 3.5 years CLBP)*

Finally, participants observed regular follow up was also a key to success. Adults with chronic pain clarified the follow up should not be done in an obligatory way, but they did appreciate receiving a message or a phone call stating they were missed at the group.

4.5.7 Consequences of PSIs

Three classifications including 13 categories contributed to this higher order classification.

4.5.7.1 Benefits of PSIs

Eight categories contributed to this classification and can be viewed in Table 4.14. These benefits included positive outlook, practical support or advice, social support, reduced loneliness, sense of purpose, importance of community and shared experience, educational and benefits specifically for HCPs. Consensus was observed across the three participant groups as all contributed to the first six categories. The final two categories of educational and HCP-specific were only contributed to by HCPs and participants (mixed) respectively.

4.5.7.2 Disadvantages of PSIs

This classification included four categories, which comprised of fixation on pain and pessimism, burden on the PSV and poor peer dynamics, fear of a worsening condition, and inaccurate information. All three participants groups were represented across the categories, although there was only one dimension which all three groups agreed together which was negativity (in the category of fixation on pain and pessimism). Indeed, participants shared how some PSIs can be overly negative and there can be competition in being unwell. Adults with chronic pain oftentimes related this negativity to a fixation on pain which ultimately worsened their pain. Many participants shared they did not want to focus on the pain, and one in particular stated it would “make the pain too real” (PwCP 5- 53-year-old female, 8 years CLBP & MSK pain). She disliked this as she made great efforts to live a life separate from her pain. A participant (mixed) also commented she doesn’t want to focus on her pain and tries hard to remain positive:

> *“I have tried looking at a few chronic pain forums and stuff. But sometimes they just feel a bit, a bit depressing? Do you know, if you're already feeling pretty crappy, they don't exactly give you that warm and fuzzy feeling that things, things may get better. It's all fairly doom and gloom. And I really am not a doom and gloom person I try so hard to stay really upbeat.” (Mixed 3: 47-year-old female, 8 years CLBP & neck pain & FM, OT)*

Table 4.14 Dimensions for Benefits of Peer Support Interventions

	Agreement	Novel		
	Multiple participant groups	**Adults with CP (1)**	**HCPs (2)**	**Mixed (3)**
Positive outlook	-Appreciate positive outlook (1,2,3)	-Became proactive to avoid progressing to worse state		-Humour helps
	-Realize not as bad as they thought (1,2)	-Positive		
		-Light-hearted		
		-Distraction from pain		
Practical support or advice	-Discuss treatments or coping strategies (1,2,3)	-Accessing services	-How to communicate with family and friends	
	-Helpful (1,2)	-Assurance		
		-Informative		
Social support	-Supportive (1,2,3)	-Sharing reduces stress	-Internal factors like hope and resilience	-Talking helps
	-Mental wellbeing (1,2,3)	-Encouraging	-External factors like social connectedness and family networks	
	-Social support was meaningful (1,3)	-Normalizing helps		
	-Accept pain to move forward (2,3)	-Built friendships		
		-Social support was helpful		
Reduced loneliness	-Reduced loneliness (1,2,3)	-Benefit from talking with others		
	-Pain is isolating (1,3)			
	-Big difference (1,3)			
Sense of purpose	-Sense of purpose (1,2,3)	-Want to help others	-Teaching others a skill	-Reduce feelings of being a burden
	-Builds confidence (2,3)		-Helps participants move forward	
Importance of community and shared experience	-Shared experience (1,2,3)	-Pain is a unique experience		-Good to connect with others
	-Valuable to have others who understand and empathize (1,2,3)	-Importance of being heard		
	-Helpful (1,2,3)	-Newfound awareness of prevalence of CP		

	-Validation (23)			
Educational		-How to live well with pain	-Important to learn how to self-manage -Less reliant on medical system -Exercise is helpful -Important to educate on exercise -Participants should choose education topics -Learn more about condition -Evidence based information	
HCP-specific	-			-PT session more efficient -PT knows Pt is emotionally supported

Key: CP=chronic pain, HCP=healthcare professional, PT=physiotherapy, Pt=patient

The next category focused on the burden on the PSV and poor peer dynamics. This category was largely comprised of dimensions contributed by HCPs, such as concerns around safeguarding and managing both domineering and emotionally unstable attendees. One HCP discussed the risk of suicidal ideation and domestic violence within her work and how PSVs should escalate these situations:

> *"The population we work with, there is often risk of suicidal ideation, actual suicide, you know, worries around safeguarding, domestic violence and whatnot. And sometimes if somebody is a lay person providing that peer support, it doesn't mean that they don't meet these situations, and they don't know what to do with it. And the risk is that they take on far too much to help the person that they're meant to be supporting, when actually, they should be escalating it to people whose responsibility it is to do that. So that is one of my concerns about the one to one peer support." HCP 1: 54-year-old female, PT, 12 years managing chronic pain*

Participants (mixed) along with HCPs observed PSVs may have difficulty setting boundaries and that matches can be unsuccessful. Multiple participants voiced concern for PSVs becoming overburdened by anyone who is overly dependent or demanding, especially as a peer living with chronic pain, a PSV has their own health to consider.

The third category centred on fear of a worsening condition. Both adults with chronic pain and participants (mixed) shared past experiences of attending groups and feeling anxious after seeing other attendees in helmets or wheelchairs, one participant reflected:

> *"I went to this group. And because there's such a vast range, there were some people there who obviously suffered and had on in helmets to protect them. And I just knew that it was too much for me to cope with. Which is really bad. Because there's all kinds of you know, but I just felt I didn't want to go back again." (PwCP 10: 71-year-old female, 46 years RA)*

A participant (mixed) indicated it could be worrying to see others in a worse state, specifically for younger people, those in an earlier condition stage or those with degenerative conditions. She felt her HCP background provided her with an awareness of her condition's progression, but she was concerned for others without that level of awareness, and whether their concerns may or may not be able to be addressed during the PSI.

The final category in this classification related to inaccurate information and harmful advice. Most of the dimensions were contributed from participants (mixed), such as concern that unhelpful coping strategies could be learned like bedrest or there could be encouragement of potentially harmful alternative therapies like cupping with bloodletting. A participant (mixed) observed some groups may perpetuate disengagement with the medical community due to negative previous experiences. Furthermore, participants (mixed) felt PSIs were unhelpful when the organisers lacked appropriate medical knowledge. Adults with chronic pain agreed that inaccurate information was a negative consequence. One HCP reported groups with an unscientific approach were also unhelpful. This HCP gave the example of a group with a religious association:

> *"…we actually had complaints from patients who attended, who were being told, oh pray over it, and your pain will go away, for example, or there was a lot of pushing around faith. And obviously, that is not everybody's cup of tea." (HCP 1: 54-year-old female, PT, 12 years managing chronic pain)*

4.5.7.3 Ambivalence

One adult with chronic pain stated she thought of both negatives and positives when it comes to peer support. This participant in particular highlighted the importance of the timing of PSI, and that it is not an equivalent to meeting with an HCP, but she also observed an individual could meet someone at a PSI with a shared experience and greatly benefit from that interaction. She concluded she felt ambivalent about PSIs.

4.5.8 Broader views on PSIs

Three classifications including six categories contributed to this higher order classification.

4.5.8.1 Need for peer support

These findings pertained to an overall need for peer support as participants identified a lack of services and support for people with chronic pain and a need for educational resources. Most dimensions came from adults with chronic pain, although four dimensions came from the other two participant groups. All participant groups agreed on one dimension, which was that the NHS is unable to provide the long-term support that people with chronic pain need:

> *"It's having that, it's having that ongoing kind of contact, isn't it that often these people with persistent pain, like and want and need, which isn't, which isn't provided in the NHS. Which, yeah, there isn't that there, isn't that availability to provide those kinds of services." (HCP 3: 41-year-old female, PT, 8 years managing chronic pain)*

Both adults with chronic pain and HCPs felt the burden of coping with pain physically and mentally was too much for an individual. Thus, participants felt more help is needed for this population and peer support could be part of that help. Beyond PSIs, a participant (mixed) observed there is a need to involve wider support networks, so people become less reliant on medical and social services:

> *"I mean, ultimately, I suppose we'll all want people to become less and less reliant on medical services, social services, and all the rest of it. So the more you can get people to come together as a group and support each other away from you. And away from the services, the better. But that, as I say, might involve the third sector, voluntary setups, and things like that." (Mixed 4: 57-year-old female, 20 years MSK & bowel and abdominal pain, PT)*

Also related to wider support, one participant reported that there is a need for greater support from employers. She stated that people will remain in jobs if they are adequately supported, but she has struggled to maintain jobs since having chronic pain and the impact pain flares had on her job performance:

> *"I think there's a massive, massive thing there with employers. Peer support as employers (*muffled) -people, employers want bums on seats. But actually, like what we're doing in the civil service at the moment, you will keep people in a job if you give them what they need. And you treat them in the way that they need to be treated. And they are getting there. Like I said, I'm very lucky at the moment in the role that I'm in and the civil service as a whole are doing that. So I think there's some big gaps with families and employers that still aren't being filled." (PwCP 6: 49-year-old female, 31 years CLBP & MSK pain)*

Adults with chronic pain were the only participants to comment on the need for educational resources for chronic pain. They wanted particular resources to help explain their pain experience to family and friends. An adult with chronic pain shared that she found her friends were more supportive after they understood her chronic pain. Another adult with chronic pain suggested it would be beneficial to have education on chronic pain in schools as both a preventative measure and to provide instruction on how best to support a friend or family member in pain:

> *"So give some people something that they can use to help them put their pain into perspective and maybe give them some advice about how they can, like signpost, people to where they can manage it help loved ones realize what pain is like for their family and friends." (PwCP 2: 25-year-old male, 10 years CLBP & neck pain)*

4.5.8.2 Impact of Covid

All three participant groups contributed to this classification on the impact of COVID on general healthcare and PSIs. Regarding wider healthcare offerings, participants noted a great reduction in face-to-face contact with healthcare professionals, which many disliked and expressed a preference for face-to-face meetings. Participants also observed long wait lists for treatments and booking into the GP or physiotherapist:

> *"Covid has changed the way we do a lot of things. And it's certainly isolated a lot of people. And, you know, I think everybody just feels like healthcare has just sort of disappeared. I mean, nobody's seen their GP for who knows how long, you know, regardless of the fact that everybody else has still been working through the pandemic." (Mixed 3: 47-year-old female, 8 years CLBP & neck pain & FM, OT)*

Considering the impact of Covid on PSIs and social connections, one adult with chronic pain felt social media usage had been largely increased to the lack of opportunity to meet with people in person. She utilized social media as a tool to find others in similar situations:

> *"…the impact of the pandemic on face-to-face contact has maybe driven this social media, maybe forward more than it maybe would have, because obviously, we've had extended periods of time where we're not allowed to see people, not allowed to meet up with people, places were closed. And I do think there's definitely been a shift since the kind of lockdown of this, this kind of internet sort of connection, because I guess, if people were going to groups, or were just maybe meeting an acquaintance for a coffee, that ability was taken away." (PwCP 8: 39-year-old female, 3.5 years CLBP)*

Participants observed Covid changed how PSIs were offered, with more being offered online. Several participants noted online delivery was beneficial as it was more flexible and accessible. Some HCPs observed the challenges of PSI since Covid, as the pandemic had negatively impacted many peoples' physical and mental health, so participants were attending PSIs with much greater needs:

> *"There has been a huge deterioration in the population, both mental health wise, but also physically as a result of COVID. And we've seen, for example, people who are perhaps just about coping prior to Covid, then lockdown, and they've just spiralled. They're not keeping their health. So that (virtual PSI) would be a good option for somebody like that." (HCP 1: 54-year-old female, PT, 12 years managing chronic pain)*

4.5.8.3 Views from participants (mixed)

Participants (mixed) contributed some novel observations such as the benefits and challenges of their dual perspectives and specific statements on the disadvantages of current HCP training programmes. Benefits of their dual perspective included a greater understanding of pain science, which enabled them to be less fearful of activity and more active, resulting in an overall reduction of pain severity and negative emotions. Additionally, their experiential knowledge of living with chronic pain provided them with genuine empathy towards their patients:

> *"It's quite different being on the other end. I mean, as much as you think you can empathize with your patients, I think until you've been through something yourself, you don't truly, you think you understand." (Mixed 4: 57-year-old female, 20 years MSK & bowel and abdominal pain, PT)*

Challenges of the dual perspective pertained to interpersonal relations with colleagues as one participant (mixed) felt her perspective as a person living with chronic pain was undervalued.

> *“Because even in one of the roles that I had, some of my colleagues knew that I had like chronic pain, I had the same training as them, but yet, they still felt like, they could say that my experience of my condition was wrong, based on what they’d been told. And I thought, well, I’ve got the same training as you and I have this condition, and surely, my experience is like valid. I think that’s kind of something that’s a bit kind of systemic in our profession, really. I don’t really know where it comes from. I’m not...sorry (*becoming emotional). I know I’m not the only one who’s experienced that.” (Mixed 1: 34-year-old female, 20 years CLBP, MSK pain, PT, 5 years managing chronic pain)*

She also expressed concern for these same colleagues and how they were communicating with their patients without fully understanding the chronic pain experience. Another participant (mixed) observed it would be challenging to attend a PSI as a participant as she was accustomed to leading groups for her patients with various conditions.

Regarding HCP training programmes, one participant (mixed) spoke at length about how it would be highly beneficial to have more HCPs with experiential knowledge of chronic pain, but there is a huge shortage. She identified the lack of physiotherapy training programmes that are accessible to people with chronic pain, due to the programmes being exclusively full-time, which is not feasible for a person in pain:

> *“And because without getting into a big rant, there's no part time physiotherapy degrees. But if somebody does have a long-term health condition, are they gonna be able to do a full time degree? Probably not. Are those not the people that you want? Who can actually relate to the patients that you're trying to treat. And then I guess also having a group, having a group of health professionals who do have these kinds of conditions. Rather than just like, a very kind of theory heavy, this is how pain works.” (Mixed 1: 34-year-old female, 20 years CLBP, MSK pain, PT, 5 years managing chronic pain)*

4.6 Summary of Qualitative Results

Participants had wide-ranging views and many preferences were voiced both for and against several components of PSI delivery and design. There were some common findings, including several participants voicing a desire for flexibility in whatever was offered. Participants wanted programmes with flexible scheduling, offered in as many delivery modes as possible (face-to-face, online, option for follow up via messaging or phone calls) and without obligation or judgment when pain flares prevented their attendance. Participants shared how chronic pain can affect people across the lifespan, so it is valuable to talk with someone from a similar life stage (retired versus working, with or without children). Finally, participants placed high value on individual preferences and suggested whenever a programme is being developed, for organizers to receive input from potential attendees. A broader summary of qualitative results is illustrated in Table 4.15, which highlights some of the key findings where all three participants groups were in agreement.

Table 4.15 Summary of Qualitative Results

	Qualitative
PSI Component	**Findings**
Format	**Mixture:** Option to develop deeper friendship outside of group, options are good **1:1** overdependence, poor match, unfair obligation
Delivery	**Hybrid:** Flexible choices are important (hybrid) **Virtual:** easy to access from home but interactions can be impersonal **F2F:** importance of human connection
Dosage	Want consistent and ongoing PSI
Topics	Clarity on aims and intended benefits of PSI, have content that is both related to pain (coping and health education) and unrelated to pain (activities can be good distractions)
Matching characteristics	Important to find someone from a similar life stage or interests, have the option to switch
PSV training	Training is important and should cover mental health first aid and how to share your story in a helpful way
Barriers and Facilitators	**Barriers:** condition-related, logistical and personal (both inter and intra) **Facilitators:** logistical (central and accessible location, adequately promoted and timely access to PSI) and socio personal (social period, build friendships share personal experiences)
Organization of PSI	Have input from those with lived experience
Individual needs and preferences	Not everyone with CP wants or needs formal PSI, determine potential attendee preferences for design and delivery components
Consequences	**Benefits:** positive outlook, practical support or advice, social support, reduced loneliness, sense of purpose, importance of community and shared experience **Disadvantages:** fixation on pain and pessimism, burden on the PSV and poor peer dynamics, fear of a worsening condition, and inaccurate information
Need for PS	The NHS is unable to provide the long-term support that people with chronic pain need
Impact of Covid	Reduction in F2F contact with HCPs
Views from participants (mixed)	Benefits and challenges of dual perspective, current HCP training programmes are inaccessible to people in CP
What is PS	Educational, supportive, reciprocal helping, community, shared understanding

4.7 Chapter Summary

This chapter presented the quantitative and qualitative results of this mixed methods study in relation to the research questions. Participant demographics were described and results were presented through figures, tables and narrative summaries. The following chapter will discuss these findings in relation to the current evidence base.

5 CHAPTER 5: DISCUSSION

5.1 Introduction to the chapter

This chapter will discuss the mixed methods study findings and situate them in relation to the existing evidence-base. This chapter will integrate the qualitative and quantitative findings. The original contribution to knowledge will be identified along with strengths and limitations of the study. Recommendations for policy, practice and future research will also be provided.

5.2 Key Findings

As this was a mixed methods sequential explanatory study, the qualitative findings provided greater depth and valuable explanations or reasons to support many of the preferences participants voiced for the PSI components in the quantitative survey findings. In this chapter, the findings from both components of the study are integrated, and the following terms in Table 5.1 are used to show the relationship between the quantitative and qualitative data.

Table 5.1 Integration Terms (Skamagki et al. 2022, p. 5)

Term	Definition
Convergence	Describes agreement between the two sets of findings
Complementarity	Occurs when the findings illustrate different but non-contradictory interpretations
Expansion	Occurs when some findings overlap but also provide space for further interpretation
Divergence	Occurs when the quantitative and the qualitative findings demonstrate conflicting interpretations

Using the above terminology to integrate the findings provides a collaborative understanding call a meta-inference (Fetters 2020). The purpose of a sequential explanatory study was to use the qualitative findings to provide direction for areas to explore in more depth in the qualitative phase, in turn the qualitative findings could help explain the quantitative findings. As such, the study was not designed to look at agreement between the two phases and none of the findings represented true convergence, but several sets of findings achieved expansion and complementarity.

Illustrated in Table 5.2, the key quantitative and qualitative findings are presented. This table shows what was preferred by most participants in relation to the PSI components, in addition to barriers and facilitators and several further findings exclusively generated from the qualitative interviews.

It can be seen from Table 5.2 that the qualitative data explained many of the areas explored in the survey, such as why participants preferred a mixture of formats; as this provided the opportunity to pursue deeper friendships outside of a group while still providing options for how people could meet. Additionally, participants preferred the delivery modes of face-to-face or hybrid as they stressed the importance of having a human connection and also liked the flexibility of multiple delivery options. Overall, the qualitative findings helped to support the quantitative findings and there were not any contradictory findings.

Due to the exploratory nature of the interviews, there were several topic areas that interview participants exclusively discussed, providing a large amount of rich and useful data. These topics included individual needs and preferences, organization of a PSI, consequences, a need for peer support, the impact of COVID-19, views from participants (mixed) and what is peer support. The key findings will now be explored and situated in relation to the evidence base.

5.2.1 Flexibility and Individual Needs

In the quantitative results, participants voiced a desire for PSIs to be flexible and delivered in multiple ways; advantages of this were expanded upon in the qualitative results, demonstrating expansion. The survey illustrated both participant groups most preferred a mixture of one-to-one and group formats, delivered by hybrid or face-to-face delivery. An area of complementarity is revealed in the interviews, as participants spoke of many negatives associated with the one-to-one format such as attendees becoming

Table 5.2 - Presentation of quantitative and qualitative results from mixed methods study

	Quantitative*	**Qualitative**	**Meta inferences and interpretation**
Format	**Most preferred:** • Mixture of 1:1 and group (72% of all participants)	**Mixture:** • Option to develop deeper friendship outside of group • Options are good **1:1** • Overdependence • Poor match • Unfair obligation	• Areas of **expansion** as qual data helped explain the quant results. Quant results showed a majority of participants (72%) most preferred a mixture and qual results showed the advantages of this format, which were the options to develop deeper friendships outside the group and the desirability of having options. • Areas of **complementarity** as qual results identified disadvantages of 1:1 as there is a tendency for overdependence, some matches are poor and PSVs can feel an unfair obligation in their role.
Delivery	**Most preferred:** • Face-to-face (88%) and hybrid (80%) **Least preferred:** • Social media (63%)	**Face-to-face:** • Importance of human connection **Hybrid:** • Importance of flexibility **Virtual:** • Easy to access from home but interactions can be impersonal	• Areas of **expansion** as quant results showed participants most preferred face-to-face (88%) or hybrid (80%) delivery and quant results expanded on advantages. These included the importance of human connection in face-to-face delivery and the importance of having flexible choices. • Areas of **complementarity** as quant results also revealed social media was the least preferred delivery mode (63%) and a disadvantage that virtual interactions can be impersonal. • Area of **divergence** as qual results found an advantage of virtual interactions as they are easy to access.
Dosage	**Duration:** • Adults with CP: 6+ months (43%) • HCPs: 6 months (29%) **Frequency:** • Once every 2 weeks (44%)	• Want consistent and ongoing PSI	• Areas of **expansion** as quant results illustrated participants wanted a duration of 6 months or longer and qual results showed participants wanted consistent and ongoing PSIs.
Topics	• Self-management strategies (19%) • Making sense of one's pain experience (17%) • Exercise and physical activity (17%)	• Want clarity on aims and intended benefits of PSI • Have content that is both related to pain (coping and health education) and unrelated to pain (activities can be good distractions)	• Areas of **complementarity** as quant results revealed participants were interested in several topics, most importantly self-management strategies along with how to make sense of one's own pain experience and exercise and physical activity. Qualitative results clarified participants wanted to have content both related and unrelated to pain because activities can be good distractions.

Matching characteristics	**Most important:** • Chronic condition (71%) • Age group (51%) • Interests (51%) **Unimportant:** • Political views (76%) • Race (72%) • Sexuality (70%)	• Important to find someone from a similar life stage or interests in order to relate and share practical advice • Have the option to switch	• Areas of **expansion** as the majority of participants found it most important to match on chronic condition, age group and interests and qual results clarified participants valued these similarities in order to relate to someone they can actually share practical advice with. • Areas of **complementarity** as quant results also found the following characteristics unimportant: political views, race and sexuality.
PSV training	**Yes/no:** • Yes (92%) **Amount:** • 8+ hours (43%)	• Training is important • Include mental health first aid • Include how to share your story in a helpful way	• Areas of **expansion** as quant results showed 92% of participants wanted training provided to PSVs and qual results showed participants believed training was important and should include mental health first aid and how to share your story in a helpful way
Barriers and Facilitators	**Barriers:** • Worries about meeting new people (22%) • Transportation difficulties (20%) • Technological issues (20%) • Interest (17%) • Lack of time/difficulty scheduling (16%) **Facilitators:** • Facilitators of the meeting are helpful and friendly (29%) • Meeting with another person you can relate to (26%) • Meeting is held in a convenient location (26%)	**Barriers:** • Condition-related ○ Impact of pain flares, fatigue, fluctuating pain levels, limited focus or energy • Logistical ○ Poor awareness or promotion of PSIs, access and familiarity with smart devices/internet, funding, travel costs • Personal (both inter and intra) ○ Relying on others for transport, hesitancy to meet new people or be vulnerable with others, emotional toll of listening to others' problems **Facilitators:** • Logistical ○ Central and accessible location	**Barriers:** • Areas of **expansion** as quant result of transportation difficulties connected with all 3 types of barriers in quant results. Participants expanded that transportation can be difficult due to condition-related reasons like pain flares (particularly due to being in a seated position), fatigue, and fluctuating pain levels. Participants also identified the logistics of travel costs and the personal barrier of relying on others for transport. • Area of **expansion** as participants also identified technological issues in quant results and clarified both condition-related reasons for this can be limited focus or energy to engage with a screen and logistical reasons of access and familiarity with smart devices/internet • Area of **expansion** as quant results found participants had worries about meeting new people and qual results expanded that could be related to a hesitancy to be vulnerable. • Area of **complementarity** as qual results also discussed the emotional toll of listening to others' problems. **Facilitators:** • Area of **complementarity** as quant results found participants wanted to meet with another personal they related to, and

		○ Adequately promoted ○ Timely access to PSI • Socio personal ○ social period ○ build friendships ○ share personal experiences	qual results also stressed the importance of a social period to build friendships and share personal experiences. • Areas of **expansion** as quant results identified importance of meeting held in a convenient location and qual results further clarified the logistics of it being central and accessible.
Findings unique to qualitative phase			
Organization of PSI	Not explored in quantitative phase	• Have input from those with lived experience	
Individual needs and preferences		• Not everyone with CP wants or needs formal PSI • Determine potential attendee preferences for design and delivery components	
Consequences		**Benefits:** • Positive outlook • Practical support or advice • Social support • Reduced loneliness • Sense of purpose • Importance of community and shared experience **Disadvantages**: • Fixation on pain and pessimism • Burden on the PSV • Poor peer dynamics • Fear of a worsening condition • Inaccurate information	
Need for PS		• NHS is unable to provide the long-term support that people with chronic pain need	
Impact of COVID-19		• Reduction in F2F contact with HCPs	

Views from participants (mixed)		• Benefits and challenges of dual perspective • Current HCP training programmes are inaccessible to people in CP	
What is PS		• Educational • Supportive • Reciprocal helping • Community • Shared understanding	

*unless otherwise noted, all preferences reflect the views of both participant groups, % is an average between the 2 groups

Key: CP=chronic pain, HCPs=healthcare professionals, PS=peer support, PSI=peer support intervention, qual = qualitative, quant = quantitative overdependent on PSVs, negative outcomes of matches and PSVs feeling unfairly obligated to a pain service. This may explain why a mixture of one-to-one and group, and not solely one-to-one format, was ranked highly in the survey. Previous studies on PSIs with adults with chronic pain have reported similar findings of one-to-one matches not always being successful (Sandhu, S. et al. 2013; Kumar et al. 2011a; Arnstein, Paul et al. 2002). Psychosocial challenges were oftentimes discussed such as some PSVs struggling with providing the correct level of engagement with their attendee as their desire to help sometimes exceeded their ability to help (Arnstein, Paul et al. 2002). Other reasons for failed matches related to challenges in building rapport due to differences in gender, sexuality, political views and disease stage (Sandhu, S. et al. 2013).

Exemplifying an area of expansion, participants provided reasons for wanting flexible offerings as barriers to attendance such as physical and logistical barriers made it difficult to consistently attend in-person gatherings. Participants were still keen to participate and appreciated a virtual attendance option. This finding is in keeping with an earlier study (Cooper et al., 2020) which found that older adults with chronic low back pain also deemed at least one face-to-face meeting to be essential. Indeed, interview participants also spoke of the importance of human connection as part of their reasoning for desiring a face-to-face meeting, demonstrating expansion. Furthermore, the survey found that social media was the least preferred delivery mode. Interview participants noted virtual interactions can be impersonal and disliked the negativity and competition in being unwell that exists on some discussion forums, illustrating expansion. These are all important considerations in light of the impact of COVID-19 and the significant increase of virtually delivered healthcare (Stamenova et al. 2022).

In order to consider the most appropriate mode of delivery for a PSI, a brief observation of the benefits and disadvantages of virtually delivered healthcare will now be provided. With regard to benefits, virtual healthcare provides a potential solution to the many global healthcare systems struggling to meet the demands of populations that are aging and increasingly complex (Figueroa et al. 2019). Virtual healthcare can provide more efficient and accessible delivery of services to those in rural areas or with restricted transportation options or who are simply less mobile for any number of reasons (Harrison, Clay-Williams and Cardenas 2022). This virtual delivery can also save costs on transportation for consumers of healthcare services (Harrison, Clay-Williams and Cardenas 2022). Regarding disadvantages, these involve ethical and social issues in relation to growing health inequalities among marginalized populations including people with sensory or cognitive impairment or low technology literacy or familiarity (Hughes et al. 2022). Disadvantages have also been noted in virtual patient-provider interactions, described in one scoping review as an “incomplete two-way interaction” (Babaei et al. 2023). Babaei et al. went on to describe the differences in virtual communication compared to face-to-face interactions reporting some patients felt they had unmet emotional needs and found a lack of empathetic care from the virtual interactions (Babaei et al. 2023). Providers also identified virtual fatigue and difficulty maintaining therapeutic communication with patients (Hughes et al. 2022).

Participants expressed an overall preference for hybrid delivery for a PSI in the quantitative phase and participants spoke at length about the advantages of hybrid delivery, demonstrating an area of expansion. As such, the author believes delivering a PSI as a hybrid can aid in both strengthening the benefits of virtual delivery and weakening the disadvantages as potential participants will have the option to attend virtually, face-to-face or both ways (if they are offered on separate occasions).

With regard to barriers identified by participants, there were many similarities with wider literature on PSIs for adults with chronic pain. Barriers that were similar were condition-related like pain flares (Arnstein, Paul et al. 2002) or the logistics of transportation (Arnstein, Paul et al. 2002). Several other logistical barriers were also supported such as scheduling (Kohut, S. A. et al. 2017), technology (Kohut, S. A. et al. 2017) and transportation costs (Matthias, M. S. et al. 2016).

Some of the novel barriers identified in this study, and particularly in the interviews, included the logistics of funding and adequate awareness and promotion of PSIs.

While the survey showed how participants identified barriers such as worries about meeting new people, the interviews provided valuable insight into this topic by clarifying a hesitancy to new people or situations was related to being vulnerable about sensitive topics. This is another area of expansion.

The viewpoints of participants are important to consider with the increased focus of many healthcare systems on person-centred care. Indeed, the 2012 NHS Mandate stated anyone with a long-term condition must be involved in a tailored care plan that reflected their preferences and agreed decisions (Department of Health and Social Care 2014). In order to see people as active contributors with skills and knowledge to improve their own health, their input must be valued when creating interventions. A 2019 systematic review examined publications related to perceived health information needs for adults with low back pain (Lim et al. 2019). This systematic review found that people with low back pain wanted clear, consistent and personalised information on self-management strategies (Lim et al. 2019).

Individual needs was a very common theme throughout the interviews and participants relayed that people have different needs dependent on their life stage, mental health, severity of condition and level of current support from family and friends. Participants stated it is important to determine the preferences of any potential attendees of a PSI so it’s design and delivery is bespoke to the needs of the people. The value that participants placed on individual needs presents a unique problem for organizers of PSIs as they are tasked with designing a programme that is both personalised and feasible to deliver.

5.2.2 Matching Characteristics

Considering matching characteristics for PSVs, the survey found that participants were most interested in matching with someone with a similar condition, age group and interests. In an act of expansion, this was also supported by interview participants, who further clarified the importance of matching with someone from a similar life stage such as working versus retired or with or without children. Participants observed that a retired person may provide advice that is not feasible for someone with work commitments. Political views, race and sexuality were all deemed unimportant characteristics by survey respondents and no interview participants commented on these characteristics. While not explicitly asking about matching preferences, other studies found successful matches were facilitated by similarities in condition (Cooper, K. et al. 2020; Kohut, S. A. et al. 2017; Sandhu, S. et al. 2013) along with in age, gender, personality, interests and life stage (Sandhu, S. et al. 2013):

> *“You don’t have to have a lot of other things in common if you both have back pain, both have an understanding” [PSV66, Male]* (Cooper, K. et al. 2020 p. 157)

As these studies have found successful matches to be facilitated by the above-listed characteristics, it would be important for organizers of future PSIs to consider these characteristics when matching participants. With interview participants discussing a variety of preferences for what is and is not important, organizers could consider a preliminary survey for interested participants to gauge the importance of matching characteristics for those who may legitimately take part in the PSI. This could present a logistical challenge, particularly for PSIs with a smaller number of people, but a preliminary survey would at least provide organizers with a baseline idea of participant preferences.

5.2.3 PSV Training

With regard to PSV training, survey respondents agreed that training should be provided and specified a minimum of eight hours would be best. Demonstrating expansion, interview participants provided further explanation and shared that training is important and should cover mental health first aid and how to share one's story in a helpful way. This idea of valuing training in order to share one’s story in a constructive way is also supported by Kohut et al. (2017):

> *“I came into the training and that weekend kind of changed my perceptions on certain things, I guess I grew in terms of learning how to do mentoring on a higher level than if I didn’t have any training, and how to use your story in more of a constructive way.” (JIA mentor 4, aged 19, male)* (Kohut, S. A. et al. 2017 p. 966)

The training of PSVs varies extensively across the wider base of literature related to chronic conditions. Some informal PSIs provide no training (Young and Heinzerling 2017) and in the case of one diabetes PSI, participants were provided with 46 hours of training over a 12-week period (Tang et al. 2011). Many formal PSIs for adults with chronic pain provide between three (Matthias, M. S. et al. 2015) to eight hours of training (Cooper, Kay et al. 2018).

Organizers of future PSIs would have to consider the delivery of training either face-to-face or virtually, and whether to provide the training in one day or spread across multiple days. With participants’ earlier emphasis on flexibility and individual preferences, the author believes it would be important to survey potential PSVs on their preferences with regards to scheduling and delivery. Hybrid delivery could be considered with online content that could be completed at the leisure of the PSV with an additional face-to-face session with the organizer(s) of the PSI. Another consideration is competency and whether this should be assessed. The author believes testing competency is significant in relation to issues of safeguarding and a brief quiz could be used to assess PSVs.

The provision of training and potential competency testing would need to be considered in light of resources and staffing available to provide the training. This would overall add to the complexity of implementing a PSI and would have to be considered by organizers of the PSI.

5.2.4 Dosage

Regarding dosage, the survey revealed that HCPs wanted a duration of six months and adults with chronic pain wanted over six months. Illustrating expansion, interview participants expanded on the reasons behind a desired duration as all participant groups agreed a PSI should be consistent and ongoing and observed that people with chronic pain need long-term support and the NHS is currently unable to provide this. Considering the wider context, NHS pain management group durations were previously based on guidelines of a minimum number of hours; directed by a 2013 evidence-based review from the British Pain Society's 2013:

> *"For commissioning purposes, it is recommended that a standard peer management programme should be the equivalent of twelve half day sessions (e.g.12x3 = 36 hours) though as outlined in 1.10, needs may vary in practice and allowances made. Longer, more intensive programmes give greater and more enduring benefit but intensive programmes are not recommended as standard for all patients."* (The British Pain Society 2013 p. 9)

However, the British Pain Society provided a 2019 update to these guidelines, recognizing that longer programmes typically produce greater changes for a person and observing the limiting factors of economies of time, staff skills or other resources, which can all contribute towards reduced effectiveness of a programme:

> *"Greater length and intensity of programme usually achieve greater change. Economies of time, staff skills or other resources risk reducing the effectiveness of the programme towards zero; however, it is not possible to specify a minimum number of hours as change results from the interaction of participant needs and staff skills during treatment."* (The British Pain Society 2019 p. 4)

Evidently these guidelines are for pain management programmes, which share a similar aim to PSIs which is to enhance the quality of life of people with chronic pain by improving their physical, emotional and social dimensions of health and improving self-management skills (The British Pain Society 2019). Pain management programmes can differ from PSIs in that they are typically group-based but could also include an element of peer support.

Pain management programmes are focussed on producing behaviour change and include methods grounded in cognitive and behavioural therapy, learning and conditioning processes, education, skills training and exercise (The British Pain Society 2019). This thesis has already explored how PSIs can vary greatly, but when considering an appropriate dosage, one must also evaluate whether an intervention is underpinned by a theory such as behaviour change. In order to best design and implement a self-management intervention like a PSI, it is vital to possess a strong theoretical understanding of how the intervention will cause change (Hancock and Hill 2016). Without this, the intervention may be driven by pragmatics instead of a grounded theoretical foundation which could in turn impact the effectiveness of the intervention. If a PSI is underpinned by behaviour change theory, an organizer must consider what dosage is appropriate to actually impact behaviour change.

5.2.5 Befriending application and HCP training

When asked what her ideal PSI would look like, one participant (mixed) suggested a platform similar to Tinder but for finding friends with chronic pain. She was keen to find others with her diagnosis and shared interests. There are a number of websites and phone applications used globally for people to find friends with similar hobbies or personalities. Applications like Meetup, Friender or Bumble BFF help individuals get connected virtually with the option to meet face-to-face. The author saw the potential for one of these applications or perhaps a new application with an added characteristic of chronic condition to help people find one another. To the author’s knowledge there are not currently any applications for people with chronic pain to connect with one another.

An application like the one described above could be especially helpful for younger adults with chronic pain, as multiple younger participants relayed they had tried visiting a chronic pain group and realized most people were 50-60 years of age and older. Participants expressed frustration at not being able to relate to those in such a different life stage. This same sentiment was reported by young adults (aged 18-29) in a study aimed at understanding the information and service needs of young adults with chronic pain (Stinson et al. 2013). The young adults stated chronic pain management programmes were tailored towards older adults and as such were not meeting their distinctive developmental needs, as described by one participant:

> *"I did the CBT…but the problem…at the time I believe I was 23 and the next youngest person in the group was like 65 and it was just a really bad fit…it was 10 session therapy with like how to change your behaviors and instead they wanted me to do it on my own because there was no purpose for me to be there, the people are crying [because] they can't pick up their grandchildren…just like no connection."* (Stinson et al. 2013 p. 608)

An application could also be beneficial for those in more rural areas or who are more housebound but still interested in using technology to find friends.

Another participant (mixed) observed the lack of HCP training programmes that are accessible to people with chronic pain. She noted that occupational therapists and physiotherapists are frequently working with people in chronic pain, but the training programmes for these two professions are only offered full-time and are thus not feasible for someone in chronic pain due to pain flares and a need for flexibility. Indeed, she believed it would be highly beneficial to have more HCPs with experiential knowledge of chronic pain, but there is a huge shortage. The author believes this is a valuable suggestion to make HCP training programmes more accessible such as offering part-time options. The NHS has become strained with increasing numbers of ageing and complex patients, along with challenges to recruit and retain HCPs (Papanicolas et al. 2019). Making training programmes more accessible to a wider range of people could help to alleviate some of this pressure on the NHS.

5.2.6 Recommendations for a Future Intervention

This study gathered valuable input from stakeholders on an array of aspects related to the design and delivery of a PSI. Based on the findings of this study, the author has produced the table below (Table 5.3) which includes recommendations for a variety of aspects related to a PSI.

Table 5.3 PSI Aspects and Recommendations

Aspect of a PSI	**Recommendation**
Development and implementation	Coproduce with adults with chronic pain
Promotion	-Promote PSI in multiple ways from social media, newsletters and word of mouth -Promote beyond the pain-related sector with GPs, HCPs and mental health providers
Individual needs	Offer a preliminary survey to potential participants to discern their needs and preferences
Scheduling	Offer multiple timeframes to suit people from different stages of life
Mode of delivery	-Offer as many delivery modes as possible (face-to-face, online, option for follow up via messaging or phone calls) -Minimum of one face-to-face meeting
Meeting format	Mix of group and one-to-one meetings
Location and environment	-Centrally located -Physically accessible -Comfortable furniture and surroundings
Matching characteristics	-Match based on similar life stage and interests -Provide option to switch
PSV	-Provide training on mental health first aid and how to share story in a helpful way
Content	-Aims and intended benefits should be clearly communicated -Content that is both related to pain (self-management strategies) and unrelated to pain (activities)
Timely access	Wait list for PSI should be no longer than 1-2 months
Flexible and welcoming	No judgment or obligation when pain flare prevents attendance

5.3 Strengths and Limitations of the Research

5.3.1 Strengths of the Research

With the prevalence of chronic pain increasing in the UK (Fayaz et al. 2016) and globally (Abrams, E. M. et al. 2020), and healthcare systems struggling to meet demands (Figueroa et al. 2019), this thesis provides valuable insight into the views of adults with chronic pain and HCPs regarding their preferences on the design and delivery of PSIs. Combining both quantitative and qualitative data helped to fully represent the perspectives of these two populations in order to make recommendations for the design and delivery of a future PSI for adults with chronic pain. Strengths regarding the rigour of the research can be viewed in Table 5.4 and additional strengths are discussed in narrative form below. Overall, the author strived to conduct research that was transparent and auditable for both the survey and interview. For example, the survey was publicly available online during recruitment and could still be requested from the author in order to maintain reliability. The interview schedule is also available upon request from the author and the author kept regular meetings with her advisor in order to discuss study processes and decisions to uphold dependability.

Within the qualitative component of the study, utilizing framework analysis was a strength as it provided systematic and comprehensive coverage of the data, meaning every unit of analysis (interview excerpt) was given the same standardized 'treatment.' Framework analysis was also beneficial as there was a clear and complete audit trail of all stages of analysis, providing transparency for the progression of interview excerpts all the way to synthesised findings. Having transparent and auditable stages of data analysis is important for proving rigorous qualitative analysis (Green and Thorogood 2018).

For both quantitative and qualitative recruitment, a robust and multipronged strategy was implemented across virtual and physical platforms, both inside the NHS and through several third-party organizations, resulting in a diversity of experiences and viewpoints being represented in both the survey and interviews. Indeed, the inclusion of both adults with chronic pain, HCPs and participants (mixed) added to the breadth of perspectives shared. Offering the survey and interviews virtually provided the added benefit of reaching a broader geographical area across the UK. Implementing a pragmatic approach enabled the author to fully address the research questions in a previously unexplored area of assessing stakeholder preferences.

Regarding the sample, the recruitment strategy garnered a representative spread of participants with regard to age, geographic area of the UK, IMD and chronic painful conditions. Women are statistically more affected with chronic pain than men, with some

Table 5.4 Research rigour and means to support survey and interview phases (adapted from *(Tuckett 2005)*

	Reliability Research was conducted in a transparent way that can be audited and replicated	**Validity** Findings reflect an accurate interpretation of the data	**Generalizability** Findings can be applied to similar population outside the study	**Objectivity** Awareness and mitigation of the researcher's position and influence
Survey	-Publicly available online and available from author on request -Replicable	-Face validity of survey questions	-Sample was representative of the CP population	-Objective administration and analysis of survey
	Dependability Research was conducted in a transparent way that can be audited and replicated	**Credibility** Findings are correct and accurate	**Transferability** Findings can be applied to other contexts	**Confirmability** Confidence that the findings reflect the participants' narratives and not the researcher's bias
Interviews	-Same set of base questions for semi-structured interviews -Interview schedule available from author on request -Regular research meetings to review study process and decisions -Kept record of processes and decisions available for external audit	-Multiple analysts in all study phases -Resolved any coding differences through discussion and consensus -Participants comfortable to share views	-Purposeful sampling	-Direct quotations from participants used to support findings

estimates finding up to 70% of people with chronic pain are women (Samulowitz et al. 2018). Between the survey and interviews for adults with chronic pain, the participants averaged 84% female, as such females were slightly over-represented. Additionally for the survey and interviews, 75% of HCP respondents were female, although considering 75% of respondents were physiotherapists, this is also representative of a female-dominated profession (Health and Care Professions Council 2018).

Conducting a mixed methods study provided several strengths by combining both qualitative and quantitative data. One strength is triangulation from both sets of findings, which increases the overall validity and credibility of the results (Creswell, John W. and Plano Clark 2011). Using both methods can also provide a more comprehensive picture of the phenomenon of peer support. The qualitative findings were helpful in explaining the quantitative findings as discussed above in Section 5.2.

5.3.2 Limitations of the Research

One potential limitation was digital exclusion as the survey and interviews were offered online and there are individuals without either access or familiarity with the internet and/or smart devices. The scale of digital exclusion is oftentimes reported as the percentage of ‘internet non-users’ and in the in the UK this number has almost halved since 2011 but remains a notable 10% of the UK population (Office for National Statistics 2019). This limitation was mitigated in also offering the survey and interviews via a phone call, or a mutually convenient location if a participant had requested this option in the local area. Three participants chose to do the interview by phone call instead of video. Therefore, the author is confident that this potential limitation was mitigated at least in part, although it is not possible to know whether participants were excluded based on this phenomenon.

Another limitation included failing to recruit to the a priori target set for the survey as the original aim for HCPs was 30, when in actuality 21 HCPs completed the survey. As recruitment was conducted in the summer of 2022, the UK healthcare system was still in a state of unprecedented pressure due to several reasons such as COVID-19 and the great number of studies vying for input from HCPs. Other potential pressures on HCPs included recruitment and retention issues in the NHS, staff illness due to COVID-19 whilst trying to remobilise services and perhaps even reduced morale of staff in response to the many demands previously listed.

Also related to participant numbers, the two participant groups were unbalanced with 44 adults with chronic pain and 21 HCPs completing the survey. Another limitation related to the survey was that it was not validated, although there were no validated surveys related to the topic of interest and a bespoke survey was necessary due to the exploratory nature of the research.

The survey was piloted by two adults with chronic pain (aged 30 and 68) who provided feedback on the content of the survey. Ideally, multiple rounds of piloting conducted with target populations would have added to the validity of the survey. Additionally, inclusion of a more diverse group would have supported survey development, for example conducting a preliminary Delphi study to ascertain the views of international experts. However, this was an unfunded study and time was also a limiting factor. Conversely, the survey was informed by the results of the systematic review of the evidence-base, along with the expertise of the supervisory team which included an academic with experience in chronic pain (Victoria Park), a researcher with peer support expertise (Kay Cooper) and the Scottish lead for chronic pain (Nicola Rhind). Creating bespoke surveys is also not unusual in survey research (Gohel et al. 2021; Carroll et al. 2020; Saggers et al. 2019) as validated tools are not always available.

Two children (both aged 11) also piloted the survey and provided feedback on the readability of the survey. Health Education England recommends piloting health information with 11–14-year-olds as this is the average reading level for the majority of adults in the UK (NHS Health Education England 2020). Piloting a survey is important in order to ensure questions are clearly articulated and response options are relevant (Ruel, Wagner and Gillespie 2015). Piloting also helps to confirm that researchers and respondents are interpreting questions in the same way (Ruel, Wagner and Gillespie 2015). Finally, piloting allowed the author to determine the response latency or the amount of time needed to complete the survey, which could then be reported in the introduction to the survey (Ruel, Wagner and Gillespie 2015).

With regard to the interviews, the author had limited interview experience although she did attend a seminar on conducting qualitative interviews and completed multiple pilot interviews, both of which were valuable learning opportunities. Three out of the 19 interviews were conducted via telephone instead of video so facial expressions and body language were unable to be viewed. Participants were still actively engaged in the interview and still seemed keen to share their perspectives. The remainder of the interviews were conducted as video calls via Microsoft Teams, which also could have limited detection of more nuanced body language, although video interviews are now frequently used in qualitative research (de Villiers, Farooq and Molinari 2022).

The order of the research should also be discussed. Preliminary interviews could have been conducted initially to inform the development of the survey, which would have been a sequential exploratory study. However, the pre-existing evidence base (Arnott, Park and

Cooper 2021) provided adequate direction for the intervention components that could be explored in a survey so a sequential explanatory study was deemed more suitable. The final limitation relates to how representative participants were of the studied population.

Gender representation was already discussed as a strength, but beyond gender, the prevalence of chronic pain also increases with age, deprivation and in certain ethnic minority groups (Fayaz et al. 2016). As demographic information was not collected with relation to ethnicity, the participant perspectives, results and recommendations cannot be generalised to specific population subgroups. It is unlikely this study achieved a representative spread of the diversity of the UK.

Ethnic and socio-cultural factors are important to consider in the development of a PSI as it is a complex intervention. In order to be effective and successfully reach a relevant target population, complex interventions must be purposefully developed and implemented (Pfadenhauer et al. 2017). Indeed, in 2017 an EU-funded project titled Integrated Health developed the Context and Implementation of Complex Interventions framework. This framework identified seven domains that should be considered with regard to the context of a complex intervention, these domains are: geographical, epidemiological, socio-cultural, socio-economic, ethical, legal, political (Pfadenhauer et al. 2017).

Survey and interview questions on demographics used verbatim questions from the Scottish Health Survey, although in the interest of making the survey accessible and considerations of time sensitivity, not all questions on demographics, race and ethnicity were included. The author recognises this limitation and would choose to include questions on ethnicity in future studies. Increased efforts by the Journal of the American Medical Association have called for the reporting of race and ethnicity in medical and science journals: “for articles published in medical and science journals, language and terminology must be accurate, clear, and precise, and must reflect fairness, equity, and consistency in use and reporting of race and ethnicity” (Flanagin, Frey and Christiansen 2021, p. 624). Furthermore, if the author were to repeat this study, she would choose to include questions on ethnicity.

5.4 Complex intervention development

The MRC framework laid out complex intervention in a series of phases that are not always sequential but do include: “development or identification of an intervention, assessment of feasibility of the intervention and evaluation design, evaluation of the intervention, and impactful implementation” (Skivington et al. 2021). Each phase must consider the following six questions (Skivington et al. 2021, p. 624):

- How does the intervention interact with its context?
- What is the underpinning programme theory?
- How can diverse stakeholder perspectives be included in the research?
- What are the key uncertainties?
- How can the intervention be refined?
- What are the comparative resource and outcome consequences of the intervention?

This study can be used as a first step to inform the development a complex intervention. Concerning the first question, context can include several different dimensions such as physical, organisational, cultural, social and features of the healthcare system in which the intervention is implemented (Skivington et al. 2021). This study revealed stakeholder preferences, the main recommendations of which can be viewed in Table 5.3. Regarding the physical context, stakeholders wanted the PSI to be delivered in hybrid formats and a physical location to be centrally located, physically accessible and with comfortable furniture and surroundings. Stakeholders also desired the organisation of the PSI to be a coproduction between HCPs and people with chronic pain. Other features of context such as cultural and the healthcare system would have to be considered based on the locale of an actual proposed intervention.

For the second question, Davidoff et al. defines a programme theory as follows:

> “A fully specified programme theory for an improvement intervention thus combines an (often diagrammatic) account of the intervention's components together with a narrative about the structures, behaviours, processes and contextual features that will be needed to achieve the aims and actions of the intervention.” (Davidoff et al. 2015, p. 230)

This research was not developing a programme theory, rather it was the first step to understanding the preferences of stakeholders so that these findings can then be used to coproduce an intervention. As such, the development of a programme theory is outwith the scope of this study.

On to the third question, diversity can look many ways and while this research had a diversity of conditions and geographical areas represented, demographic information was not collected and this has already been discussed in the limitations. Again referring to the recommendations displayed in Table 5.3, wherever a proposed intervention would be delivered, the author recommends offering a preliminary survey to potential participants to discern their needs and preferences. This survey could include a demographic section in order to ensure a diversity of potential participants are having their voices heard.

Regarding the fourth question on uncertainties, the systematic review found limited research had been conducted on assessing patient preferences regarding the components of peer support; specifically no evidence was found in the areas of intervention format, length of intervention and frequency of contact between PSVs and participants. This primary research helped to address these uncertainties and present stakeholder preferences on the previously mentioned components. Further uncertainties were also identified such as funding, resources and staffing.

Concerning the fifth question on intervention refinement, this research again has made recommendations for a PSI which could inform a pilot study to be coproduced with adults with chronic pain. Further refinement would also be guided by the development of a programme theory and feasibility and acceptability piloting of an intervention.

In contrast to a programme theory which is defined above and outwith the scope of this study, a theory such as behaviour change and the use of the behaviour change wheel could be used in the refinement of the intervention. The purpose of the behaviour change wheel is to guide intervention developers so they are equipped with how to best design an intervention with an awareness of the nature of the behaviour to be changed. This would help to provide a foundation for the intervention and consider the full range of possible influences on behaviour. To incorporate the COM-B system, developers of an intervention can consider how to optimally modify capability, opportunity and motivation as the intervention is being refined.

The final question on comparative resource and outcome consequences, or the economic evaluation of an intervention was outside of the scope of this study. Stakeholders did identify funding as an important factor and potential limitation, but further piloting with a focus on cost-benefit analysis would be required to fully address this question. Indeed, Barnett et al. reported that early involvement of economic expertise is helpful in identifying the scope of costs and benefits to address questions that are important to decision-makers (2020).

Overall, this study can be used as a first step to inform the development a complex intervention. Next steps can be viewed in the recommendations for further research listed below.

5.5 Recommendations for practice

The recommendations provided in Table 5.2 can be used by organizers of PSIs.

5.6 Recommendations for future research

A number of recommendations for future research can be made, including:

- Coproduce a PSI with adults with chronic pain. This should involve a representative group of adults with chronic pain, working with a research team and might use methodology such as intervention mapping.
- Develop, pilot and evaluate a PSI incorporating the key findings from this research.
- Consideration of the barriers and facilitators identified in this study is also crucial for future research.
- Coproduce a befriending app for people with chronic pain.

5.7 Original contribution to knowledge and impact

This was the first study to explore stakeholder preferences on several PSI intervention components, namely meeting format, role of the PSV, length of intervention and frequency of contact between PSVs and participants. The findings and recommendations produced by this study are significant for organizers of PSIs to be cognizant of the preferences of stakeholders in order to design and implement PSIs that are best suited to the needs and preferences of stakeholders. The participants in this study with chronic pain were keen to have their voices heard and stressed the importance of further support needed for people with chronic pain:

> *"I think there's a huge need for this. I think there's a massive, massive gap. And that's why I've agreed to do this interview. I think there's a massive gap in the provision of services for people in pain and a huge opportunity for peer support to make a difference." (PwCP 4- 58-year-old female, 20 years FM)*

Set forth by the UK Research and Innovation (UKRI) Body, quality research must demonstrate contributions that are academic, economic and societal (2019). In order to maximise the application of research and ensure its impact, the UKRI body recommends this should be done through the sharing of knowledge and innovation, developing new and improving existing policies and public services as well as enhancing the quality of life and health (2019). Table 5.5 illustrates the pathways to impact and the evidence provided in this thesis.

This thesis demonstrated personal academic impact as it improved the author's research experience over the course of 3 years. The author attended numerous online workshops and training sessions to enrich her knowledge of methods and methodology, communication, presentation skills and academic writing.

Table 5.5 Pathways to impact and supporting evidence in this thesis

Level of impact	**Evidence**
Academic	contribute novel research to the subject area and disseminate knowledge to research participants, wider stakeholders and the public
Economic	successful PSI could reduce cost to an individual (by improving functional level), health systems and the wider economy (after further research to coproduce and test a resulting intervention)
Societal	Potential for improved health, wellbeing and quality of life for adults with chronic pain

5.8 Reflexivity

Reflexivity refers to a researcher's awareness of the effects of his or her own experiences, biases and values in a qualitative study (Creswell, J. David and Creswell 2023). In an effort to minimise researcher bias, the author's research supervisor was consulted throughout the development, piloting and conducting of the interviews. The supervisor was also involved in reviewing every stage of the framework analysis. During interviews, approximately seven participants asked the author about her motivations for conducting the research and she in turn shared about her previous work as a medical scribe in a pain clinic along with her current position as a physiotherapist in the NHS. The author considered whether any of these participants would feel hesitant to share negative views of physiotherapy or the NHS. The author aimed to develop good rapport with each participant to ensure a comfortable interviewing environment, and multiple participants evidently were comfortable as they did share negative views of physiotherapy and the NHS.

The author also considered whether her work in a pain clinic or as a physiotherapist contributed towards any preconceptions or bias to the study. The author's experience in the pain clinic was her initial catalyst to do research in chronic pain as opioids were commonly prescribed and very few patients were encouraged to engage with other management options such as physiotherapy, psychological support or support groups. The author was keen to investigate other management options (in the form of peer support) but also strived to remain neutral as she heard the stories and experiences of both adults with chronic pain and HCPs.

5.9 Summary of Chapter

This chapter discussed the key findings of the study, which related to the overarching themes of flexibility and individual preferences of stakeholders. The findings were considered in relation to the existing evidence base and a list of recommendations was provided for a future PSI. Strengths and limitations of the study were identified along with an examination of how this study contributed original knowledge. The next and final chapter will provide a conclusion to the study as a whole.

6 CHAPTER 6: CONCLUSION

Set out in chapter one, this thesis aimed to address some of the notable gaps in the current research base on peer support for adults with chronic pain. A major gap was identified in the 2015 evidence summary of peer support conducted by Nesta (Nesta 2015). This gap related to what kinds of PSIs are most appealing to participants. The author's systematic review (Chapter two) examined existing literature on adults with chronic pain and their experiences of participating in peer support interventions (Arnott, Park and Cooper 2021). The qualitative systematic review (Chapter two) presented findings related to participant preferences on delivery and PSV training, but no evidence was found on the remaining intervention components, namely the meeting format, role of the PSV, length of intervention and frequency of contact between PSVs and participants. This review demonstrated there were significant gaps in the research that must be addressed. These included understanding the perceptions of those that develop and participate in peer support interventions. This information is crucial for healthcare services, charities and community groups to be able to develop and implement interventions that are both feasible and optimally beneficial for those involved.

The mixed methods study (Chapters 3 and 4) therefore explored PSI components and to the author's knowledge was the first study to explore in this way participant preferences on meeting format, role of the PSV, length of intervention and frequency of contact between PSVs and participants. The key findings from the mixed method study were focussed on participants expressing a desire for PSIs to be flexible and delivered in multiple ways. Participants wanted programmes with flexible scheduling, offered in as many delivery modes as possible (face-to-face, online, option for follow up via messaging or phone calls) and without obligation or judgment when pain flares prevented their attendance. Participants also expanded on the reasons for wanting flexible offerings as barriers to attendance such as physical and logistical barriers made it difficult to consistently attend in person gatherings. Participants shared how chronic pain can affect people across the lifespan, so it is valuable to talk with someone from a similar life stage (retired versus working, with or without children). Finally, participants placed high value on individual preferences and suggested whenever a programme is being developed, for organizers to receive input from potential attendees.

This research has generated new knowledge which can be used to make recommendations for the design and development of peer support interventions tailored to adults with chronic pain. This information is crucial as chronic pain is a prevalent and costly issue (Abrams, Elissa M. et al. 2020) and strained healthcare systems like the NHS are struggling to meet the demands of increasing numbers of ageing and complex patients (Papanicolas et al. 2019). The NHS and other healthcare systems can utilise PSIs as an alternative way to support people living with pain and value person-centred care. Additional exploratory work is required to coproduce, pilot and evaluate a PSI incorporating the key findings from this research.

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APPENDIX I – LITERATURE REVIEW SEARCH STRATEGY

Database (& date searched)	Search Terms	Records Retrieved
CINAHL (EBSCO) 27.9.22	1. MH "Chronic Pain" OR KW "chronic pain" OR MH "Pain" OR TX “persist* pain” OR TX "long term pain" 2. MH “peer counseling” OR MH “peer group” or KW “peer support” OR TX “peer support*” OR TX “peer group” OR TX “peer mentor*” OR TX “peer coach*” 3. **1 and 2**	1. 123,400 2. 33,867 3. **397**
Medline (EBSCO) 27.9.22	1. MH "Chronic Pain" OR KW "chronic pain" OR MH "Pain" OR TX “persist* pain” OR TX "long term pain" 2. MH "Peer Group" OR KW "peer support" OR TX "peer support*" OR TX "peer group" OR TX "peer counsel*" OR TX "peer mentor*" OR TX "peer coach*" 3. **1 and 2**	1. 224,152 2. 34,393 3. **174**
AMED (EBSCO) 27.9.22	1. KW "chronic pain" OR TX "chronic Pain" OR KW "Pain" OR TX "pain" OR TX “persist* pain” OR TX "long term pain" 2. KW "peer support" OR TX "peer support*" OR TX "peer counsel*" OR TX "peer mentor*" OR TX "peer coach*" OR TX "peer group" 3. **1 and 2**	1. 37,186 2. 624 3. **24**

APPENDIX II - SYSTEMATIC REVIEW SEARCH STRATEGY

Database (& date searched)	**Search Terms**	**Records Retrieved**
Medline (EBSCO) April 20, 2021	1. MH "Social Support” OR TX "social support" OR MH "Peer Group" OR TX "peer group" OR KW "peer support" OR TX "peer support*" OR TX "peer counsel*" OR TX "peer mentor*" OR TX "peer coach*" 2. MH "Patient Preference" OR TX "patient preference" OR KW "patient experience" OR TX "patient experience" OR TX "patient perception" OR AB attitude* OR AB opinion* OR AB experience* OR AB perspective* OR AB view* OR AB feeling* OR AB thought* 3. MH "Chronic Pain" OR KW "chronic pain" OR MH "Pain" OR KW "pain" OR MH “Arthritis, rheumatoid” OR TX arthritis* OR MH “Fibromyalgia” OR TX fibromyalgia OR TX “persist* pain” OR TX "long term pain" **4. 1 and 2 and 3**	1. 120,571 2. 1,964234 3. 1,237,644 **4. 1,560**
CINAHL (EBSCO) April 20, 2021	1. MH "Peer Counseling" OR MH "Peer Group” OR KW "peer support" OR TX "peer support*" OR TX "peer counsel*" OR TX "peer mentor*" OR TX "peer coach*" OR TX "social support" OR TX "peer group" 2. MH "Patient Preference" OR KW "patient preference" OR TX "patient experience" OR TX "patient perception" OR TX "patient preference" OR AB attitude* OR AB opinion* OR AB experience* OR AB perspective* OR AB view* OR AB feeling* OR AB thought* 3. MH "Chronic Pain" OR KW "chronic pain" OR MH "Pain" OR KW "pain" OR MH "Arthritis, Rheumatoid” OR TX “persist* pain” OR TX "long term pain" OR TX "chronic pain" **4. 1 and 2 and 3**	1. 85,192 2. 659,581 3. 332,511 **4. 1,553**
AMED (EBSCO) April 21, 2021	1. KW "peer support" OR TX "peer support*" OR TX "peer counsel*" OR TX "peer mentor*" OR TX "peer coach*" OR TX "social support" OR TX "peer group" 2. KW "patient preference" OR TX "patient preference OR TX "patient experience" OR TX "patient perception" OR AB attitude* OR AB opinion* OR AB experience* OR AB perspective* OR AB view* OR AB feeling* OR AB thought* 3. KW "chronic pain" OR TX "chronic Pain" OR KW "Pain" OR TX "pain" OR TX *arthritis OR TX “persist* pain” OR TX "long term pain" OR TX fibromyalgia **4. 1 and 2 and 3**	1. 3,873 2. 32,387 3. 39,105 **4. 81**

EmBase (Ovid) April 28, 2021	1. KW "peer support" OR TX "peer support*" OR TX "peer counsel*" OR TX "peer mentor*" OR TX "peer coach*" OR TX "social support" OR TX "peer group" 2. KW "patient preference" OR TX "patient preference OR TX "patient experience" OR TX "patient perception" OR AB attitude* OR AB opinion* OR AB perspective* OR AB view* OR AB feeling* OR AB thought* 3. KW "chronic pain" OR TX "chronic Pain" OR KW "Pain" OR TX "pain" OR TX arthritis OR TX “persist* pain” OR TX "long term pain" OR TX fibromyalgia **4. 1 and 2 and 3**	1. 63,155 2. 1,524,419 3. 1,234,16 4. **695**
PsycArticles (EBSCO) April 28, 2021	1. DE "Social Support" OR DE "Peer Tutoring" OR DE "Peer Counseling" OR TX "peer support*" OR TX "peer counsel*" OR TX "peer mentor*" OR TX "peer coach*" OR TX "social support" OR TX "peer group" 2. DE "Client Attitudes" OR DE "Preferences" OR TX "patient experience" OR TX "patient perception" OR TX "patient preference" OR AB attitude* OR AB opinion* OR AB experience* OR AB perspective* OR AB view* OR AB feeling* OR AB thought* 3. DE "Chronic Pain" OR TX “chronic pain” OR TX “persist* pain” OR TX “long term pain” **4. 1 and 2 and 3**	1. 22,241 2. 61,632 3. 3,125 **4. 384**
PsycInfo (Ovid) April 28, 2021	1. Peer support 2. Chronic pain 3. Patient experience **4. 1 and 2 and 3**	1. 15,127 2. 58,079 3. 4,015 **4. 6**
SPORTDiscus (EBSCO) April 28, 2021	1. KW "peer support" OR TX "peer support*" OR TX "peer counsel*" OR TX "peer mentor*" OR TX "peer coach*" OR TX "social support" OR TX "peer group" 2. KW "Patient Preference" OR TX "patient preference" OR TX "patient experience" OR TX "patient perception" OR AB attitude* OR AB opinion* OR AB experience* OR AB perspective* OR AB view* OR AB feeling* OR AB thought* 3. DE "CHRONIC pain" OR TX “chronic pain” OR TX “persist* pain” OR TX “long term pain” **4. 1 and 2 and 3**	1. 25,251 2. 210,251 3. 14,713 **4. 395**
Web of Science (Clarivate Analytics) April 28, 2021	All searched in category “Topic” (title, abstract, keyword) 1. Peer support 2. Chronic pain **3. 1 and 2**	1. 45,895 2. 121,387 **3. 230**
Google Scholar	1. Peer support	1. 4,200,000

April 28, 2021	2. Chronic pain **3. 1 and 2**	2. 2,910,000 3. 722,000 **(120 results)** First 25 pages reviewed and discontinued after 3 pages of consecutive irrelevant terms

APPENDIX III - STUDIES INELIGIBLE FOLLOWING FULL TEXT REVIEW

1. Alliance CI, Mawson E. Peer Support for Chronic and Complex Conditions. 2019.
   Reason for exclusion: Wrong study design

2. Badger K, Royse D. Adult burn survivors' views of peer support: a qualitative study. Soc Work Health Care 2010;49(4):299-313.
   Reason for exclusion: Wrong phenomena of interest

3. Badger K, Royse D. Helping others heal: burn survivors and peer support. Soc Work Health Care 2010;49(1):1-18.
   Reason for exclusion: Wrong study design

4. Bauer SM, McGuire AB, Kukla M, McGuire S, Bair MJ, Matthias MS. Veterans' pain management goals: Changes during the course of a peer-led pain self-management program. Patient Educ Couns 2016;99(12):2080-2086.
   Reason for exclusion: Wrong phenomena of interest

5. Peer to peer mentoring: Facilitating individuals with early inflammatory arthritis to manage their arthritis - Exploring learning and support needs. Journal of Rheumatology. Conference: 65th Annual Meeting of the Canadian Rheumatology Association, CRA. Quebec City, QC Canada. Conference Publication: (var.pagings). 37 (6 SUPPL. 2) (pp 1317); Journal of Rheumatology; 2010.
   Reason for exclusion: Wrong study design

6. Peer to peer mentoring: Facilitating individuals with early inflammatory arthritis to manage their arthritis. Arthritis and Rheumatism. Conference: American College of Rheumatology/Association of Rheumatology Health Professionals Annual Scientific Meeting, ACR/ARHP 09. Atlanta, GA United States. Conference Publication: (var.pagings). 60 (SUPPL. 10) (pp 1366); John Wiley and Sons Inc; 2009.
   Reason for exclusion: Wrong study design

7. Peer to peer mentoring for individuals with early inflammatory arthritis: Feasibility pilot. Journal of Rheumatology. Conference: Canadian Rheumatology Association Meeting 2012. Victoria, BC Canada. Conference Publication: (var.pagings). 39 (8) (pp 1717-1718); Journal of Rheumatology; 2012.
   Reason for exclusion: Duplicate study

8. Bridgman H, Todd A, Maine G, Hardcastle S, Bird M, Radford J, et al. Piloting an interprofessional chronic pain management program: Perspectives of health students and community clients. Journal of Interprofessional Care.
   Reason for exclusion: Wrong phenomena of interest

9. Brooks JM, Umucu E, Storm M, Chiu C, Wu J, Fortuna KL. Preliminary Outcomes of an Older Peer and Clinician co-Facilitated Pain Rehabilitation Intervention among Adults Aged 50 Years and Older with Comorbid Chronic Pain and Mental Health Conditions. Psychiatr Q 2020:1-11.
   Reason for exclusion: Wrong patient population

10. Brown L. Implementation of a Peer Support Group for Adolescents with Persistent Pain. Pain Management Nursing 2017;18(2):66.
    Reason for exclusion: Wrong study design
11. Chang PF, Bazarova NN, Wethington E. How Older Adults with Chronic Pain Manage Social Support Interactions with Mobile Media. Health Commun 2020:1-13.
    Reason for exclusion: Wrong phenomena of interest
12. Cooper K, Klein S, Smith BH, Schofield P. Peer support for community dwelling older adults with chronic low back pain: a mixed-methods feasibility study. Physiotherapy 2017;103:e13-e14.
    Reason for exclusion: Wrong study design
13. Cooper K, Jehu LM, Klein S, Smith BH, Schofield P. Training peers to support older people with chronic low back pain following physiotherapy discharge: a feasibility study. Physiotherapy 2018;104(2):239-247.
    Reason for exclusion: Wrong phenomena of interest
14. Cooper K, Schofield P, Klein S, Smith BH, Jehu LM. Exploring peer-mentoring for community dwelling older adults with chronic low back pain: a qualitative study. Physiotherapy 2017;103(2):138-145.
    Reason for exclusion: Wrong phenomena of interest
15. Crotty M, Prendergast J, Battersby MW, Rowett D, Graves SE, Leach G, et al. Self-management and peer support among people with arthritis on a hospital joint replacement waiting list: a randomised controlled trial. Osteoarthritis and Cartilage 2009;17(11):1428-1433.
    Reason for exclusion: Wrong study design
16. Davison KP, Pennebaker JW, Dickerson SS. Who talks? The social psychology of illness support groups. Am Psychol 2000;55(2):205-217.
    Reason for exclusion: Wrong phenomena of interest
17. Doull M, O'Connor A,M., Welch V, Tugwell P, Wells GA. Peer support strategies for improving the health and well-being of individuals with chronic diseases. The Cochrane database of systematic reviews 2017;2017(6).
    Reason for exclusion: Wrong study design
18. Dresner, D.; Resnick, K.; Gardiner, P.; Barnett, K. G.; Laird, L. Qualitative evaluation of an integrative medicine group visits program for patients with chronic pain and associated comorbidities. Journal of Alternative and Complementary Medicine. Conference: International

Research Congress on Integrative Medicine and Health, IRCIMH 2014. Miami, FL United States. Conference Publication: (var.pagings). 20 (5) (pp A55-A56); Mary Ann Liebert Inc; 2014.
Reason for exclusion: Wrong study design

19. Druett, K.; Morris, M.; Minaur, N.; Silverthorne, C. Personal experiences of the 'living well with arthritis' self management course. Annals of the Rheumatic Diseases. Conference: Annual European Congress of Rheumatology of the European League Against Rheumatism, EULAR 2015. Rome Italy. Conference Publication: (var.pagings). 74 (SUPPL. 2) (pp 1343-1344); BMJ Publishing Group; 2015.
    Reason for exclusion: Wrong study design
20. Dunbar, M.; McCowatt, M.; Wallace, H. The effects of peer led, chronic pain education in primary care on attitudes to self-management: An NHS and third sector partnership. British Journal of Pain. Conference: 52nd Annual Scientific Meeting of the British Pain Society, BPS 2019. London United Kingdom. 13 (Supplement 2) (pp 43-44); SAGE Publications Ltd; 2019.
    Reason for exclusion: Wrong study design
21. Faith TD, Flournoy Floyd M, Ortiz K, Egede LE, Oates JC, Williams EM. My life with lupus: Contextual responses of African-American women with systemic lupus participating in a peer mentoring intervention to improve disease self-management. BMJ Open. 2018;8(11).
    Reason for exclusion: Wrong phenomena of interest
22. Finlay KA, Elander J. Reflecting the transition from pain management services to chronic pain support group attendance: An interpretative phenomenological analysis. British Journal of Health Psychology 2016;21(3):660-676.
    Reason for exclusion: Wrong phenomena of interest
23. Finlay KA, Peacock S, Elander J. Developing successful social support: An interpretative phenomenological analysis of mechanisms and processes in a chronic pain support group. Psychol Health 2018;33(7):846-871.
    Reason for exclusion: Wrong phenomena of interest
24. Fitchett, K.; Weedon, G.; Jacklin, C.; Murrell, J. Peer-to-peer innovative online training. Rheumatology (United Kingdom). Conference: Rheumatology 2015. Manchester United Kingdom. 54 (Supplement 1) (pp i144-i145); Oxford University Press; 2015.
    Reason for exclusion: Wrong study design
25. Goldenberg D, Payne LA, Hayes LP, Zeltzer LK, Tsao JCI. Peer mentorship teaches social tools for pain self-management: A case study. Journal of pain management 2013;6(1):61.
    Reason for exclusion: Wrong patient population

26. Grasaas E, Fegran L, Helseth S, Stinson J, Martinez S, Lalloo C, et al. iCanCope With Pain: Cultural Adaptation and Usability Testing of a Self-Management App for Adolescents With Persistent Pain in Norway. JMIR research protocols 2019;8(6).
    Reason for exclusion: Wrong phenomena of interest
27. Guillory J, Chang P, Henderson,Charles R.,,Jr, Shengelia R, Lama S, Warmington M, et al. Piloting a Text Message-based Social Support Intervention for Patients With Chronic Pain: Establishing Feasibility and Preliminary Efficacy. Clin J Pain 2015;31(6):548-556.
    Reason for exclusion: Wrong phenomena of interest
28. HadleyBarrows, T.; Quicke, J.; Evans, N.; Duffy, H.; Chatwin, L.; Stevenson, K.; Jones, S.; Shipway, C.; Simpson, J.; Hurley, M.; Dziedzic, K. Optimising resources for patient benefit: implementing ESCAPE-pain in collaboration with leisure and third sector community partners. A pilot study. Physiotherapy (United Kingdom). Conference: Physiotherapy UK Conference 2019. Birmingham United Kingdom. 107 (Supplement 1) (pp e122); Elsevier Ltd; 2020.
    Reason for exclusion: Wrong phenomena of interest
29. Hainsworth J, Barlow J. The training experiences of older, volunteer lay leaders on an arthritis self-management course. Health education journal. 2003;62(3):266–77.
    Reason for exclusion: Wrong phenomena of interest

30. Haldar, Shefali; Mishra, Sonali R.; Khelifi, Maher; Pollack, Ari H.; Pratt, Wanda. Exploring the design of an inpatient peer support tool: views of adult patients. : American Medical Informatics Association; 2018.
    Reason for exclusion: Wrong patient population
31. Henry, J. L.; Hutzul, G.; Forgeron, P.; Kohut, S. A. Peer-to-peer support for people with chronic pain: The need, the delivery models, and the next steps. Pain Research and Management. Conference: 2013 Annual Conference of the Canadian Pain Society. Winnipeg, MB Canada. Conference Publication: (var.pagings). 18 (2) (pp e16); Pulsus Group Inc; 2013.
    Reason for exclusion: Wrong study design
32. Khodneva Y, Richman J, Andreae S, Cherrington A, Safford MM. Peer Support Intervention Improves Pain-Related Outcomes Among Rural Adults With Diabetes and Chronic Pain at 12-Month Follow-Up. Journal of Rural Health 2021;37(2):394-405.
    Reason for exclusion: Wrong study design
33. Khodneva Y, Richman J, Andreae S, Cherrington A, Safford MM. Peer Support Intervention Improves Pain-Related Outcomes Among Rural Adults With Diabetes and Chronic Pain at 12-Month Follow-Up. The Journal of Rural Health 2020.
    Reason for exclusion: Wrong phenomena of interest

34. Kulandaivelu Y, Kohut SA. Peer Support for Adolescents with Chronic Illness. Peer Support in Medicine: A Quick Guide 2021:95-113.
    Reason for exclusion: Wrong study design
35. Kulnik ST, Pöstges H, Brimicombe L, Hammond J, Jones F. Implementing an interprofessional model of self-management support across a community workforce: A mixed-methods evaluation study. Journal of Interprofessional Care 2017;31(1):75-84.
    Reason for exclusion: Wrong patient population
36. Kumar, K.; Gordhan, C.; Situnayake, D.; Raza, K.; Bacon, P. Breaking communication barriers for RA patients of South Asian origin: The use of a bilingual audio cd and linguistically appropriate peer support. Rheumatology. Conference: Rheumatology 2010 - British Society for Rheumatology, BSR and British Health Professionals in Rheumatology, BHPR Annual Meeting 2010. Birmingham United Kingdom. Conference Publication: (var.pagings). 49 (SUPPL. 1) (pp i141); Oxford University Press; 2010.
    Reason for exclusion: Duplicate study
37. Lewis DJ, Frain KA, Donnelly MH. Chronic pain management support group: a program designed to facilitate coping. Rehabilitation nursing : the official journal of the Association of Rehabilitation Nurses 1993;18(5):318-320.
    Reason for exclusion: Wrong study design
38. Mathias B, Parry-Jones B, Huws JC. Individual experiences of an acceptance-based pain management programme: An interpretative phenomenological analysis. Psychol Health 2014;29(3):279-296.
    Reason for exclusion: Wrong phenomena of interest
39. Matthias M, Kukla M, McGuire A, Bair M. (518) Facilitators and barriers to peer support for chronic pain self-management in veterans. The Journal of Pain 2015;16(4).
    Reason for exclusion: Duplicate study
40. Matthias MS, Bair MJ, Ofner S, Heisler M, Kukla M, McGuire AB, et al. Peer Support for Self-Management of Chronic Pain: the Evaluation of a Peer Coach-Led Intervention to Improve Pain Symptoms (ECLIPSE) Trial. Journal of General Internal Medicine 2020;35(12):3525-3533.
    Reason for exclusion: Wrong study design
41. Matthias MS, Daggy J, Adams J, Menen T, McCalley S, Kukla M, et al. Evaluation of a peer coach-led intervention to improve pain symptoms (ECLIPSE): rationale, study design, methods, and sample characteristics. Contemporary clinical trials 2019;81:71-79.
    Reason for exclusion: Wrong study design
42. Matthias MS, Daggy J, Ofner S, McGuire AB, Kukla M, Bair MJ. Exploring peer coaches' outcomes: Findings from a clinical trial of patients with chronic pain. Patient Educ Couns 2020;103(7):1366-1372.

Reason for exclusion: Wrong study design

43. Matthias MS, Kukla M, McGuire AB, Bair MJ. Peer Support for Chronic Pain Self-Management: a Qualitative Study of Peer Coaches' Experiences. Journal of General Internal Medicine 2014;29:S169-S170.

    Reason for exclusion: Wrong study design

44. Matthias MS, Kukla M, McGuire AB, Damush TM, Gill N, Bair MJ. Facilitators and barriers to participation in a peer support intervention for veterans with chronic pain. Clin J Pain 2016;32(6):534.

    Reason for exclusion: Duplicate study

45. Matthias MS, McGuire AB, Kukla M, Daggy J, Myers LJ, Bair MJ. A brief peer support intervention for veterans with chronic musculoskeletal pain: a pilot study of feasibility and effectiveness. Pain Medicine 2015;16(1):81-87.

    Reason for exclusion: Wrong study design

46. Matthias MS, McGuire AB, Kukla M, Daggy J, Myers LJ, Bair MJ. Effectiveness of a Brief Peer Support Intervention for Veterans with Chronic Pain. Journal of General Internal Medicine 2014;29.

    Reason for exclusion: Wrong study design

47. Matthias MS, Miech EJ, Myers LJ, Sargent C, Bair MJ. A Qualitative Study of Chronic Pain in Operation Enduring Freedom/Operation Iraqi Freedom Veterans: "A Burden on My Soul". Mil Med 2014;179(1):26-30.

    Reason for exclusion: Wrong phenomena of interest

48. Matthias MS, Miech EJ, Myers LJ, Sargent C, Bair MJ. An Expanded View of Self-Management: Patients' Perceptions of Education and Support in an Intervention for Chronic Musculoskeletal Pain. Pain Medicine 2012;13(8):1018-1028.

    Reason for exclusion: Wrong phenomena of interest

49. McGuire AB, Powell KG, Treitler PC, Wagner KD, Smith KP, Cooperman N, et al. Emergency department-based peer support for opioid use disorder: emergent functions and forms. J Subst Abuse Treat 2020;108:82-87.

    Reason for exclusion: Wrong patient population

50. McNairy, S.; Dols, R.; Keple, T. The Benefits of Combined Peer Support Group With Buprenorphine Medication Management for Opioid Dependence. ; 2010.

    Reason for exclusion: Wrong patient population

51. Nøst TH, Steinsbekk A, Riseth L, Bratås O, Grønning K. Expectations towards participation in easily accessible pain management interventions: a qualitative study. BMC health services research 2017;17(1):712.

    Reason for exclusion: Wrong phenomena of interest

52. Park J, Hirz CE, Manotas K, Hooyman N. Nonpharmacological pain management by ethnically diverse older adults with chronic pain: barriers and facilitators. Journal of gerontological social work 2013;56(6):487-508.

    Reason for exclusion: Wrong phenomena of interest

53. Plinsinga ML, Besomi M, Maclachlan L, Melo L, Robbins S, Lawford BJ, et al. Exploring the Characteristics and Preferences for Online Support Groups: Mixed Method Study. Journal of Medical Internet Research 2019;21(12).

    Reason for exclusion: Wrong phenomena of interest

54. Richardson L-J, Molyneaux V, Murray CD. Being a peer support mentor for individuals who have had a lower limb amputation: an interpretative phenomenological analysis. Disability and rehabilitation. 2020;42(26):3850–7.

    Reason for exclusion: Wrong phenomena of interest

55. Sallinen M, Kukkurainen ML, Peltokallio L. Finally heard, believed and accepted - Peer support in the narratives of women with fibromyalgia. Patient Educ Couns 2011;85(2):e126-e130.

    Reason for exclusion: Wrong phenomena of interest

56. Salmon, V.; Hewlett, S.; Walsh, N.; Kirwan, J. R.; Morris, M.; Urban, M.; Cramp, F. Acceptability of a novel physical activity and self-management intervention for managing fatigue in rheumatoid arthritis. Annals of the Rheumatic Diseases. Conference: Annual European Congress of Rheumatology of the European League Against Rheumatism, EULAR 2015. Rome Italy. Conference Publication: (var.pagings). 74 (SUPPL. 2) (pp 1322); BMJ Publishing Group; 2015.

    Reason for exclusion: Wrong study design

57. Scherzer CR, Ranney ML, Jain S, Bommaraju SP, Patena J, Langdon K, et al. Mobile Peer-Support for Opioid Use Disorders: Refinement of an Innovative Machine Learning Tool. Journal of psychiatry and brain science 2020;5(1).

    Reason for exclusion: Wrong patient population

58. Schwartz CE, Sendor RM. Helping others helps oneself: response shift effects in peer support. Soc Sci Med 1999;48(11):1563-1575.

    Reason for exclusion: Wrong patient population

59. Schwarz F. Peer consultants: Missing link in the treatment of chronic pain. Canadian Family Physician 2015;61(10):837.

    Reason for exclusion: Wrong study design

60. Schweier R, Romppel M, Richter C, Hoberg E, Hahmann H, Scherwinski I, et al. A web-based peer-modeling intervention aimed at lifestyle changes in patients with coronary heart disease and chronic back pain: sequential controlled trial. Journal of medical Internet research 2014;16(7).

Reason for exclusion: Wrong study design

61. Shadick NA, Zibit MJ, Iannaccone CK, Thrower R, Sowell NF, Weinblatt ME, et al. A Development and Feasibility study of a peer support telephone program in rheumatoid arthritis. Journal of clinical rheumatology: practical reports on rheumatic & musculoskeletal diseases 2018;24(6):346.
Reason for exclusion: Wrong study design
62. Shigaki CL, Smarr KL, Gong Y, DonovanHanson K, Siva C, Johnson RA, et al. Social interactions in an online self-management program for rheumatoid arthritis. Chronic Illness 2008;4(4):239-246.
Reason for exclusion: Wrong phenomena of interest
63. Shue SA, McGuire AB, Matthias MS. Facilitators and Barriers to Implementation of a Peer Support Intervention for Patients with Chronic Pain: A Qualitative Study. Pain Medicine 2019;20(7):1311-1320.
Reason for exclusion: Wrong patient population
64. Simmonds MJ, Finley EP, Vale S, Pugh MJ, Turner BJ. A Qualitative Study of Veterans on Long-Term Opioid Analgesics: Barriers and Facilitators to Multimodality Pain Management. Pain Medicine 2015;16(4):726-732.
Reason for exclusion: Wrong patient population
65. Strøm J, Høybye MT, Laursen M, Jørgensen LB, Nielsen CV. Lumbar Spine Fusion Patients' Use of an Internet Support Group: Mixed Methods Study. Journal of medical Internet research 2019;21(7).
Reason for exclusion: Wrong phenomena of interest
66. Tse MMY, Yeung S, Lee PH, Ng S. Peer-assisted pain management program for nursing home residents: does it help to relieve chronic pain and enhance physical and psychological health. Journal of Gerontology Geriatric Research S 2015;3(003).
Reason for exclusion: Wrong study design
67. Tse MMY, Yajie LI, Tang SK, Ng SSM, Bai X, Lee PH, et al. A randomized controlled trial of a peer-led pain management program for older adults: Baseline characteristics and preliminary results. 2020.
Reason for exclusion: Wrong study design
68. Tse S, Mak WWS, Lo IWK, Liu LL, Yuen WWY, Yau S, et al. A one-year longitudinal qualitative study of peer support services in a non-Western context: The perspectives of peer support workers, service users, and co-workers. Psychiatry Res 2017;255:27-35.
Reason for exclusion: Wrong patient population
69. Van Der Elst, K.; Bangels, L.; Peerlings, L.; De Caluwe, L.; Langers, I.; Stouten, V.; De Cock, D.; Westhovens, R.; Verschueren, P. Do we need a patient peer mentor program in daily practice for patients with early rheumatoid arthritis and if so, how should this be organized? Annals of the

Rheumatic Diseases. Conference: Annual European Congress of Rheumatology, EULAR 2019. Madrid Spain. 78 (Supplement 2) (pp 2140); BMJ Publishing Group; 2019.

Reason for exclusion: Wrong study design

70. WaiteJones JM, Swallow V. Peer-based Social Support for Young-People with Juvenile Arthritis: Views of Young People, Parents/Carers and Healthcare Professionals within the UK. J Pediatr Nurs 2018;43:e85-e91.

    Reason for exclusion: Wrong patient population
71. Weir B, Cunningham M, Abraham L, Allanson-Oddy C. Military veteran engagement with mental health and well-being services: A qualitative study of the role of the peer support worker. Journal of Mental Health 2019;28(6):647-653.

    Reason for exclusion: Wrong patient population
72. Werner EL, Lærum E, Wormgoor MEA, Lindh E, Indahl A. Peer support in an occupational setting preventing LBP-related sick leave. Occupational medicine 2007;57(8):590-595.

    Reason for exclusion: Wrong patient population
73. Williams EM, Egede L, Faith T, Oates J. Effective Self-Management Interventions for Patients With Lupus: Potential Impact of Peer Mentoring. Am J Med Sci 2017;353(6):580-592.

    Reason for exclusion: Wrong study design
74. Young SD, Heinzerling K. The Harnessing Online Peer Education (HOPE) intervention for reducing prescription drug abuse: a qualitative study. J Subst Use 2017;22(6):592-596.

    Reason for exclusion: Wrong phenomena of interest
75. Young SD, Koussa M, Lee S, Perez H, Gill N, Gelberg L, et al. Feasibility of a social media/online community support group intervention among chronic pain patients on opioid therapy. Journal of Addictive Diseases 2018;37(1-2):96-101.

    Reason for exclusion: Wrong patient population
76. Young SD, Lee S, Perez H, Gill N, Gelberg L, Heinzerling K. Social media as an emerging tool for reducing prescription opioid misuse risk factors. Heliyon 2020;6(3).

    Reason for exclusion: Wrong patient population
77. Yu X, Convoy S, Singh PA, Png C, Yoong CS, Pal P. Early Experience of a Multidisciplinary Group Pain Program with Cognitive Behavioural Strategies, Physiotherapy and Peer Support for Patients with Chronic Noncancer Pain. Pain Management Nursing 2020.

    Reason for exclusion: Wrong phenomena of interest

APPENDIX IV - STUDY FINDINGS AND ILLUSTRATIONS

Arnstein P, Vidal M, Wells-Federman C, Morgan B, Caudill M. From chronic pain patient to peer: benefits and risks of volunteering. Pain Management Nursing. 2002;3(3):94–103.(Arnstein, P., Vidal, Wells-Federman et al. 2002a)	
Finding	Making a connection (U)
Illustration	"The connection helps validate feelings for both involved, the whole thing was very gratifying." (p. 99)
Finding	Sense of purpose (U)
Illustration	"When they started thinking of more ways to help themselves I felt good, I felt like I had purpose." (p. 99)
Finding	Physical Challenges (C)
Illustration	The physical challenges they identified included enduring the duration of therapy, and transportation to the clinic, especially during their own pain-flares. (p. 99)
Finding	Psychosocial challenges (C)
Illustration	Examples of psychosocial challenges were avoiding the tendency to get overly involved and dealing with frustration when their desire to help exceeded their ability to help. (p. 99)
Finding	Protocol-related challenges (C)
Illustration	Examples of protocol-related challenges included the time commitment required (3 to 7 hours per week), completing the requested paperwork, and establishing initial contact with the patient if not done in person (p. 99)
Finding	Reported benefits (C)
Illustration	These rewards included helping themselves (e.g., improved communication skills, confidence, and functioning), helping others (e.g., having positive influence, empowering the patients, seeing them improve), and boosting their sense of self-worth (p. 99-100)
Cooper K, Schofield P, Smith BH, Klein S. PALS: peer support for community dwelling older people with chronic low back pain: a feasibility and acceptability study. Physiotherapy. 2020;106:154–62(Cooper, Kay et al. 2020)	
Finding	Matching: Participants were generally positive about their matches (U)
Illustration	"You don't have to have a lot of other things in common if you both have back pain, both have an understanding" [PSV66, Male] (p. 159)
Finding	Delivery: All participants, including those who had one or more telephone meetings, felt that a face-to-face element was essential (U)
Illustration	"Both [face-to-face & telephone] were good. . .just as easy over the phone. . .but it' s vital to see a face, you couldn't do them all by phone" [P52, Male] (p. 159)
Finding	What I got out of it: participants reported benefit, although not always in the way they had anticipated (U)
Illustration	"Think I got as much out of it as the patients have. I learned a lot about pain and different people's pain thresholds, ways of managing. Think I'm more tolerant of back pain as a result of the study". [PSV40,Female] (p. 159)
Finding	PALS Manual: Participants spoke variably of the manual and resources, with some liking the information provided, some using the manual as a step-by-step guide, and some not using it at all (U)

Illustration	“The best thing I found was the manual it gave criteria to work to. If the patient went off on a tangent I could bring it back to focus using the manual and topic for that session. . .but the content could be halved” [PSV66, Male] (p. 159)
Kohut SA, Stinson J, Luca S, Forgeron P, Harris L, Ahola Kohut S. Been There, Done That: The Experience of Acting as a Young Adult Mentor to Adolescents Living With Chronic Illness. Journal of pediatric psychology. 2017;42(9):962–9(Kohut, Sara Ahola et al. 2017)	
Finding	Developing a relationship (U)
Illustration	“After the first few sessions, most of my mentees would come out of their shell and start conversing with me a little bit more, but I think it might also help to just talk about things that are going on in their life that had nothing to do with their pain.” (Pain mentor 8, aged 19, female) (p. 966)
Finding	Benefits of connection (U)
Illustration	“I think the biggest thing is [talking to] somebody that shared your general experiences. Probably the hardest thing is finding somebody that has the same condition or very similar condition and just knowing that you’re not the only one that has problems.” (JIA mentor 5, aged 17, female) (p. 966)
Finding	Mentor–mentor connection (U)
Illustration	“I think it would be really great just to be like ‘great, I’m working with this men- tee, I’m having a really hard time, getting her to have a conversation. She seems really shy, have you experienced this, what do you do to, like how do you, you know, get your mentee talking?’” (Pain mentor 8, aged 19, female) (p. 966)
Finding	Mentor growth (U)
Illustration	“I found it helped me grow a lot as a person too. Even when I work with my patients, I take things I’ve learned from my mentees.” (JIA mentor 6, aged 19, female, in school to become a health professional) (p. 966)
Finding	Mentor training (U)
Illustration	“I came into the training and that weekend kind of changed my perceptions on certain things, I guess I grew in terms of learning how to do mentoring on a higher level than if I didn’t have any training, and how to use your story in more of a constructive way.” (JIA mentor 4, aged 19, male) (p. 966)
Finding	Mentor role (U)
Illustration	“I don’t have to counsel them, they don’t have to be counselling me, we just talked, we had a conversation but we still helped each other so. . .that was nice to know.” (Pain mentor 11, aged 19, female) (p. 966)
Finding	Illness self-management (U)
Illustration	“I was able to guide them in terms of what to do when you’re at high school, going to university, applying for accommodations and all that kind of stuff so I shared a lot.” (JIA mentor 1, aged 21, female) (p. 966)
Finding	Hope for the future (U)
Illustration	“Just sharing of hope almost because a lot of the time there are some feelings of anxiety, or fear of the future and then having us as mentors there, like you can actually live your life like this and you can live it really well and this is what we’re doing and just kind of being there, I thought that was amazing on both ends.” (JIA mentor 4, aged 19, male) (p. 966)
Finding	Mentee characteristics (U)
Illustration	“I did have one mentee who was more shy and then one who wasn’t so at the same time, I’d have a call and it would go really well and we’d talk about any- thing and everything and then when I did my call with the other one, I had to drive the conversation.” (JIA mentor 3, aged 19, female) (p. 966)

Finding	Scheduling issues (U)
Illustration	“Mostly I had a lot of conflict with my schedule in university and working two jobs and then the high school or elementary schedule, them working a job or two plus all these commitments with family and friends, so I mean, my avail- ability was almost the opposite of theirs.” (JIA mentor 1, aged 21, female) (p. 966)
Finding	Technological issues (U)
Illustration	“There were errors with the Internet. It isn’t perfect so there were some issues [interruption in transmission of voice or video] but nothing that couldn’t be handled and nothing that really devastated the quality of the calls.” (Pain men- tor 9, aged 19, female) (p. 966)
Finding	Programmatic issues (U)
Illustration	“It was harder for me to connect with someone if we didn’t follow the call scheme. If there were a couple missed calls in the middle, then you started and you were getting there and there was a period of stopping and you had to pick it up from the beginning again.” (JIA mentor 4, aged 19, male) (p. 966)
Kumar K, John H, Gordhan C, Situnayake D, Raza K, Bacon PA. Breaking communication barriers for RA patients of south Asian origin: The use of a bilingual educational audio CD and linguistically appropriate peer support and education. Musculoskeletal Care. 2011;9(1):11–8.(Kumar et al. 2011b)	
Finding	Patients were particularly impressed by the fact that the volunteer listened to their story (U)
Illustration	The main thing was the support that they are offering. [N.L.] was listening to me, and that was nice. (60 years old, disease duration 10 years). (p. 15)
Finding	They found it very helpful to be able to communicate with her directly in their spoken language (U)
Illustration	It was good to talk to [N.L.] because she spoke my language and that really helped me to get my feelings across and this wouldn’t happen otherwise. (56 years old, disease duration 10 years). (p. 15)
Finding	The majority of patients also stated that there was mutual understanding between them and the volunteer, as they both suffered with RA (U)
Illustration	It was like you could talk to her because she was a patient and you felt unburdening yourself. I looked at her and thought she is like me....She has the same thing as me...it’s difficult to talk to a nurse or doctor isn’t it? The other thing was that she was very positive about things. I liked that. (60 years old, disease duration 10 years). (p. 15)
Finding	They found it helpful to talk to someone who had been through the experience of living with RA and had remained positive about the future (U)
Illustration	Yeah . . . she did give us motivation and in a sense made me see a vision that is separate to my disease. (46 years old, disease duration three years). (p. 15)
Finding	Two patients stood out in expressing some negative feelings about the interaction (U)
Illustration	When I first saw her I felt very afraid. For a whole week I was upset, I was thinking, gosh. . . . will I be like this in another 10 years time? Then I tried to make myself understand that, no, I will not end up like that because I have been treated reasonably early. Then I thought that it could be that some people have different disease and patterns. (45 years old, disease duration three years). (p. 16)
Matthias MS, Kukla M, Bair MJ, McGuire AB. How Do Patients with Chronic Pain Benefit from a Peer-Supported Pain Self-Management Intervention? A Qualitative Investigation. Pain Medicine. 2016;17(12):2247–55(Matthias, Marianne S., Kukla, Bair et al. 2016)	
Finding	Participants valued the purely social nature of connecting with another veteran, being able to get to know one another, and having the opportunity to discuss common interests that were often unrelated to pain (U)

Illustration	I think what was most beneficial is taking the time out of your regular day and just sitting down and discussing and relaxing, and then putting everything behind you, forgetting things for an hour or so (Veteran 204). (p. 2249)
Finding	Listening was a key component of the peer support experience (U)
Illustration	"He's a real understanding guy. He listens. He knows when to listen. He knows when to talk. He don't give you any advice or anything like that. He just tells you his experiences and stuff and lets you decide what to do on your own" (Veteran 207). (p. 2250)
Finding	Changes in Attitude Toward and Acceptance of Pain (U)
Illustration	"Instead of thinking about what I can't do, I like to think about what I can do. That's more fun. It's a lot more fun. It gives the day a better outlook" (Veteran 213). (p. 2251)
Finding	Discussing Exercises and Activity (U)
Illustration	"It gets my body going. It's like a warm-up. It gets me going and then I can do things around the house, or walk or something" (Veteran 214). (p. 2252)
Finding	Helping Veterans to Navigate Health Care Resources (U)
Illustration	"He gave me a lot of advice—how to get my old medical records and, uh, dental records and history stuck back in the military so that I could put in for some disability. So he's really helped me a lot on that" (Veteran 219). (p.2252)
Finding	Sharing Ideas About Pain Self Management Strategies (U)
Illustration	"getting some ideas, maybe a little feedback on what might be a little bit easier, getting [my peer coach's] input and his experiences. He had enough experience to maybe show me some things I might not have thought about" (Veteran 208). (p. 2252)
Finding	Challenging and Motivating (U)
Illustration	My exercise and stuff like that, we talked more about that than anything. He felt that it would probably help me a whole lot by trying to do something a little bit more than what I'm already doing, and to keep doing a little bit more. He said it seemed like that helped him a lot: The more he could do, it cut down on his pain (Veteran 205). (p. 2252)
Matthias MS, Kukla M, McGuire AB, Damush TM, Gill N, Bair MJ. Facilitators and Barriers to Participation in a Peer Support Intervention for Veterans With Chronic Pain. Clinical Journal of Pain. 2016;32(6):534–40.(Matthias, Marianne S. et al. 2016b)	
Finding	Facilitators to Participation: Shared veteran identity (U)
Illustration	'Cause we both been in the service together, and that was something we could talk about. We had a lot of things in common, things we did, things that he went through, I went through. (Veteran 214) (p. 5)
Finding	Facilitator to Participation: Having a partner with chronic pain (U)
Illustration	It's so much better if you talk to someone, and if that person understands what you're going through that's so much better...If you have someone to talk to that understands what you're going through it makes a ton of difference, it really does. (Veteran 213) (p. 6)
Finding	Facilitator to Participation: Support from study staff (U)
Illustration	"I felt that [study staff] had my back just in case, you know. Just in case." (p. 7)
Finding	Barriers to Participation: Logistical Challenges (U)

Illustration	I told [my peer coach], I got to ride the bus to get [to the medical center to meet]. I said that's four bucks. I said I have to look at that money because I'm on a fixed income. I said I know it's a lot of gas for you, and gas at that time was almost $4 a gallon. That's why we decided to do the phone calls. (Veteran 210) (p. 8)
Finding	Barriers to Participation: Challenges to motivation and engagement (U)
Illustration	Sometimes I was also weak. I didn't call or nothing because I was spaced out. My disabilities were taking over, and I just would come into the house and just sit in the corner in my chair... and watch TV. (Peer 109) (p. 10)
Sandhu S, Veinot P, Embuldeniya G, Brooks S, Sale J, Huang S, et al. Peer-to-peer mentoring for individuals with early inflammatory arthritis: feasibility pilot. BMJ open. 2013;3(3).(Sandhu, Sharron et al. 2013)	
Finding	A few mentors experienced challenges (C)
Illustration	eg mentee reluctant to stop consuming alcohol to take methotrexate (PM7); mentee with problems returning to work after being on long-term disability (PM7, PM8) (p. 6)
Finding	Mentors reported personally benefiting from the programme (C)
Illustration	They reported that it increased their knowledge, provided new self-management techniques and coping strategies (PM3, PM4, PM7, PM9, PM12), reinforced self-management strategies they were familiar with and made them realise how far they had come in their disease experience (PM12, PM8) (p. 6)
Finding	Emotional and informational supports were most commonly reported (U)
Illustration	“I would ask her when she encountered bad weather, how were her joints? What did she do about that? …Can I do something prior to, when you know the weather is coming.” (EIA3) (p. 6)
Finding	Appraisal and instrumental support were also exchanged (U)
Illustration	“It was great being able to sit down and have a normal conversation, but at the same time throw in, oh yeah, I’m thinking about switching to biologics so what’s your opinion?” (EIA1) (p. 6)
Finding	Participants’ experience of peer support was informed by the unique relationship they forged with their peer (U)
Illustration	Many participants spoke of having ‘a connection’ with his/her peer. This was facilitated by similarities in personality, age, gender, interests, life stage, position of responsibility at work, diagnosis, disease severity and similarity of affected joints. ‘My hands felt like her hands’, said one mentee (EIA4). (p. 6)
Finding	Four participants faced challenges building rapport due to differences in gender, sexuality, political views and disease stage (U)
Illustration	Gender differences restricted the type of conversations in one mixed gender dyad. In another dyad, a mentee found herself disassociating from her wheelchair-bound mentor, as she was not able to cope with this ‘... I found myself looking at my mentor and going, that’s not me, I don’t have that, I’m not going there, I’m not going to be in a wheelchair...or be badly deformed’. (EIA6) (p. 6)
Finding	All participants were unequivocal about the need for a peer support programme for individuals with EIA (U)
Illustration	Mentees spoke about the programme as ‘critical’ (EIA1), declaring, ‘It can’t stop. It can’t’ (EIA3). Mentors wished that similar peer support interventions had been available when they were first diagnosed. (p. 7)
Tse MMY, Ng SSM, Bai X, Lee PH, Lo R, Cheung DSK, et al. Lesson learned from peer volunteers in a peer-led pain management program among nursing home residents. International journal of environmental research and public health. 2019;16(17):3097 (Tse, Mimi Mun Yee et al. 2019)	
Finding	PV's described leading the pain management program (PAP) as a meaningful experience (U)
Illustration	I was appreciated by nursing home residents (p. 6)

Finding	Perceived benefits: helping themselves and helping others (U)
Illustration	I can see that the participants are happier and feel less lonely (p. 6)
Finding	Boosted my sense of self-worth (U)
Illustration	I get satisfaction in giving something back to the society and providing support to the participants (p. 6)
Finding	Barriers encountered in leading the PAP (U)
Illustration	Some nursing home residents were too frail and required more assistance (p. 7)
Finding	Feedback on the content of the PAP (U)
Illustration	I like the PAP (p. 7)
Tse M, Li Y, Tang SK, Ng SSM, Bai X, Lee PH, et al. An Exploration of the Effectiveness of a Peer-Led Pain Management Program (PAP) for Nursing Home Residents with Chronic Pain and an Evaluation of Their Experiences: A Pilot Randomized Controlled Trial. International journal of environmental research and public health. 2020;17(11).(Tse, Mimi et al. 2020a)	
Finding	About the program (U)
Illustration	I feel happy and relaxed when taking part in the program every week (p. 9)
Finding	About the peer volunteers (U)
Illustration	The volunteers are very patient and nice (p. 9)

APPENDIX V - PARTICIPANT INFORMATION SHEET ADULTS WITH CHRONIC PAIN

Participant Information Sheet

Study Title: Exploring stakeholders' perceptions of peer support for adults with chronic non-cancer pain: a mixed-methods study

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether you wish to take part. Thank you for reading this information sheet.

What is the purpose of this study?

The purpose of this study is to develop a peer support intervention for people with chronic pain. Peer support links people living with a chronic condition together so they can share knowledge and experiences in order to help them manage their condition. There are several types of peer support. One type is where someone with experience of successfully managing their condition (peer support volunteer) is matched with and provides support to a person/people with that same condition. We want to develop this type of peer support intervention for people with chronic pain as we think it could be beneficial for some people. In order to do that, we need to find out from people with chronic pain what they think would be useful to include in the intervention and how it should be delivered. We will also explore the views of healthcare professionals and other individuals who have experience of treating people with chronic pain or of delivering peer support interventions. We will use the study findings to develop a peer support intervention which we will then try out in a future study. We hope that some people living with chronic pain will find the intervention beneficial.

Why have I been chosen?

You have been chosen because you are an adult with experience of chronic noncancer pain, and you may be eligible to take part.

Do I have to take part?

No, it is up to you to decide whether to take part. If you do decide to take part, you will be given this information sheet and be asked to provide consent before taking part. If you decide to take part, you are free to withdraw at any time and without giving a reason.

What does taking part in this study involve?

Taking part in this study involves up to three activities:

1. Online survey exploring your views of peer support for chronic pain – completion time approximately 15-minutes

2. Online interview (Microsoft Teams) to further explore your views of peer support for chronic pain – completion time up to 1-hour
3. Online workshop where the researcher will present the study findings and ask for feedback from participants in order to finalise a peer support intervention that will be tested in a future study – up to 1-hour

You can choose to take part in just the survey, or the survey and interview, or all three activities (survey, interview, workshop). If you would like to complete a paper copy of the survey please contact the researcher using the contact details provided below.

What are the possible disadvantages of taking part?

You will be giving up 15-minutes of your time for the survey and up to 2-hours for the interview and workshop (if you choose to take part in these). It is possible that you may become upset during or following an interview focussed on your chronic pain. If this happens, please speak to someone who can support you. If you feel distressed, please contact your GP or seek support from one of the organisations listed at the end of this information sheet.

What are the possible benefits of taking part?

There will be no direct benefit to you from participating in this research. The findings will be used to inform the development of a peer support intervention, which we hope will provide a useful future resource for adults with chronic pain. We are unable to compensate you for taking part in this research, as it is an unfunded doctoral student project.

What if something goes wrong?

If you have any complaint about the conduct of this study, you should contact the Convenor, School of Health Sciences Research Ethics Committee, Robert Gordon University (SREC@rgu.ac.uk) or Mrs Laura Binnie, Head of school, School of Health Sciences (l.m.binnie@rgu.ac.uk).

Will my taking part in the study be kept confidential?

The surveys will be anonymous as the study team will only see your participant code and will not be able to link it with your name. Data from paper surveys will be transferred to a password-protected computer file, only accessible by the research team, and will be combined with any surveys completed online. The paper copies will be kept in a locked filing cabinet until the data has been analysed, after which they will be destroyed. If you provide your name and contact details for the interview, these will be stored on a separate password-protected file and will only be used for the purpose of contacting you about the interview. The interview and workshop will be recorded (audio only using a hand-held voice recorder) and a transcript of the interview will be produced by a professional transcription service approved by the University. We will not use your name in the transcript, and only the research team will see the transcript, it will not be shared with anyone else. We will use anonymised quotes from the interview and workshop to illustrate research findings in papers and reports, but it will not be possible to identify you from any of these quotes. All information will be collected and stored within the requirements of the General Data Protection Regulation (GDPR, 2018), please see further information on the last page of this information sheet.

What will happen to the results of the research study?

The results will be written as part of a Doctoral thesis. The results will be shared widely with healthcare professionals and relevant organisations such as Pain Association Scotland and Pain UK. We will combine the results from the survey with the results from the interviews and with focus groups that we will conduct with healthcare professionals. We will make recommendations on the proposed design of a future peer support intervention. We will hold a stakeholder workshop at the end of the study to share the results with all participants and interested stakeholders. The results will be published in a pain or physiotherapy-related journal and presented at a professional conference. You will not be identified in any reports or publications. You will receive a summary of the findings and how the information you provided is being used.

Who is organising and funding the research?

The research is being conducted by Rachel Arnott in part-fulfilment of a Doctorate of Physiotherapy. She is supervised by a Clinical Professor and Specialist Physiotherapist from Robert Gordon University and NHS Grampian.

Who has reviewed the study?

The Tyne and Wear South Research Ethics Committee and NHS Grampian R & D Department have approved this study.

What do I do now?

If you are interested in taking part, please proceed to the survey link.

https://robertgordonuniversity.onlinesurveys.ac.uk/chronic-pain-and-peer-support-survey-1

You can also contact the researcher who will answer any questions you may have, and who can send a paper copy of the survey if you prefer. If leaving a voicemail, please state you are enquiring about the “Peer support for chronic pain study.”

Contacts for further information

Researcher	**Principal Supervisor**
Rachel Arnott Doctorate of Physiotherapy Candidate	Professor Kay Cooper

Email: r.arnott@rgu.ac.uk Tel: 01224 262677	Clinical Professor Allied Health Professions, Robert Gordon University & NHS Grampian Email: k.cooper@rgu.ac.uk Tel: 01224 262677

Data Protection Statement

Robert Gordon University (RGU) is sponsoring this research. This section explains how we (RGU) will use information about you for the purposes of this research.

How will we use the information we collect about you?

We will need to use information from you for this research project. This information will include:

- Age
- Gender
- Education
- Profession

People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.
- If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study stored anonymously on RGU's research repository OpenAir.

Where can you find out more about how your information is used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- by asking one of the research team (contact above)
- Our leaflet available from http://www.hra.nhs.uk/patientdataandresearch

- by sending an email to Robert Gordon University’s Data Protection Officer (DP@rgu.ac.uk)

If you would like further information on managing chronic pain, the following resources may be of use:

NHS Inform

Pain Association UK

If you are distressed, the following organisations may be of use:

Samaritans: https://www.samaritans.org/?nation=scotland Tel: 116123

Breathing space: https://breathingspace.scot/ Tel: 0800 83 85 87

NHS inform: https://www.nhsinform.scot/illnesses-andhttps://www.nhsinform.scot/illnesses-and-conditions/mental-health**conditions/mental-health**

APPENDIX VI - LETTER OF INVITATION FROM HCPS

Physiotherapy Department
(Insert hospital location)
NHS Grampian
Aberdeen

Dear Sir/Madam

Rachel Arnott is a doctorate of physiotherapy candidate at Robert Gordon University in Aberdeen. She is conducting a research project in collaboration with colleagues from NHS Grampian, and you are being invited to take part. The study is titled, "Exploring stakeholders' perceptions of peer support for adults with chronic non-cancer pain." It has been approved by the NHS Health Research Authority Ethics Committee and NHS Grampian Research and Development Department. Rachel's academic supervisory team includes a clinical-academic professor, specialist physiotherapist and physiotherapy lecturer.

The purpose of this study is to understand the preferences of stakeholders surrounding peer support interventions so that future peer support interventions can be developed that are both feasible and beneficial for those involved. Stakeholders include adults with chronic non-cancer pain and individuals with experience of treating chronic pain or delivering peer support interventions. You have been chosen because you have recently received care for a chronic painful condition. The research team are keen to hear your views on peer support for helping to manage chronic pain.

I would be grateful if you could read the enclosed participant information sheet. If you are interested in taking part in the study, please follow the survey link below:

https://robertgordonuniversity.onlinesurveys.ac.uk/chronic-pain-and-peer-support-survey-1

Kind regards,

Insert HCP signature here

+ work title

APPENDIX VII - PARTICIPANT FLYER 1

Have you experienced chronic pain?

Can you spare some time for an online survey and/or an interview?

We would love to hear from you!

Survey ↓

Or contact the research team: r.arnott@rgu.ac.uk

ROBERT GORDON UNIVERSITY ABERDEEN

APPENDIX VIII - PARTICIPANT INFORMATION SHEET HCPS

Participant Information Sheet

Study Title: Exploring stakeholders' perceptions of peer support for adults with chronic non-cancer pain: a mixed-methods study

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether you wish to take part. Thank you for reading this information sheet.

What is the purpose of this study?

The purpose of this study is to understand the preferences of stakeholders surrounding peer support interventions so that future interventions can be developed that are both practical and helpful.

Stakeholders include people who may participate or help deliver a peer support intervention. For this research it includes adults with chronic non-cancer pain and healthcare professionals with experience of treating chronic non-cancer pain.

Peer support links together people living with a chronic condition so that they can share knowledge and experiences. This type of support can be provided by phone calls, text messaging, group meetings, home visits, going for walks together, and even grocery shopping. It complements and enhances other health care services by creating the emotional, social and practical assistance necessary for managing the condition and staying healthy.

Peer support interventions can vary in several ways, including:

- Format: group, one-to-one or hybrid
- Delivery: face-to-face or virtual such as audio or video call, messaging/emailing, social media platform or hybrid
- Length of the intervention
- Frequency and duration of contact between peers

Research evidence suggests that peer support interventions could play an important role in the management of chronic pain. However, there has not yet been a study to explore the views and preferences of adults with chronic non-cancer pain or healthcare professionals regarding how a peer support intervention for chronic pain should be developed. This research aims to address this gap.

Why have I been chosen?

You have been chosen because you are an individual with experience of delivering care to adults with chronic pain and/or implementing a peer support intervention, and you are eligible to take part.

Do I have to take part?

No, it is up to you to decide whether to take part. If you do decide to take part, you will be given this information sheet and be asked to provide consent before taking part. If you decide to take part, you are free to withdraw at any time and without giving a reason.

What does taking part in this study involve?

Taking part in this study involves up to three activities:

1. Online survey exploring your views of peer support for chronic pain – completion time approximately 15-minutes
2. Online focus group (Microsoft Teams) with 4-10 other healthcare professionals and other individuals with experience of chronic pain management and/or peer support – completion time up to 1-hour
3. Online workshop where the researcher will present the study findings and ask for feedback from participants in order to finalise a peer support intervention that will be tested in a future study

You can choose to take part in just the survey, or the survey and focus group, or all three activities (survey, focus group, workshop).

What are the possible disadvantages of taking part?

We do not anticipate any risks or disadvantages, besides you giving up 15 minutes of your time for the survey and an additional 1-2 hours for the focus group and final workshop (if you choose to participate).

What are the possible benefits of taking part?

There will be no direct benefit to you from participating in this research. The findings will be used to inform the development of a peer support intervention, which we hope will provide a useful future resource for adults with chronic pain. We are unable to compensate you for taking part in the study due to this being an unfunded doctoral student project.

What if something goes wrong?

If you have any complaint about the conduct of this study, you should contact the Convenor, School of Health Sciences Research Ethics Committee, Robert Gordon University (SREC@rgu.ac.uk) or Mrs. Laura Binnie, Head of school, School of Health Sciences (l.m.binnie@rgu.ac.uk).

Will my taking part in the study be kept confidential?

The surveys will be anonymous as the study team will only see your participant code and will not be able to link it with your name. Data from paper surveys will be transferred to a password-protected computer file, only accessible by the research team, and will be combined with any surveys completed online. The paper copies will be kept in a locked filing cabinet until the data has been analysed, after which they will be destroyed. If you provide your name and contact details for the focus group, these will be stored on a separate password-protected file and will only be used for the purpose of contacting you about the focus group. The focus group and workshop will be recorded (audio only using a hand-held voice-recorder) and a transcript of the focus group will be produced by a professional transcription service approved by the University. We will not use your name in the transcript, and only the research team will see the transcript, it will not be shared with anyone else. We will use anonymised quotes from the focus group and workshop to illustrate research findings in papers and reports, but it will not be possible to identify you from these anonymised quotes. All information will be collected and stored within the requirements of the General Data Protection Regulation (GDPR, 2018), please see further information on the last page of this information sheet.

What will happen to the results of the research study?

The results will be written as part of a Doctoral thesis. The results will be shared widely with healthcare professionals and relevant organisations such as Pain Association Scotland and Pain UK. We will combine the results from the surveys with the results from the focus groups. We will make recommendations on the design of future peer support interventions. We will hold a stakeholder workshop at the end of the study to share the results with all participants and interested stakeholders. The results will be published in a pain or physiotherapy-related journal and presented at a professional conference. You will not be identified in any reports or publications. You will receive a summary of the findings and how the information you provided is being used.

Who is organising and funding the research?

The research is being conducted by Rachel Arnott in part-fulfilment of a Doctorate of Physiotherapy. She is supervised by a Clinical Professor, Specialist Physiotherapist and Physiotherapy Lecturer, from Robert Gordon University and NHS Grampian.

Who has reviewed the study?

The Tyne and Wear South Research Ethics Committee and NHS Grampian R & D Department have approved this study.

What do I do now?

If you are interested in participating in the study, please proceed to the survey link.

https://robertgordonuniversity.onlinesurveys.ac.uk/chronic-pain-and-peer-support-survey-2-hcp You can also contact the researcher who will answer any questions you may have. If leaving a voicemail, please state you are enquiring about the "Peer support for chronic pain study."

Contacts for further information

Researcher	Principal Supervisor
Rachel Arnott Doctorate of Physiotherapy Candidate Email: r.arnott@rgu.ac.uk Tel: 01224 262677	Professor Kay Cooper Clinical Professor Allied Health Professions, Robert Gordon University & NHS Grampian Email: k.cooper@rgu.ac.uk Tel: 01224 262677

Data Protection Statement

Robert Gordon University (RGU) is sponsoring this research. This section explains how we (RGU) will use information about you for the purposes of this research.

How will we use the information we collect about you?

We will need to use information from you for this research project. This information will include:

- Age
- Gender
- Education
- Profession

People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

- If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study stored anonymously on RGU's research repository OpenAir.

Where can you find out more about how your information is used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- by asking one of the research team (contact above)
- Our leaflet available from http://www.hra.nhs.uk/patientdataandresearch
- by sending an email to Robert Gordon University's Data Protection Officer (DP@rgu.ac.uk)

APPENDIX IX - PARTICIPANT FLYER 2

Have you treated adults with chronic pain OR delivered a peer support intervention?

Can you spare some time for an online survey and/or take part in a focus group?

We would love to hear from you!

Survey ↓

Or contact the research team: r.arnott@rgu.ac.uk

RGU ROBERT GORDON UNIVERSITY ABERDEEN

APPENDIX X – VERBAL CONSENT FOR INTERVIEWS

For ***interviews*** consent will be audio recorded immediately prior to the interview commencing, saved and stored separately from the interview itself.

Instructions: The researcher must read each statement and the participant must reply "Yes" to each question to take part in the study.

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time and without giving a reason.
3. I understand that data collected during the study may be looked at by individuals from Robert Gordon University or from NHS Grampian, for purposes of monitoring the research. I give permission for these individuals to have access to the data.
4. I agree to taking part in an interview for the above study.
5. I agree to my interview being audio recorded.
6. I agree to anonymised quotes from my interview being used in research outputs from this study (e.g., academic articles, professional papers, conference presentations).
7. I understand that my personal data will be destroyed 3-months after the study has ended, and that anonymised data will be stored by Robert Gordon University for 10-years, after which time it will also be destroyed.
8. I understand that anonymised information collected about me may be used to support other research in the future and may be shared anonymously with other researchers for up to 10-years after the study has ended.
9. I agree to take part in the study.

APPENDIX XI – WRITTEN CONSENT FOR FOCUS GROUPS

STATEMENT	INITIALS
1. I confirm that I have read and understand the information sheet dated 20.5.22 for the above study. I have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time and without giving a reason.	
3. I understand that data collected during the study may be looked at by individuals from Robert Gordon University or from NHS Grampian, for purposes of monitoring the research. I give permission for these individuals to have access to the data.	
4. I agree to taking part in a focus group for the above study.	
5. I agree to my focus group being audio recorded.	
6. I agree to anonymised quotes from my focus group being used in research outputs from this study (e.g., academic articles, professional papers, conference presentations).	
7. I understand that my personal data will be destroyed 3-months after the study has ended, and that anonymised data will be stored by Robert Gordon University for 10-years, after which time it will also be destroyed.	
8. I understand that anonymised information collected about me may be used to support other research in the future and may be shared anonymously with other researchers for up to 10-years after the study has ended.	
9. I agree to take part in the study.	

Signature:

Date:

APPENDIX XII – NHS HEALTH RESEARCH AUTHORITY APPROVAL LETTER

NHS
Health Research
Authority

North East - Tyne & Wear South Research Ethics Committee
NHSBT Newcastle Blood Donor Centre
Holland Drive
Newcastle upon Tyne
NE2 4NQ

31 May 2022

Professor Kay Cooper
Clinical Professor Allied Health Professions
Robert Gordon University
School of Health Sciences
Robert Gordon University
Aberdeen
AB10 7QG

Dear Professor Cooper

Study title:	**Exploring stakeholders' perceptions of peer support for adults with chronic pain: a mixed-methods study**
REC reference:	**22/NE/0092**
IRAS project ID:	**306864**

Thank you for your letter of response on the 25th of May 2022, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved on behalf of the PR sub-committee.

Confirmation of ethical opinion

On behalf of the Research Ethics Committee (REC), I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Good practice principles and responsibilities

The UK Policy Framework for Health and Social Care Research sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of research transparency:

registering research studies
reporting results

informing participants
sharing study data and tissue

Conditions of the favourable opinion

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

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

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

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

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

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database within six weeks of recruiting the first research participant. For this purpose, ‘clinical trials’ are defined as:

clinical trial of an investigational medicinal product
clinical investigation or other study of a medical device
combined trial of an investigational medicinal product and an investigational medical device
other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice.

Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by the HRA (for more information on registration and requesting a deferral see: Research registration and research project identifiers).

If you have not already included registration details in your IRAS application form you should notify the REC of the registration details as soon as possible.

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit:
https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-sum maries/

N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so, please register your study on a public registry as soon as possible and provide the REC with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at:
https://www.hra.nhs.uk/covid-19-research/approved-covid-19-research/

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

After ethical review: Reporting requirements

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

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

The latest guidance on these topics can be found at https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/.

Ethical review of research sites

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

Approved documents

The documents reviewed and approved by the Committee are:

Document	*Version*	*Date*
Copies of materials calling attention of potential participants to the research [Flyer Healthcare professional recruitment]	1.0	08 March 2022
Copies of materials calling attention of potential participants to the research [Flyer Patient recruitment]	1.0	08 March 2022
Copies of materials calling attention of potential participants to the research [Social Media Recruitment]	1.0	08 March 2022
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [RGU Insurance Cover]	1.0	01 August 2021
Interview schedules or topic guides for participants [Interview topic patients]	1.0	08 March 2022
Interview schedules or topic guides for participants [Focus group topic healthcare professionals]	1.0	08 March 2022
Interview schedules or topic guides for participants [Stakeholder workshop - Draft outline]	1.0	20 April 2022
Interview schedules or topic guides for participants [Proposed intervention for stakeholder workshop]	1.0	20 April 2022
IRAS Application Form [IRAS_Form_25052022]		25 May 2022
Letters of invitation to participant [Patient letter of invitation]	1.0	08 March 2022
Letters of invitation to participant [Email invitation healthcare professionals]	1.0	08 March 2022
Non-validated questionnaire [Survey outline - Patients]		
Non-validated questionnaire [Survey outline - Healthcare professionals]		
Other [Response to validation queries]		25 April 2022
Participant consent form [Consent page online survey]	2.0	20 May 2022
Participant consent form [Consent for interviews (verbal)]	2.0	20 May 2022
Participant consent form [Consent form focus groups]	2.0	20 May 2022
Participant consent form [Consent form - stakeholder workshop]	2.0	20 May 2022
Participant information sheet (PIS) [PIS - Patients]	2.0	20 May 2022
Participant information sheet (PIS) [PIS - Healthcare professionals]	2.0	20 May 2022
Referee's report or other scientific critique report [IRAS_306864_SRECApproval]	1.0	01 March 2022
Research protocol or project proposal [Mixed Methods Protocol V1.0]	1.0	08 March 2022
Response to Request for Further Information [Response to Points Raised]		
Summary CV for Chief Investigator (CI) [Kay Cooper IRAS CV]	1.0	10 March 2022
Summary CV for student		
Summary CV for student [CV_Rachel Arnott]	1.0	08 March 2022
Summary CV for supervisor (student research) [CV_Nicola Rhind]	1.0	08 March 2022

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at:
https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS project ID: 306864 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

p.p. Christopher Cole (HRA Approvals Specialist) On behalf of the Chair

Mr Ian Campbell

Chair of the REC

Email: tyneandwearsouth.rec@hra.nhs.uk

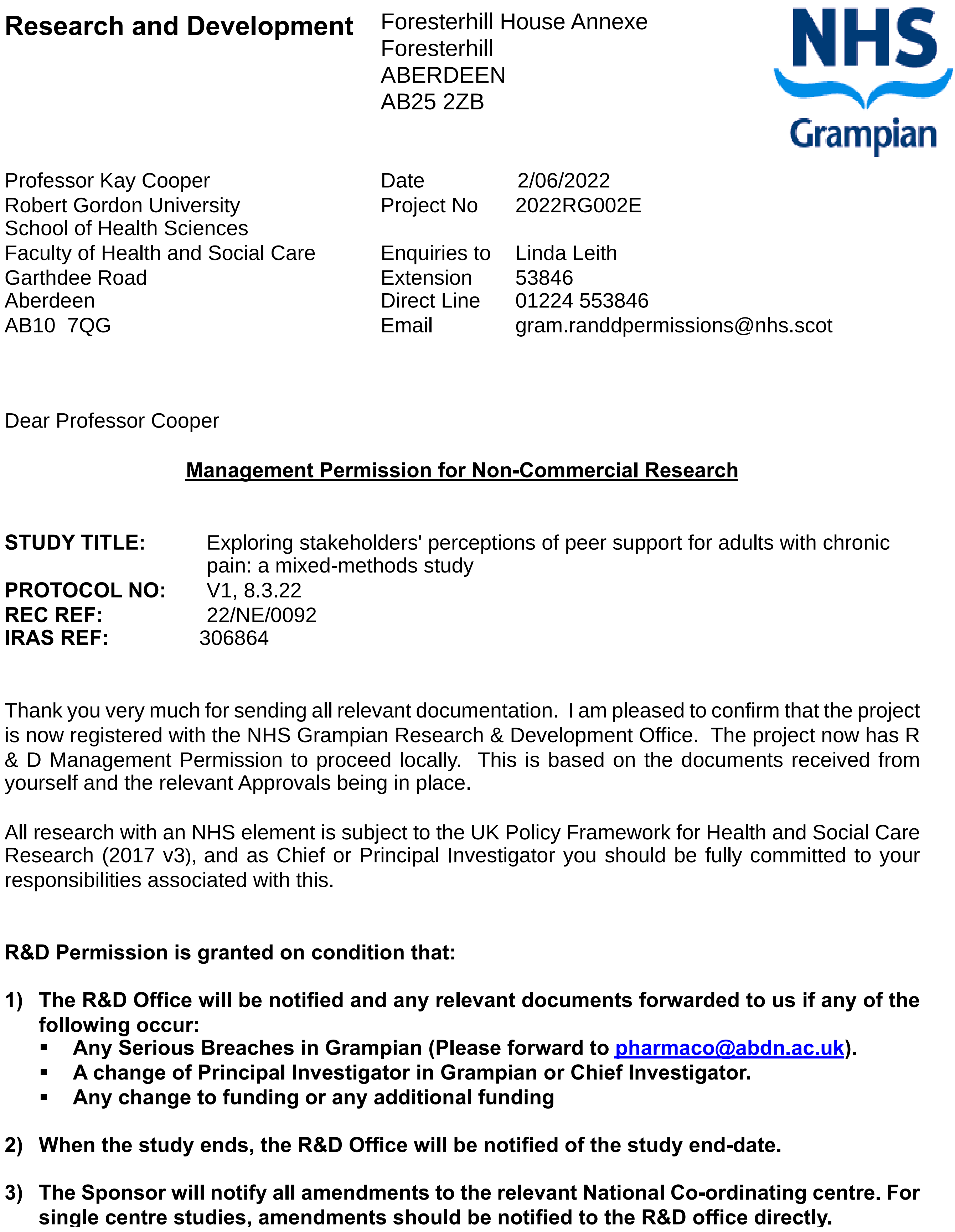
Enclosures: "After ethical review – guidance for researchers"

Non CTIMP Standard Conditions of Approval

Copy to: Ms Jill Johnston

Lead Nation: Scotland (gram.nrspcc@nhs.scot)

APPENDIX XIII – NHS GRAMPIAN RESEARCH AND DEVELOPMENT APPROVAL LETTER



Research and Development

Foresterhill House Annexe
Foresterhill
ABERDEEN
AB25 2ZB

Grampian

Professor Kay Cooper
Robert Gordon University
School of Health Sciences
Faculty of Health and Social Care
Garthdee Road
Aberdeen
AB10 7QG

Date 2/06/2022
Project No 2022RG002E

Enquiries to Linda Leith
Extension 53846
Direct Line 01224 553846
Email gram.randdpermissions@nhs.scot

Dear Professor Cooper

Management Permission for Non-Commercial Research

STUDY TITLE: Exploring stakeholders' perceptions of peer support for adults with chronic pain: a mixed-methods study
PROTOCOL NO: V1, 8.3.22
REC REF: 22/NE/0092
IRAS REF: 306864

Thank you very much for sending all relevant documentation. I am pleased to confirm that the project is now registered with the NHS Grampian Research & Development Office. The project now has R & D Management Permission to proceed locally. This is based on the documents received from yourself and the relevant Approvals being in place.

All research with an NHS element is subject to the UK Policy Framework for Health and Social Care Research (2017 v3), and as Chief or Principal Investigator you should be fully committed to your responsibilities associated with this.

R&D Permission is granted on condition that:

1) **The R&D Office will be notified and any relevant documents forwarded to us if any of the following occur:**
    - **Any Serious Breaches in Grampian (Please forward to pharmaco@abdn.ac.uk).**
    - **A change of Principal Investigator in Grampian or Chief Investigator.**
    - **Any change to funding or any additional funding**

2) **When the study ends, the R&D Office will be notified of the study end-date.**

3) **The Sponsor will notify all amendments to the relevant National Co-ordinating centre. For single centre studies, amendments should be notified to the R&D office directly.**

We hope the project goes well, and if you need any help or advice relating to your R&D Management Permission, please do not hesitate to contact the office.

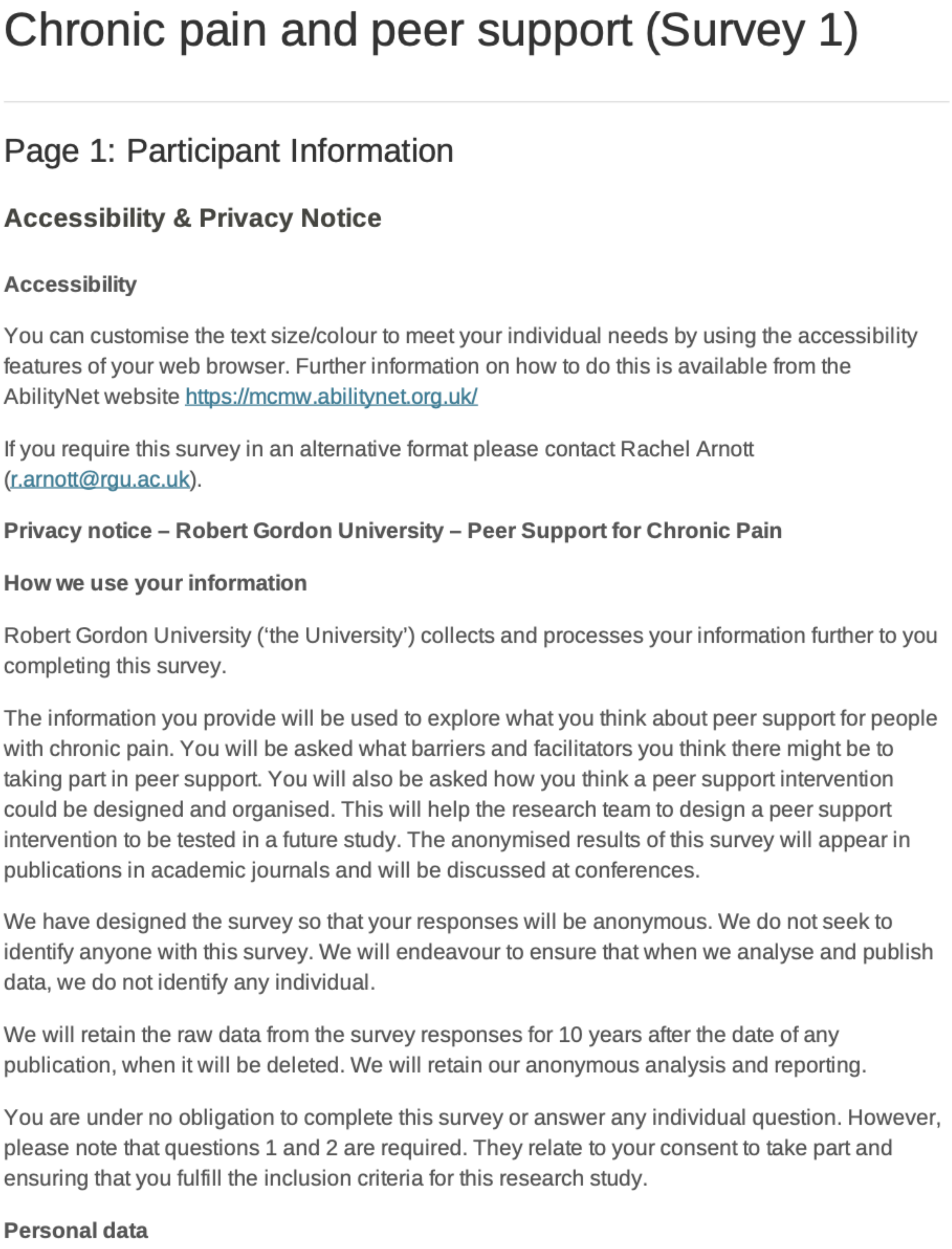
Yours sincerely

Susan Ridge
Non-Commercial Manager

cc: Ms Jill Johnson
Research Monitor
Ms Rachel Arnott
Ms Nicola Rhind
Dr Nicola Price
Dr Rituka Richardson
Ms Louise Osborne

Sponsor: Robert Gordon University

APPENDIX XIV – SURVEY FOR ADULTS WITH CHRONIC PAIN



Chronic pain and peer support (Survey 1)

Page 1: Participant Information

Accessibility & Privacy Notice

Accessibility

You can customise the text size/colour to meet your individual needs by using the accessibility features of your web browser. Further information on how to do this is available from the AbilityNet website https://mcmw.abilitynet.org.uk/

If you require this survey in an alternative format please contact Rachel Arnott (r.arnott@rgu.ac.uk).

Privacy notice – Robert Gordon University – Peer Support for Chronic Pain

How we use your information

Robert Gordon University ('the University') collects and processes your information further to you completing this survey.

The information you provide will be used to explore what you think about peer support for people with chronic pain. You will be asked what barriers and facilitators you think there might be to taking part in peer support. You will also be asked how you think a peer support intervention could be designed and organised. This will help the research team to design a peer support intervention to be tested in a future study. The anonymised results of this survey will appear in publications in academic journals and will be discussed at conferences.

We have designed the survey so that your responses will be anonymous. We do not seek to identify anyone with this survey. We will endeavour to ensure that when we analyse and publish data, we do not identify any individual.

We will retain the raw data from the survey responses for 10 years after the date of any publication, when it will be deleted. We will retain our anonymous analysis and reporting.

You are under no obligation to complete this survey or answer any individual question. However, please note that questions 1 and 2 are required. They relate to your consent to take part and ensuring that you fulfill the inclusion criteria for this research study.

Personal data

The personal data required for this survey is: your age, gender, highest level of education, and experience of chronic pain. It is unlikely that any individual will be identified from this data. Should you provide personal data in response to any of our questions, please consider whether your words reveal circumstances which may identify you and whether you wish to include them. Any disclosure of personal data is at your own discretion.

Special categories of personal data

The University does not require any special categories of personal data in the completion of this survey.

Data controller

Should you provide personal data in response to this survey Robert Gordon University would be the data controller for this information. This data may be processed by the University's nominated agents such as software or service providers. Data will be processed using the University's business systems, including Microsoft 365.

The University uses an online survey run by JISC to collect this information. For information on how this service secures your data please see https://www.jisc.ac.uk/online-surveys.

Lawful processing

If you choose to provide personal data in response to our questions, the University asserts that it is lawful for it to process your personal data for the purposes detailed above as necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller.

Your rights

The University respects your rights and preferences in relation to you. If you wish to update, access, erase, or limit the use of your information please let us know by emailing: r.arnott@rgu.ac.uk. If you wish to complain about the University's use of your information please contact the University's Data Protection Officer in the first instance by emailing DP@rgu.ac.uk. You may also wish to contact the Information Commissioner's Office.

Page 2: Consent

- The purpose of this survey is to explore what adults who experience chronic pain think of peer support as an intervention for supporting them to manage their condition.
- The survey will take 10-20 minutes to complete.

Please read the relevant study information sheet.
https://static.onlinesurveys.ac.uk/media/account/1162/survey/882723/question/participant_info_sheet_survey_.pdf
I have read and understood the study information and consent to taking part in the survey.
✱ *Required*

○ Yes, I consent to taking part in this study.
○ No, I do not want to take part in this study.

Thank you.

Rachel Arnott

Doctorate of Physiotherapy Candidate - Robert Gordon University

For more information, please feel free to contact me or my academic supervisor:

Rachel Arnott, School of Health Sciences, RGU, Garthdee Road, Aberdeen, AB10 7QG

E-mail: r.arnott@rgu.ac.uk

Tel: 01224 262677

Professor Kay Cooper, School of Health Sciences, RGU, Garthdee Road, Aberdeen, AB10 7QG

Email: k.cooper@rgu.ac.uk

Tel: 01224 262677

Page 3: Chronic pain

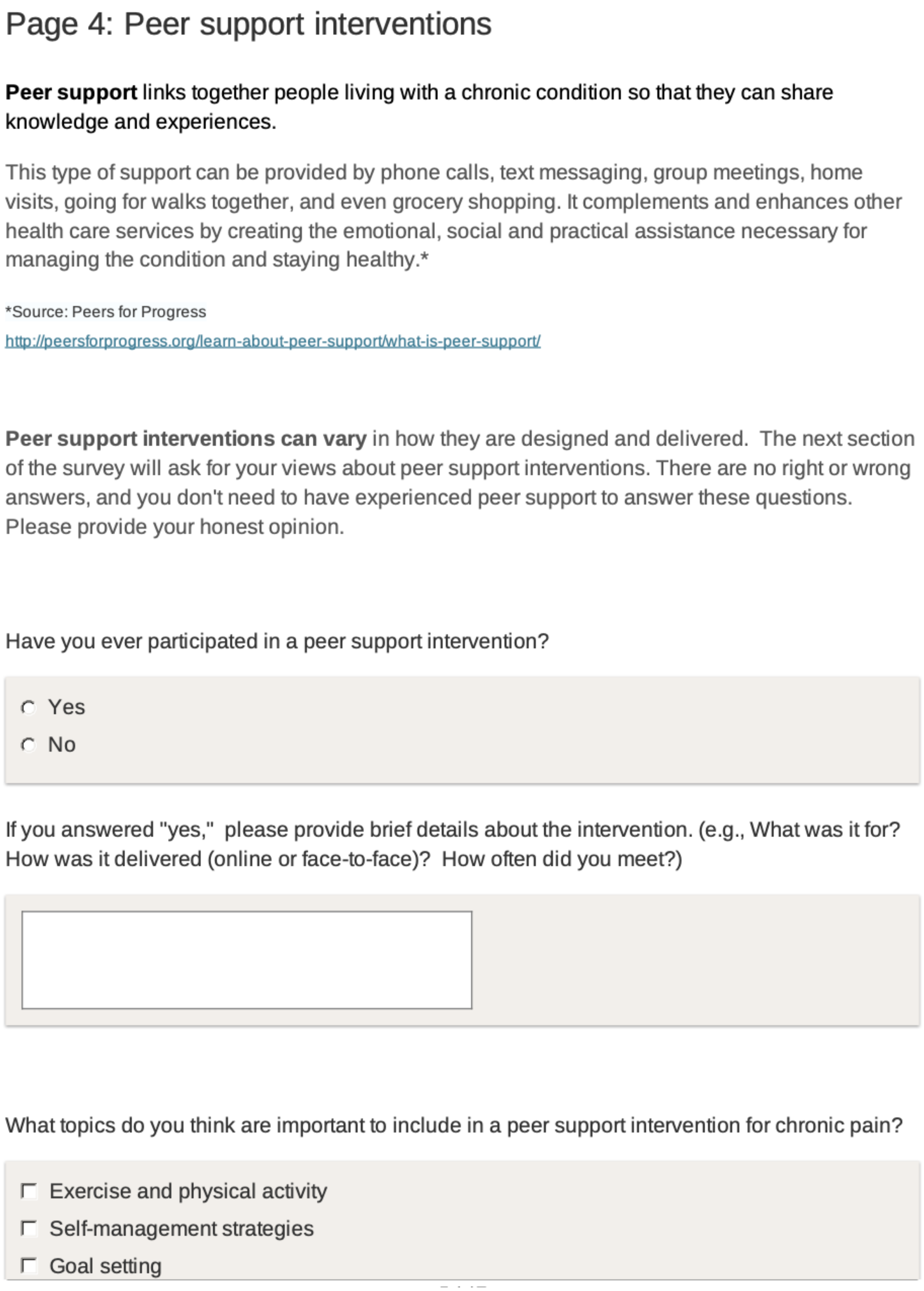
Chronic pain can be defined as pain that persists or recurs for longer than three months. It is a separate condition in its own right, and not merely an accompanying symptom of other diseases.

This is a survey for:

- adults
- living in the UK
- with experience of chronic non-cancer pain

Do you meet these criteria? ✱ *Required*

○ Yes
○ No
○ Don’t know



Page 4: Peer support interventions

Peer support links together people living with a chronic condition so that they can share knowledge and experiences.

This type of support can be provided by phone calls, text messaging, group meetings, home visits, going for walks together, and even grocery shopping. It complements and enhances other health care services by creating the emotional, social and practical assistance necessary for managing the condition and staying healthy.*

*Source: Peers for Progress
http://peersforprogress.org/learn-about-peer-support/what-is-peer-support/

Peer support interventions can vary in how they are designed and delivered. The next section of the survey will ask for your views about peer support interventions. There are no right or wrong answers, and you don't need to have experienced peer support to answer these questions. Please provide your honest opinion.

Have you ever participated in a peer support intervention?

○ Yes
○ No

If you answered "yes," please provide brief details about the intervention. (e.g., What was it for? How was it delivered (online or face-to-face)? How often did you meet?)

What topics do you think are important to include in a peer support intervention for chronic pain?

☐ Exercise and physical activity
☐ Self-management strategies
☐ Goal setting

☐ Pain science and pain education
☐ Making sense of one's pain experience
☐ Pain and pacing
☐ Other

If you selected Other, please specify:

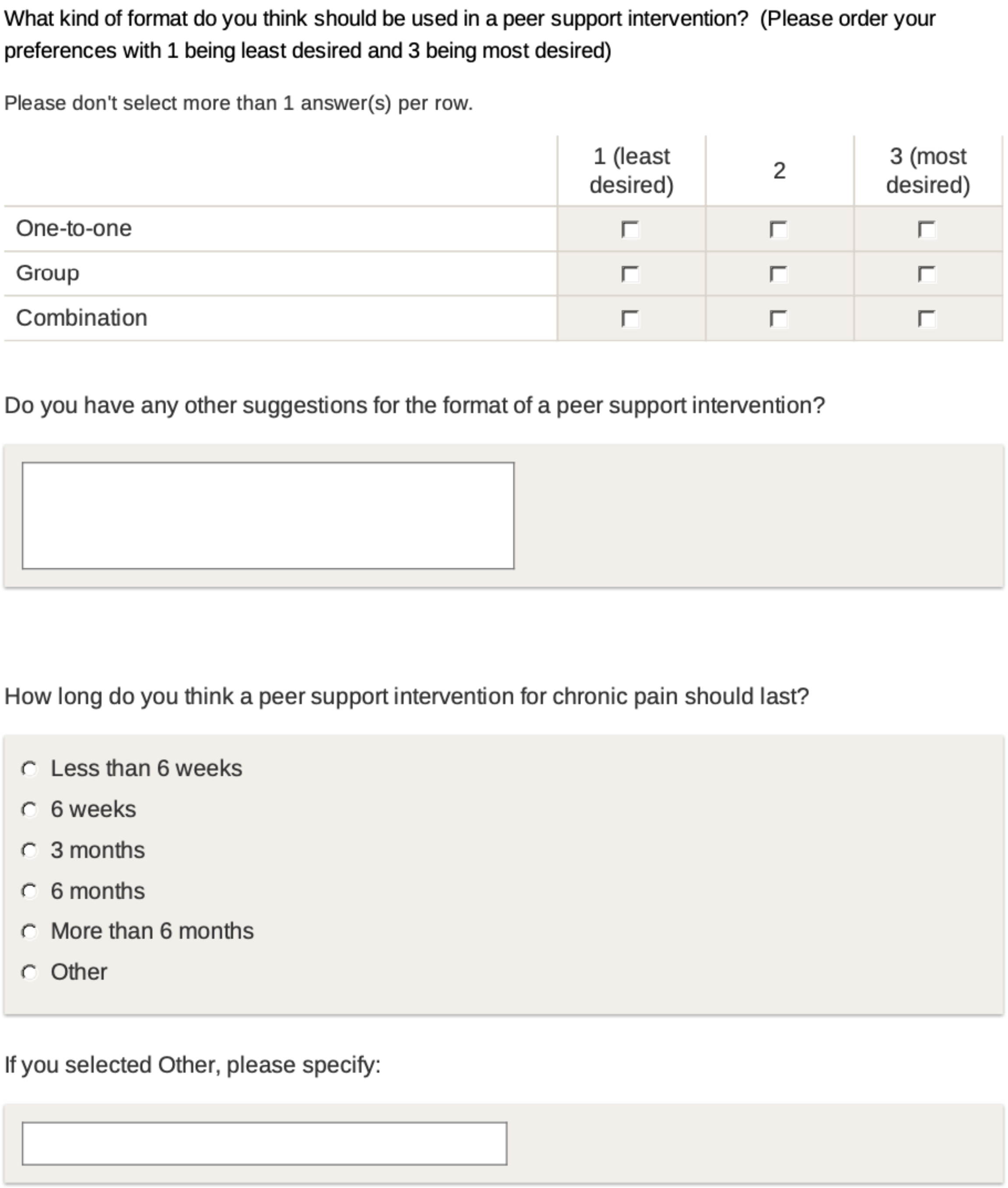
How do you think a peer support intervention for adults with chronic pain should be delivered? (Please order your preferences with 1 being least desired and 6 being most desired)

Please don't select more than 1 answer(s) per row.

	1 (least desired)	2	3	4	5	6 (most desired)
Face-to-face	☐	☐	☐	☐	☐	☐
Phone call	☐	☐	☐	☐	☐	☐
Video call	☐	☐	☐	☐	☐	☐
Messaging/email	☐	☐	☐	☐	☐	☐
Social media	☐	☐	☐	☐	☐	☐
*Combination of 2 or more of the above	☐	☐	☐	☐	☐	☐

*Combination of 2 or more of the above: Please specify which delivery modes you think should be combined:

Do you have any other suggestions for how peer support should be delivered?



What kind of format do you think should be used in a peer support intervention? (Please order your preferences with 1 being least desired and 3 being most desired)

Please don't select more than 1 answer(s) per row.

	1 (least desired)	2	3 (most desired)
One-to-one	☐	☐	☐
Group	☐	☐	☐
Combination	☐	☐	☐

Do you have any other suggestions for the format of a peer support intervention?

How long do you think a peer support intervention for chronic pain should last?

○ Less than 6 weeks
○ 6 weeks
○ 3 months
○ 6 months
○ More than 6 months
○ Other

If you selected Other, please specify:

How often do you think peers should meet together?

- ○ Once per week
- ○ Once every 2 weeks
- ○ Once per month
- ○ Other

If you selected Other, please specify (e.g. once per week individually + once every two weeks in a group):

☐

Consider an adult with chronic pain being matched with a peer support volunteer. How important do you think it is for the two people to have the same: gender, age group, chronic condition, interests, personality, politics, race, or sexuality. **Please indicate your response using the table below.**

Please don't select more than 1 answer(s) per row.

	Very unimportant	Somewhat unimportant	No opinion	Somewhat important	Very important
Gender	☐	☐	☐	☐	☐
Age group (+/- 5 years)	☐	☐	☐	☐	☐
Chronic condition	☐	☐	☐	☐	☐
Interests	☐	☐	☐	☐	☐
Personality	☐	☐	☐	☐	☐
Political views	☐	☐	☐	☐	☐
Race	☐	☐	☐	☐	☐
Sexuality	☐	☐	☐	☐	☐

Do you think peer support volunteers should receive training?

○ Yes
○ No

What topics do you think the training should cover?

How much training do you think peer support volunteers should receive?

○ 0-2 hours
○ 2-4 hours
○ 4-8 hours
○ 8+ hours
○ Other

If you selected Other, please specify:

What do you think would prevent someone from participating in a peer support intervention? (tick all that apply)

☐ Technological issues (access to smart device or WiFi connection)
☐ Transportation difficulties
☐ Lack of time/difficulty scheduling
☐ Worries about meeting new people
☐ Interest (do not want to be involved with a peer support intervention)
☐ Other

If you selected Other, please specify:

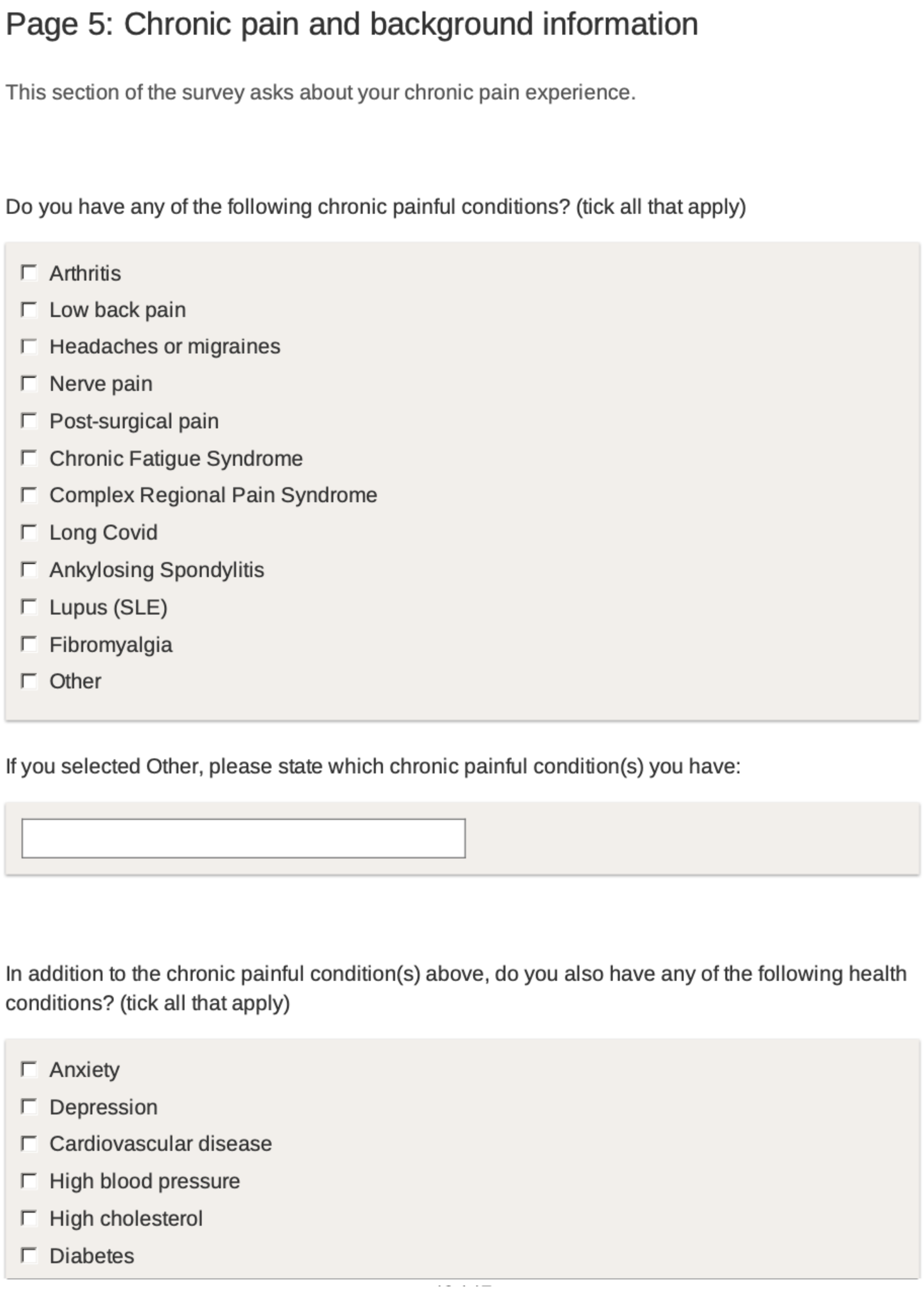
What do you think would help someone participate in a peer support intervention? (tick all that apply)

☐ Meeting with another person you can relate to
☐ Meeting is held in a convenient location
☐ Meeting is held online
☐ Facilitators of the meeting are helpful and friendly
☐ Other

If you selected Other, please specify:

Overall, what is your opinion of peer support for chronic pain? (i.e. Do you think it is valuable, important, helpful or not?)

Do you have any other comments you would like to make about peer support for chronic pain?



Page 5: Chronic pain and background information

This section of the survey asks about your chronic pain experience.

Do you have any of the following chronic painful conditions? (tick all that apply)

- ☐ Arthritis
- ☐ Low back pain
- ☐ Headaches or migraines
- ☐ Nerve pain
- ☐ Post-surgical pain
- ☐ Chronic Fatigue Syndrome
- ☐ Complex Regional Pain Syndrome
- ☐ Long Covid
- ☐ Ankylosing Spondylitis
- ☐ Lupus (SLE)
- ☐ Fibromyalgia
- ☐ Other

If you selected Other, please state which chronic painful condition(s) you have:

In addition to the chronic painful condition(s) above, do you also have any of the following health conditions? (tick all that apply)

- ☐ Anxiety
- ☐ Depression
- ☐ Cardiovascular disease
- ☐ High blood pressure
- ☐ High cholesterol
- ☐ Diabetes

☐ Other

If you selected Other, please state which condition(s) you have:

Have you ever had any of the following treatments for your chronic painful condition? (tick all that apply)

☐ Physiotherapy
☐ Chiropractic
☐ Osteopathy
☐ Acupuncture
☐ Talking therapies, such as cognitive behavioural therapy or counselling
☐ Exercise
☐ Support to improve sleep
☐ Paracetamol
☐ Anti-inflammatories such as ibuprofen, naproxen, celecoxib or diclofenac
☐ Steroid injections
☐ Weak opioids such as codeine or co-codamol
☐ Strong opioids such as tramadol tablets, morphine, buprenorphine or fentanyl patches
☐ Antidepressants, such as amitriptyline, nortriptyline or duloxetine
☐ Gabapentinoids, such as pregabalin or gabapentin
☐ None of these
☐ Other

If you selected Other, please state which treatment(s) you have had:

Page 6: Demographics

This is the last section of the survey. It asks for some information about you. It will not ask you for any information that could identify you such as your name.

What age are you?

- ○ 18-24
- ○ 25-34
- ○ 35-44
- ○ 45-54
- ○ 55-64
- ○ 65+

How would you describe your gender identity?

- ○ Woman
- ○ Man
- ○ In another way (if you would like, please specify what other words you use)
- ○ Prefer not to say

In another way (if you would like, please specify what other words you use)

How would you describe your current situation?

- ○ Self employed
- ○ Employed full time
- ○ Employed part time

○ Looking after the home or family
○ Permanently retired from work
○ Unemployed and seeking work
○ At school
○ In further/higher education
○ Government work or training scheme
○ Permanently sick or disabled
○ Unable to work due to short-term illness or injury
○ Other

If you selected Other, please specify:

What is your highest level of education?

○ No formal qualifications
○ National 5/O-level or equivalent
○ Higher/A-level or equivalent
○ Degree level e.g. BSc, BA
○ Master's Degree level e.g. MSc, MA
○ Doctorate
○ Other

If you selected Other, please specify:

What is your postcode?

Page 7: Final page

We are very grateful to you for taking the time to complete the survey, and your views will be very useful. We will use the views of everyone who completes this survey to inform the development of a peer support intervention.

The next stage of the study will be an online interview (approximately 1 hour) to explore some of these ideas further. If you would like to participate in the interview, please follow the link to provide your contact information. Your contact details will be kept separate from your survey response.

https://robertgordonuniversity.onlinesurveys.ac.uk/contact-details-interviews-

If you would like further information on managing chronic pain, the following sources may be of use:

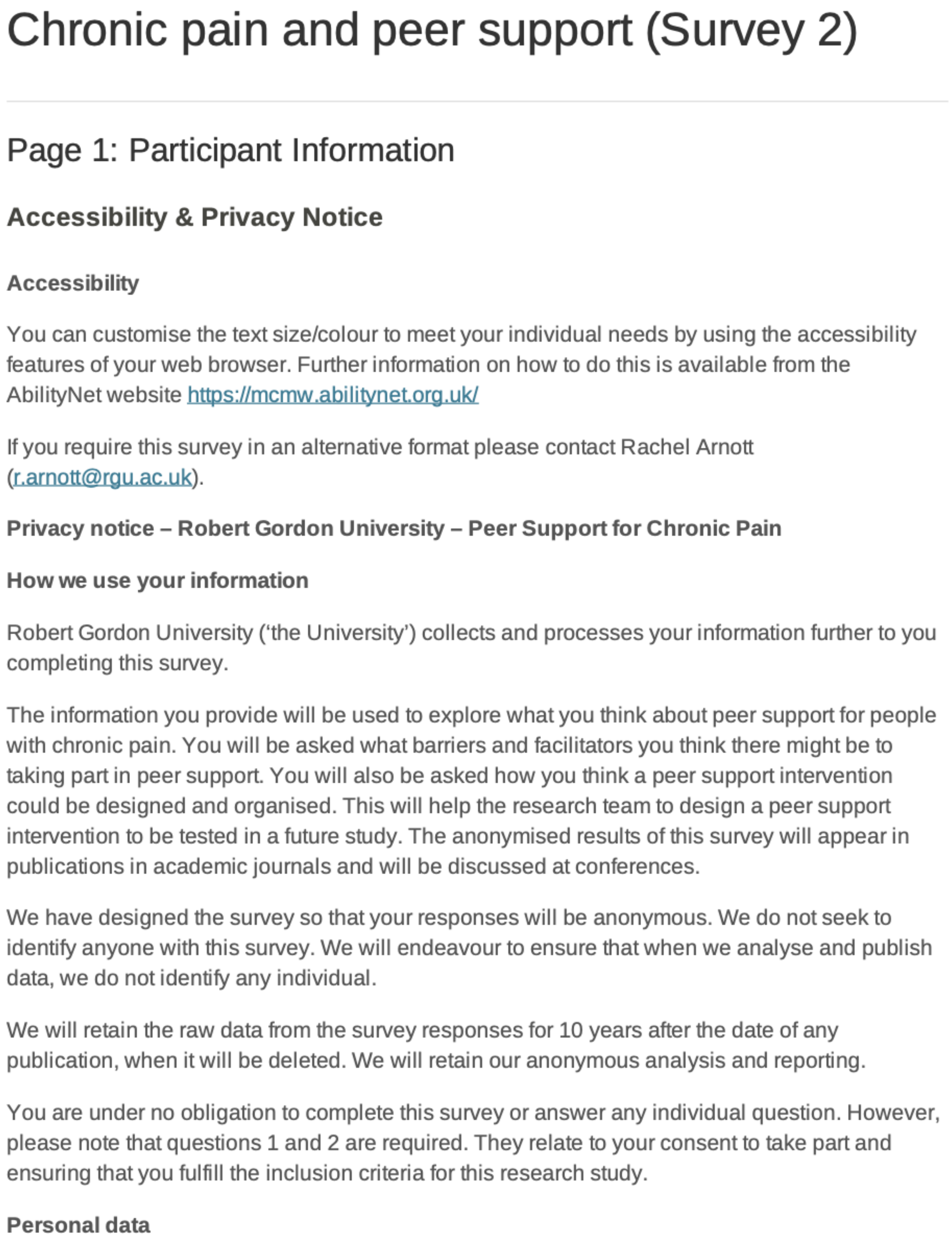
NHS Inform:

https://www.nhsinform.scot/illnesses-and-conditions/brain-nerves-and-spinal-cord/chronic-pain

Pain Association UK

https://painassociation.co.uk/

APPENDIX XV – SURVEY FOR HEALTHCARE PROFESSIONALS AND THOSE WITH EXPERIENCE WITH PEER SUPPORT INTERVENTIONS



Chronic pain and peer support (Survey 2)

Page 1: Participant Information

Accessibility & Privacy Notice

Accessibility

You can customise the text size/colour to meet your individual needs by using the accessibility features of your web browser. Further information on how to do this is available from the AbilityNet website https://mcmw.abilitynet.org.uk/

If you require this survey in an alternative format please contact Rachel Arnott (r.arnott@rgu.ac.uk).

Privacy notice – Robert Gordon University – Peer Support for Chronic Pain

How we use your information

Robert Gordon University ('the University') collects and processes your information further to you completing this survey.

The information you provide will be used to explore what you think about peer support for people with chronic pain. You will be asked what barriers and facilitators you think there might be to taking part in peer support. You will also be asked how you think a peer support intervention could be designed and organised. This will help the research team to design a peer support intervention to be tested in a future study. The anonymised results of this survey will appear in publications in academic journals and will be discussed at conferences.

We have designed the survey so that your responses will be anonymous. We do not seek to identify anyone with this survey. We will endeavour to ensure that when we analyse and publish data, we do not identify any individual.

We will retain the raw data from the survey responses for 10 years after the date of any publication, when it will be deleted. We will retain our anonymous analysis and reporting.

You are under no obligation to complete this survey or answer any individual question. However, please note that questions 1 and 2 are required. They relate to your consent to take part and ensuring that you fulfill the inclusion criteria for this research study.

Personal data

The personal data required for this survey is: your age, gender, education and profession. It is unlikely that any individual will be identified from this data. Should you provide personal data in response to any of our questions, please consider whether your words reveal circumstances which may identify you and whether you wish to include them. Any disclosure of personal data is at your own discretion.

Special categories of personal data

The University does not require any special categories of personal data in the completion of this survey.

Data controller

Should you provide personal data in response to this survey Robert Gordon University would be the data controller for this information. This data may be processed by the University's nominated agents such as software or service providers. Data will be processed using the University's business systems, including Microsoft 365.

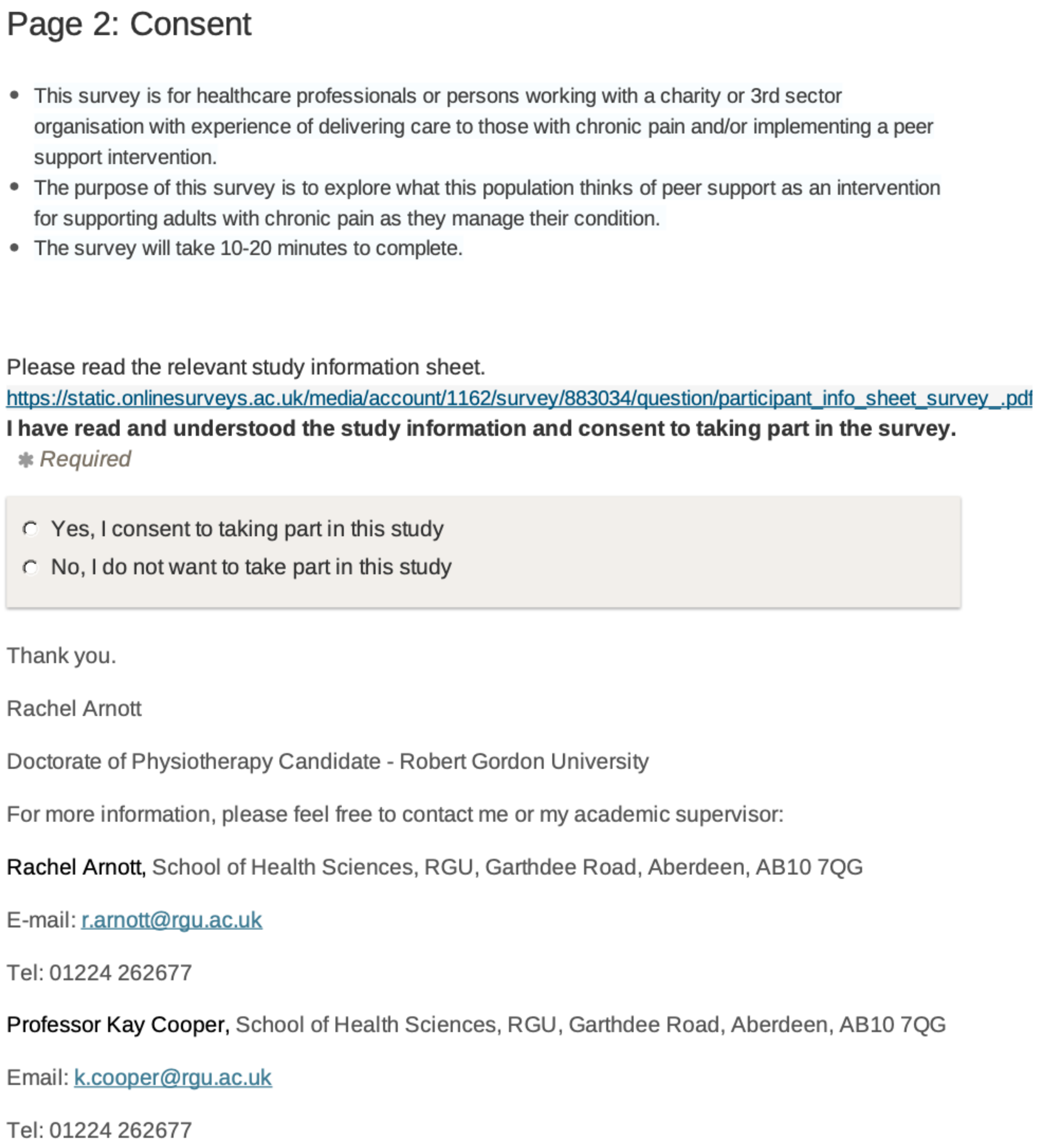
The University uses an online survey run by JISC to collect this information. For information on how this service secures your data please see https://www.jisc.ac.uk/online-surveys.

Lawful processing

If you choose to provide personal data in response to our questions, the University asserts that it is lawful for it to process your personal data for the purposes detailed above as necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller.

Your rights

The University respects your rights and preferences in relation to you. If you wish to update, access, erase, or limit the use of your information please let us know by emailing: r.arnott@rgu.ac.uk. If you wish to complain about the University's use of your information please contact the University's Data Protection Officer in the first instance by emailing DP@rgu.ac.uk. You may also wish to contact the Information Commissioner's Office.



Page 2: Consent

- This survey is for healthcare professionals or persons working with a charity or 3rd sector organisation with experience of delivering care to those with chronic pain and/or implementing a peer support intervention.
- The purpose of this survey is to explore what this population thinks of peer support as an intervention for supporting adults with chronic pain as they manage their condition.
- The survey will take 10-20 minutes to complete.

Please read the relevant study information sheet.
https://static.onlinesurveys.ac.uk/media/account/1162/survey/883034/question/participant_info_sheet_survey_.pdf
I have read and understood the study information and consent to taking part in the survey.
✱ *Required*

○ Yes, I consent to taking part in this study
○ No, I do not want to take part in this study

Thank you.

Rachel Arnott

Doctorate of Physiotherapy Candidate - Robert Gordon University

For more information, please feel free to contact me or my academic supervisor:

Rachel Arnott, School of Health Sciences, RGU, Garthdee Road, Aberdeen, AB10 7QG

E-mail: r.arnott@rgu.ac.uk

Tel: 01224 262677

Professor Kay Cooper, School of Health Sciences, RGU, Garthdee Road, Aberdeen, AB10 7QG

Email: k.cooper@rgu.ac.uk

Tel: 01224 262677

Page 3: Chronic pain and peer support interventions

Chronic pain can be defined as pain that persists or recurs for longer than three months. It is a separate condition in its own right, and not merely an accompanying symptom of other diseases.

Peer support links together people living with a chronic condition so that they can share knowledge and experiences.

This type of support can be provided by phone calls, text messaging, group meetings, home visits, going for walks together, and even grocery shopping. It complements and enhances other health care services by creating the emotional, social and practical assistance necessary for managing the condition and staying healthy.*

*Source: Peers for Progress
http://peersforprogress.org/learn-about-peer-support/what-is-peer-support/

This is a survey for:

- healthcare professionals OR persons working in a charity or 3rd sector organisation
- who are living in the UK
- with experience of treating individuals with chronic non-cancer pain AND/OR designing or delivering a peer support intervention

Do you meet these criteria? ✱ *Required*

○ Yes
○ No
○ Don’t know

Page 4: Peer support interventions

Peer support interventions can vary in how they are designed and delivered. The purpose of this survey is to understand professional opinions of various intervention components in order to inform the development of a future peer support intervention.

The next series of questions will ask about your professional opinion regarding intervention components.

Have you ever been involved with the design or delivery of a peer support intervention?

○ Yes
○ No

Please provide brief details about the intervention. (e.g., What was if for? How was it delivered (online or face-to-face)? How often did participants meet?)

What topics do you think are important to include in a peer support intervention for chronic pain?

☐ Exercise and physical activity
☐ Self-management strategies
☐ Goal setting
☐ Pain science and pain education
☐ Making sense of one's pain experience
☐ Pain and pacing
☐ Other

If you selected Other, please specify:

What do you think is the optimal delivery mode for a peer support intervention for adults with chronic pain? (Please order your preferences with 1 being least desired and 6 being most desired)

Please don't select more than 1 answer(s) per row.

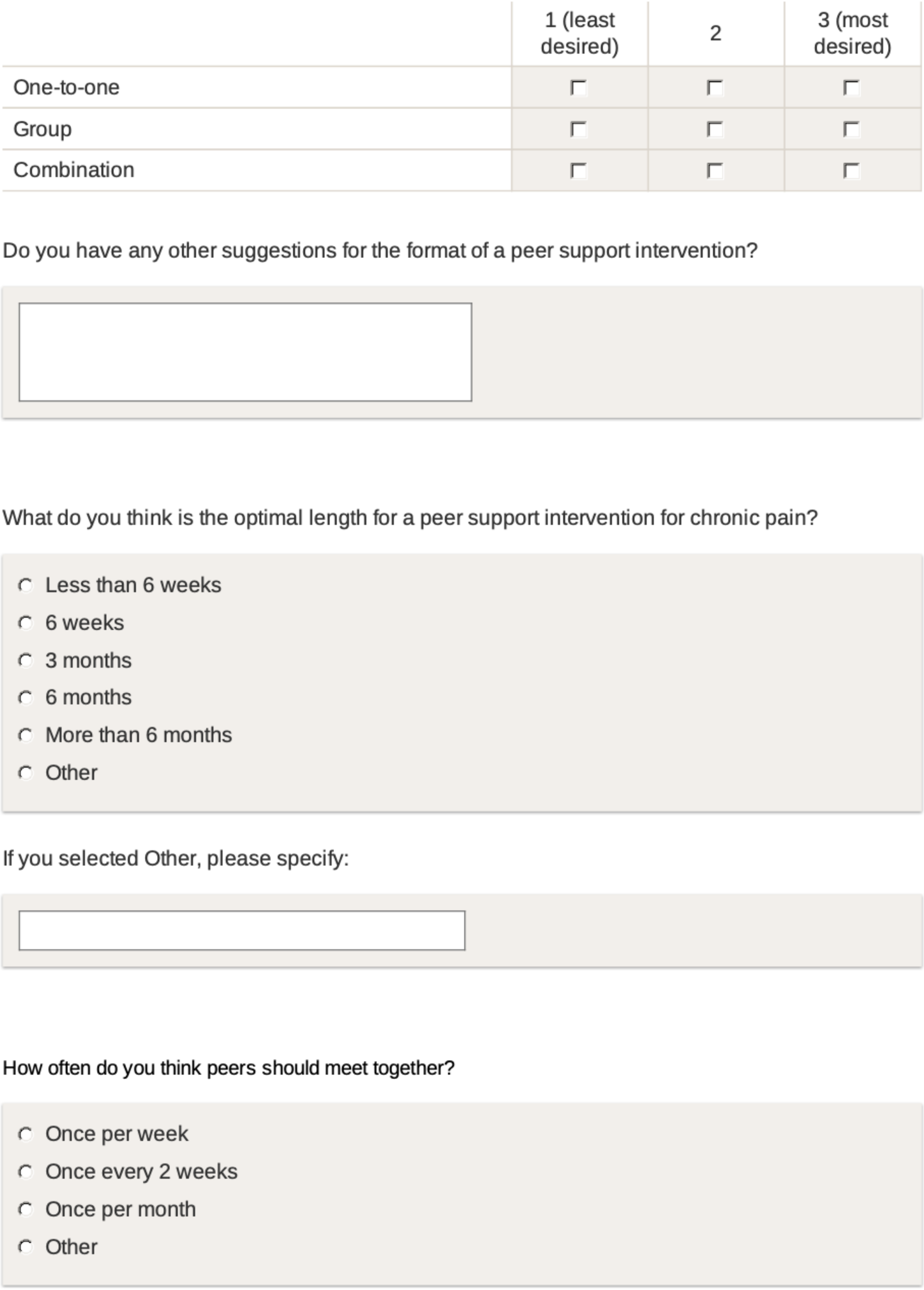
	1 (least desired)	2	3	4	5	6 (most desired)
Face-to-face	☐	☐	☐	☐	☐	☐
Phone call	☐	☐	☐	☐	☐	☐
Video call	☐	☐	☐	☐	☐	☐
Messaging/email	☐	☐	☐	☐	☐	☐
Social media	☐	☐	☐	☐	☐	☐
*Combination of 2 or more of the above	☐	☐	☐	☐	☐	☐

*Combination of 2 or more of the above: Please specify which delivery modes you think should be combined:

Do you have any other suggestions for how peer support should be delivered?

What do you think is the optimal format for a peer support intervention for adults with chronic pain? (Please order your preferences with 1 being least desired and 3 being most desired)

Please don't select more than 1 answer(s) per row.



	1 (least desired)	2	3 (most desired)
One-to-one	☐	☐	☐
Group	☐	☐	☐
Combination	☐	☐	☐

Do you have any other suggestions for the format of a peer support intervention?

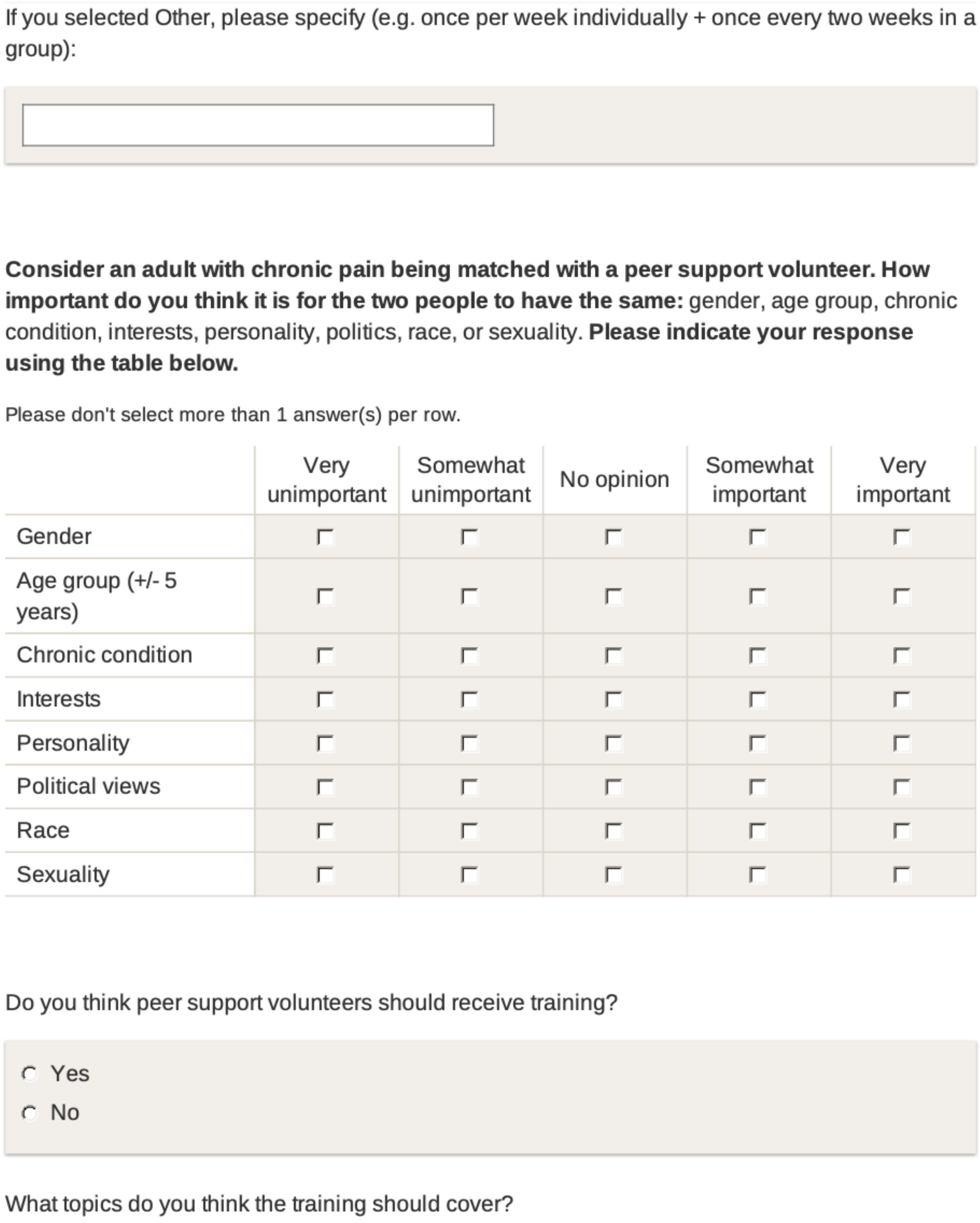
What do you think is the optimal length for a peer support intervention for chronic pain?

- ○ Less than 6 weeks
- ○ 6 weeks
- ○ 3 months
- ○ 6 months
- ○ More than 6 months
- ○ Other

If you selected Other, please specify:

How often do you think peers should meet together?

- ○ Once per week
- ○ Once every 2 weeks
- ○ Once per month
- ○ Other



If you selected Other, please specify (e.g. once per week individually + once every two weeks in a group):

Consider an adult with chronic pain being matched with a peer support volunteer. How important do you think it is for the two people to have the same: gender, age group, chronic condition, interests, personality, politics, race, or sexuality. **Please indicate your response using the table below.**

Please don't select more than 1 answer(s) per row.

	Very unimportant	Somewhat unimportant	No opinion	Somewhat important	Very important
Gender	☐	☐	☐	☐	☐
Age group (+/- 5 years)	☐	☐	☐	☐	☐
Chronic condition	☐	☐	☐	☐	☐
Interests	☐	☐	☐	☐	☐
Personality	☐	☐	☐	☐	☐
Political views	☐	☐	☐	☐	☐
Race	☐	☐	☐	☐	☐
Sexuality	☐	☐	☐	☐	☐

Do you think peer support volunteers should receive training?

○ Yes
○ No

What topics do you think the training should cover?

How much training do you think peer support volunteers should receive?

- ☐ 0-2 hours
- ☐ 2-4 hours
- ☐ 4-8 hours
- ☐ 8+ hours
- ☐ Other

If you selected Other, please specify:

What do you think would prevent someone from participating in a peer support intervention? (tick all that apply)

- ☐ Technological issues (access to smart device or WiFi connection)
- ☐ Transportation difficulties
- ☐ Time/Scheduling issues
- ☐ Psychosocial barriers (unsure of successfully building rapport with other participants)
- ☐ Interest (do not want to be involved with a peer support intervention)
- ☐ Other

If you selected Other, please specify:

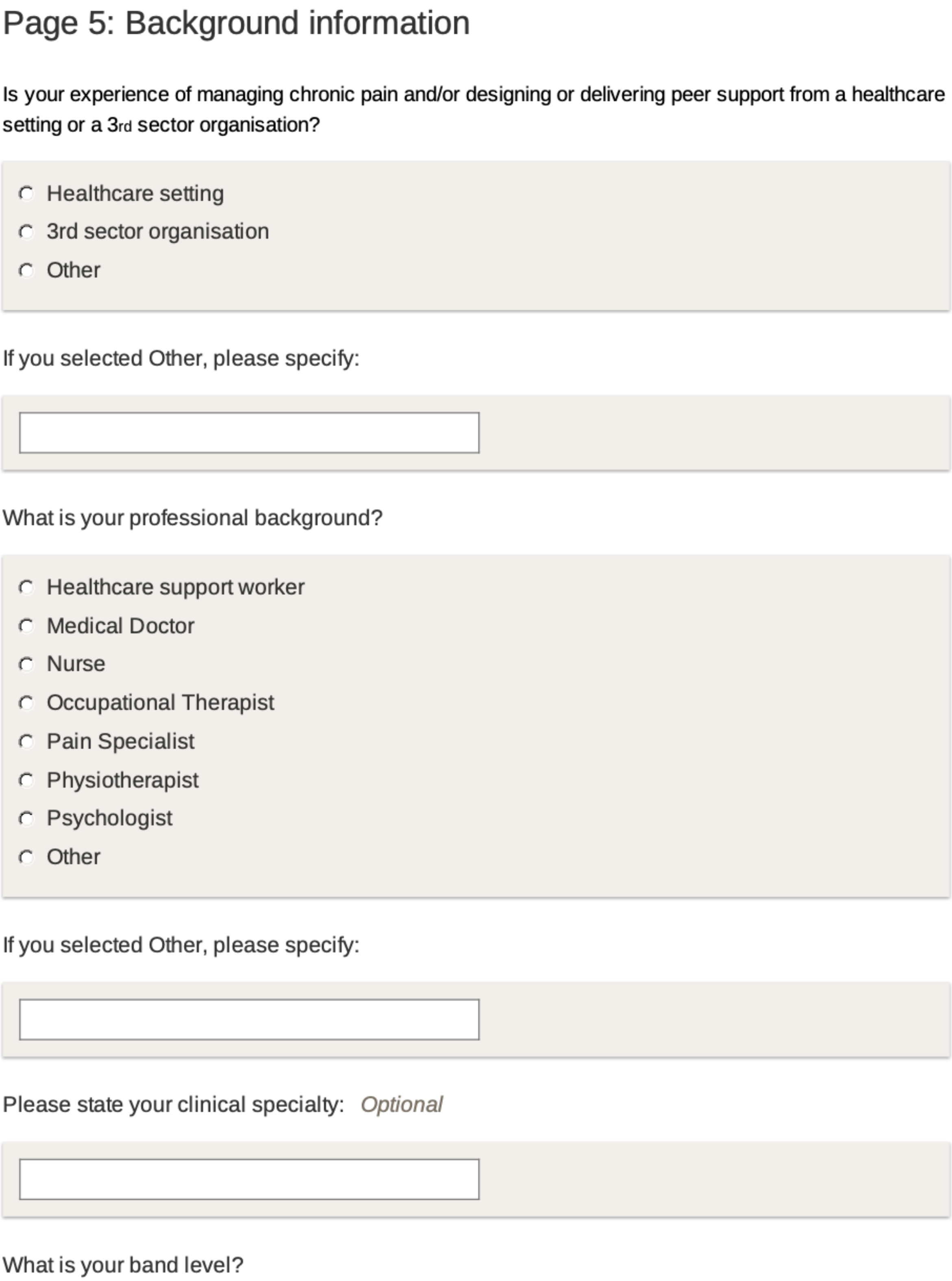
What do you think would help someone participate in a peer support intervention? (tick all that apply)

☐ Connecting with another participant they can relate to
☐ Intervention is held in a convenient location
☐ Intervention is held online
☐ Facilitators of intervention are helpful and friendly
☐ Other

If you selected Other, please specify:

Overall, what is your opinion of peer support for chronic pain? (i.e. Do you think it is valuable, important, helpful or not?)

Do you have any other comments you would like to make about peer support for chronic pain?



Page 5: Background information

Is your experience of managing chronic pain and/or designing or delivering peer support from a healthcare setting or a 3rd sector organisation?

- ○ Healthcare setting
- ○ 3rd sector organisation
- ○ Other

If you selected Other, please specify:

What is your professional background?

- ○ Healthcare support worker
- ○ Medical Doctor
- ○ Nurse
- ○ Occupational Therapist
- ○ Pain Specialist
- ○ Physiotherapist
- ○ Psychologist
- ○ Other

If you selected Other, please specify:

Please state your clinical specialty: *Optional*

What is your band level?

○ Healthcare support worker (Band 1-4)
○ Band 5
○ Band 6
○ Band 7
○ Band 8

What is your role in the 3rd sector organisation?

☐

How many years have you been: managing people with chronic pain and/or designing or delivering peer support? **Please indicate your response using the table below.**

Please don't select more than 1 answer(s) per row.

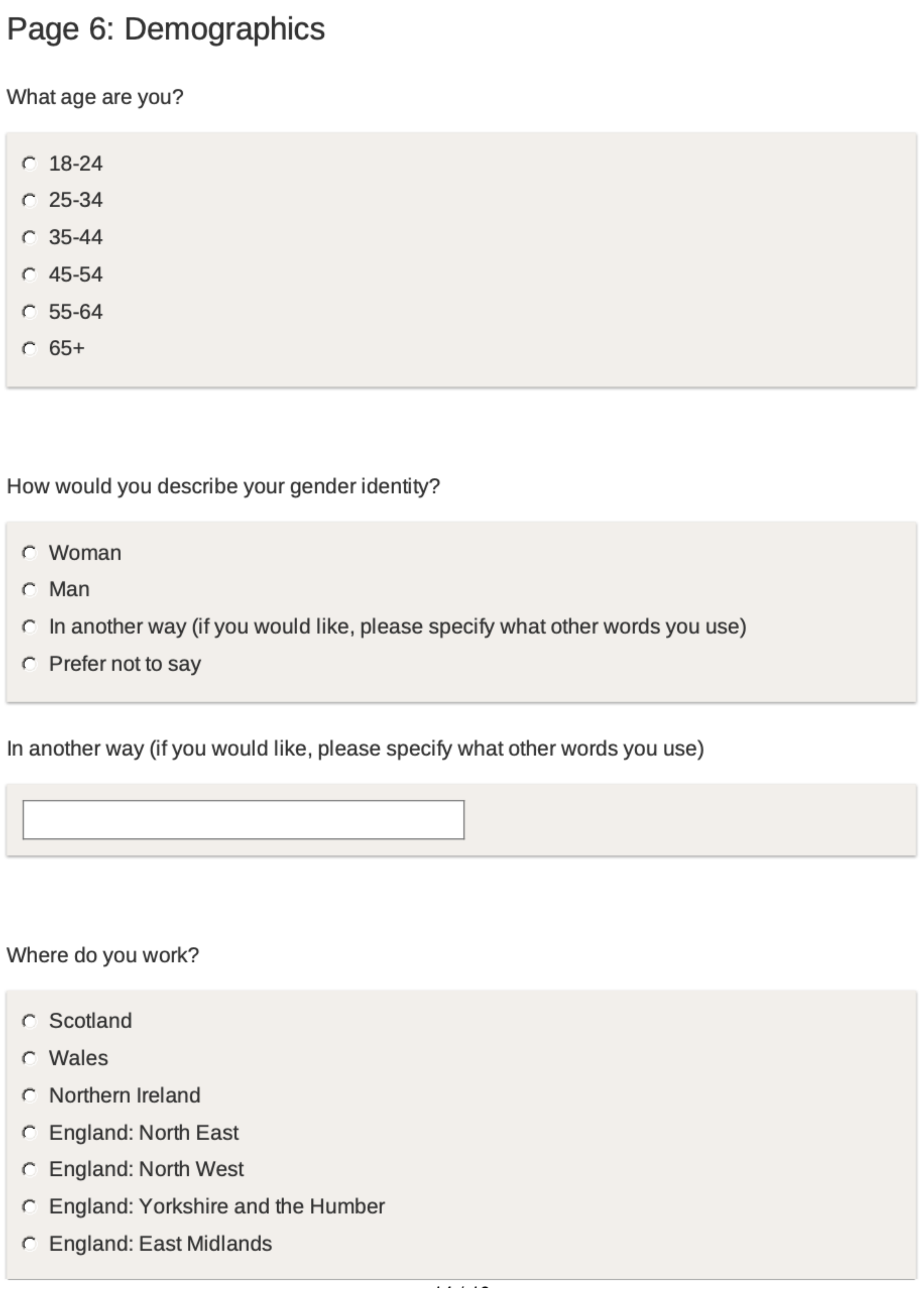
	Managing people with chronic pain	Designing or delivering peer support
N/A	☐	☐
0-5 years	☐	☐
6-10 years	☐	☐
11-20 years	☐	☐
21+ years	☐	☐

Please indicate your highest professional qualification

○ Undergraduate degree
○ Postgraduate degree
○ PhD
○ Diploma
○ None

○ Prefer not to say
○ Other

If you selected Other, please specify:



Page 6: Demographics

What age are you?

- ○ 18-24
- ○ 25-34
- ○ 35-44
- ○ 45-54
- ○ 55-64
- ○ 65+

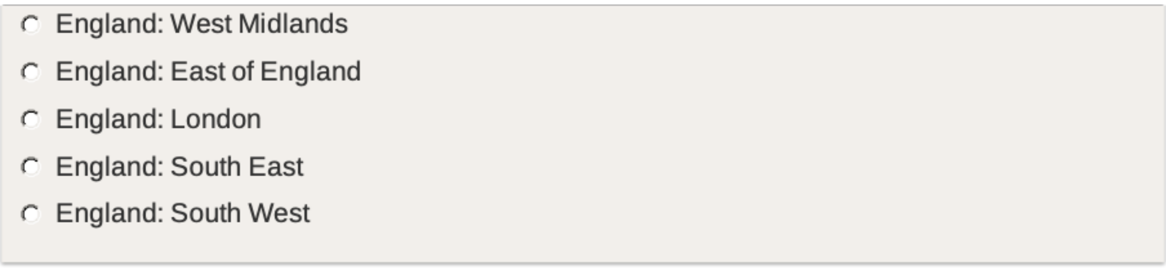
How would you describe your gender identity?

- ○ Woman
- ○ Man
- ○ In another way (if you would like, please specify what other words you use)
- ○ Prefer not to say

In another way (if you would like, please specify what other words you use)

Where do you work?

- ○ Scotland
- ○ Wales
- ○ Northern Ireland
- ○ England: North East
- ○ England: North West
- ○ England: Yorkshire and the Humber
- ○ England: East Midlands



○ England: West Midlands
○ England: East of England
○ England: London
○ England: South East
○ England: South West

Page 7: Final page

We are very grateful to you for taking the time to complete the survey, and your views will be very useful. We will use the views of everyone who completes this survey to inform the development of a peer support intervention.

The next stage of the study will be an online focus group (approximately 1 hour) to explore some of these ideas further. If you would like to participate in the focus group, please follow the link to provide your contact information. Your contact details will be kept separate from your survey response.

https://robertgordonuniversity.onlinesurveys.ac.uk/contact-details-focus-groups-

APPENDIX XVI – INTERVIEW SCHEDULE WITH ADULTS WITH CHRONIC PAIN

I: Housekeeping

- Welcome participant
- Explain purpose of interview
    - Some of these questions will be familiar to you (from the survey) but the purpose of the interview is to learn a bit more about the reasoning behind how you may have answered some of the survey questions, getting into more of the "Why" behind your answer
    - Just for your information, I don't know how you personally answered in the survey as your responses are anonymous
    - When you signed up for this interview, it was a separate form and all of your survey responses are completely anonymous
- Explain how confidentiality & anonymity will be ensured
    - Anonymous
        - Name (or any identifiable information) will not be associated with answers
    - Confidential
        - Interview will be recorded on encrypted device
        - I will listen back to our conversation, write it up into a transcript, and delete it from this device
        - Any names or places will be removed in the transcript
- Remind of length of interview (should last up to an hour)
- Consent to start recording & for notes to be taken

***Begin audio recording**

- Obtain verbal informed consent (verbalise participant ID number)
    - Required to do this by ethics committee
    - Demographics
    - **STOP RECORDER**

II: Interview starts

***Begin audio recording** (verbalise participant ID number)

Peer Support Interventions

1. So how would you describe your pain?
2. What kinds of treatments have you had for your condition?
    a. Prompts, if needed:
    b. Physiotherapy
    c. Chiropractic
    d. Osteopathy
    e. Acupuncture
    f. Talking therapies, such as cognitive behavioural therapy or counselling
    g. Exercise
    h. Support to improve sleep
    i. Paracetamol
    j. Anti-inflammatories such as ibuprofen, naproxen, celecoxib or diclofenac
    k. Steroid injections
    l. Weak opioids such as codeine or co-codamol
    m. Strong opioids such as tramadol tablets, morphine, buprenorphine or fentanyl patches
    n. Antidepressants, such as amitriptyline, nortriptyline or duloxetine
    o. Gabapentinoids, such as pregabalin or gabapentin
    p. None of these
    q. Other

3. In addition to this chronic painful condition, do you have any other health conditions?
    a. Prompts, if needed:
    b. Anxiety
    c. Depression
    d. Cardiovascular disease
    e. High blood pressure
    f. High cholesterol
    g. Diabetes
    h. Other
4. **What do you think of when you hear "peer support"**

What do you understand by the term "peer support? "

    a. Prompt: here's a definition of peer support, is that what you think of or would you think of anything else?
    b. **Peer support** links together people living with a chronic condition so that they can share knowledge and experiences.
    c. This type of support can be provided by phone calls, text messaging, group meetings, going for walks together, and even grocery shopping. It complements and enhances other health care services by creating the emotional, social and practical assistance necessary for managing the condition and staying healthy. (Source: Peers for Progress)
5. What's your experience of peer support?
    a. Probes: can you tell me a bit about it? Who delivered it? What did you think of it?
6. Do you think you would potentially benefit from a peer support intervention?
    a. How?
    b. Do you think other people would benefit?
        i. And if yes, think through this lens for further questions
        ii. Who and why it's beneficial for them or not
    c. In what way? Why or how?
    d. If no, tell me why
    e. E.g. learning of other resources/management or treatment options, reduced loneliness/depression, improved quality of life, socialization, etc.
7. Our aim with this research is to develop a peer support intervention for adults with chronic non-cancer pain, what do you think it should include?
    a. Think aloud vignette
    b. Prompt: Different things have been suggested that could be helpful
    Prompts e.g. pacing, goal setting, self-management techniques…
        i. And how do you think it should be delivered?
            1. Face-to-face, online, telephone, combination?
        ii. In a group setting or 1:1?
        iii. Who by?
            1. Trained vs untrained?
        iv. How long?
        v. Consider being matched with another peer, what characteristics are important to you?
            1. Gender, age, condition, interests, personality, political views, sexuality
8. Do you think there would be any barriers to setting it up or getting people to take part?
    a. And how might these be overcome?
9. What would help these programs run well or be successful?
10. Anything else you'd like to discuss or share?

*STOP audio recorder

III: Ending the interview

- Review answers/ensure these have been documented accurately
    - So we've talked about:
        - your own experience with chronic pain,
        - your thoughts around the idea of peer support,
        - how it could be beneficial,
        - how you'd like a program to be designed and what things would help it be successful
- Thank participant for taking part in interview and providing valuable information
- Reminder re: confidentiality & anonymity
- Inform participant that a summary of results will be made available to them if they wish – note this and make sure have preferred contact details
    - Would you like to receive a summary of the results, autumn time...
    - How to contact them, email?
- Any final questions

APPENDIX XVII – FOCUS GROUP/INTERVIEW SCHEDULE WITH HCPS

***Rachel check written consent already received for all participants**

I: Housekeeping

- Welcome participant
- Explain purpose of focus group
    - Some of these questions will be familiar to you (from the survey) but the purpose of this focus group is to learn a bit more about the reasoning behind how you may have answered some of the survey questions, getting into more of the "Why" behind your answer
    - Just for your information, I don't know how you personally answered in the survey as your responses are anonymous
    - When you signed up for this focus group, it was a separate form and all of your survey responses are completely anonymous
- Explain how confidentiality & anonymity will be ensured
    - Anonymous
        - Name (or any identifiable information) will not be associated with answers
    - Confidential
        - Focus group will be recorded on encrypted device
        - I will listen back to our conversation, write it up into a transcript, and delete it from this device
        - Any names or places will be removed in the transcript
- Remind of length of focus group (should last up to an hour)
- *Focus group Ground rules:*
    - *Everything that is said is confidential*
    - *Can speak in general terms about what we discussed, but nothing identifiable*
- Consent to start recording & for notes to be taken

II: Focus group starts

*Begin audio recording

Introductions

a. Ask participants: Introduce self, where they are working, experience in terms of chronic pain

Peer Support Interventions

1) **What do you think of when you hear "peer support"**
   What do you understand by the term, "peer support?"
   a) Prompt: here's a definition of peer support, is that what you think of or would you think of anything else?

- b) **Peer support** links together people living with a chronic condition so that they can share knowledge and experiences.
- c) This type of support can be provided by phone calls, text messaging, group meetings, going for walks together, and even grocery shopping. It complements and enhances other health care services by creating the emotional, social and practical assistance necessary for managing the condition and staying healthy. (Source: Peers for Progress)

2) **Have you ever been involved in the design or delivery of a PSI?**
   - a) Probes: Can you tell me a bit about it? What did you think of it?
   - b) What was it for? How was it delivered (online or face-to-face)

3) **Do you think any of your patients would potentially benefit from a peer support intervention?**
   - **a) What sort of conditions or types of patients would it be most beneficial for?**
     - i) Alternatively, which types of patients may not benefit?
   - **b) How would they benefit?**
     - i) E.g. learning of other resources/management or treatment options, reduced loneliness/depression, improved quality of life, socialization, etc.

4) **Our aim with this research is to develop a peer support intervention for adults with chronic non-cancer pain, what do you think it should include?**

   Prompt: Different things have been suggested that could be helpful, such as…

   Think aloud…
   - a) What topics should it include?
     - i) Prompt: pacing, goal setting, self-management techniques, etc.
   - b) And how do you think it should be delivered?
     - i) Face-to-face, online, telephone, combination?
   - c) In a group setting or 1:1?
   - d) Who by?
     - i) Trained vs untrained?
   - e) How long?
   - f) Consider someone with chronic pain being matched with another peer, what characteristics do you think are important for them to match on?
     - i) Gender, age, condition, interests, personality, political views, sexuality

5) Do you think there would be any barriers to setting it up or getting people to take part?
   - a) And how might these be overcome?

6) What would help these programs run well or be successful?
7) Anything else you'd like to discuss or share?

*Stop audio recording

III: Ending the focus group

- Review answers
  - o So we've talked about:
    - ▪ your thoughts around the idea of peer support,
    - ▪ what kinds of patients it could be helpful for (or not)
    - ▪ how you'd like a program to be designed and what things would help it be successful

- Thank participant for taking part in the focus group and providing valuable information
- Reminder re: confidentiality & anonymity
- Inform participant that a summary of results will be made available to them if they wish – note this and make sure have preferred contact details
    - Would you like to receive a summary of the results, autumn time...
    - How to contact them, email?
- Any final questions