Chronic pain patients' perspectives of treatment: A qualitative exploration of multidisciplinary pain management programmes and decision-making when considering CBD in aiding the management of their chronic pain condition.

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Introduction Chapter

Defining chronic pain

According to the International Classification of Diseases, 11th Edition (ICD-11) (World Health Organisation, 2022), chronic pain (CP) is defined as pain that persists longer than 3 months. The International Association for the Study of Pain (IASP) task force that supported the development of guidance and defining CP for ICD-11 state that CP is "a major source of suffering" and "interferes with daily functioning and is often accompanied by distress" (Treede et al., 2019; P19). As part of this guidance, CP has been divided in to two types; 'chronic primary pain', whereby pain cannot be explained by any other condition, and 'chronic secondary pain', pain related to an underlying disease and this is further divided up in to 6 subcategories. Pain, dependent on complexity, may be classified in more than one of these types or categories.

The impact of chronic pain

A recent systematic review (Fayaz, et al., 2016) estimated that CP affects a third to a half of the UK population, approximately 28 million adults. Research indicates that CP diagnoses place a high demand on the National Health Service (NHS), with musculoskeletal pain conditions, a subcategory of chronic secondary pain, accounting for a large proportion of general practitioner (GP) appointments (Department of Health, 2006; Chief Medical Officer, 2008; Skills for Health, 2018), with the likelihood that the cost and demand on the NHS will increase (Health Education England, 2020).

CP differs from acute pain, in duration of symptoms and because the body is typically not signalling physiological damage or the need for repair or medical intervention (Loeser & Melzack, 1999). As a result of the limited medical interventions available in the treatment of CP, it can have deleterious effects on an individual's physical, psychological and social

wellbeing (Breivik et al., 2006). CP patients' overall quality of life has been posited to be poorer when compared with the general public and individuals living with other long-term conditions (Hadi et al., 2019). Moreover, the physical and psychosocial impact on individuals are important factors in the classification of CP (Turk et al., 2016).

The reduced functioning associated with CP can have a profound impact on an individual's quality of life (Vetter, 2007). Reduced functioning is reported to have negative consequences on CP patients' employment (Smith et al., 2001) and household income when compared to non-chronic populations (Kemler and Furnée, 2022). Further to this, evidence suggests that this can have a huge impact on the UK economy, due to reduced work performance (Blyth et al., 2003), productivity and absenteeism (Phillips, 2009) during employment. Although this research provides some insight in to the interaction between pain and functioning, this still remains a complex relationship, whereby each are influenced by various other factors such as the resources and coping strategies available to help cope with pain, pain intensity, and psychosocial factors (Perruchoud et al., 2014).

The psychological impact of pain has been shown to have deleterious effects on self-regulation, executive functioning (Solberg Nes et al., 2009) and cognitive functioning (McGuire, 2013). Mental health difficulties and CP appear to exhibit a bi-directional relationship, with CP and disability resulting in distress and difficulties with motivation, self-efficacy and anxiety posing a barrier to engaging in coping strategies or activity (Bair et al., 2003; McWilliams et al., 2003; Holmes et al., 2013). This provides evidence to suggest that functional and psychological factors are closely related and consequently impact quality of life.

CP can also have a serious detrimental effect beyond the individual's life, to those in their social network and family environment, by restricting social interactions (Moulin et

al., 2002) due to the unpredictable nature of pain (Closs et al., 2009). Consequently, this has an impact on their family and partner's sense of family satisfaction (Callado et al., 2014).

Further to this, the management of CP rarely involves solely reducing the level of pain experienced; it can also be the management of concomitant symptoms such as depression, fatigue, difficulties with sleep and overall functioning (Ashburn & Staats, 1999). As a result of how these subjective, complex, and multifaceted experiences negatively compound the management of their condition or quality of life, a shift towards a biopsychosocial approach to inform support and treatment of CP patients is required to address the widespread impact these conditions can have.

The current studies

As discussed, in order to address the impact of CP, a biopsychosocial approach has been advised (The British Pain Society, 2013). The biopsychosocial model was first introduced by Engel (1977), where he posited that patients' illnesses needed to be better understood through the biological, psychological and social dimensions of illness in order for treatment to be effective. This has been applied to the CP population and is considered a heuristic approach to pain management, allowing for effective multidisciplinary and patient centred treatment (Bevers et al., 2016). A systematic review is presented in Chapter 1 which explores patients' perspectives of multidisciplinary interventions, specifically those that are psychologically-informed. The paper adopts a systematic and narrative review of nine qualitative studies of participants perspectives of these types of interventions. By doing so, the review contributes to a limited evidence base concerning patients' perspectives of pain management and identifies domains and outcomes that were deemed important to patients which might be considered in future research. The empirical paper continues to explore CP patients' perspectives of considering and taking cannabidiol (CBD) for their CP condition. The paper considers the decision-making processes that patients might undergo and also the

mechanisms and context in which these processes exist. In an attempt to pharmacologically reduce pain intensity, research posits we can inadvertently increase suffering due to adverse side effects and dependency. Various studies have focused on the potential for iatrogenic harm caused by opioid (Ballantyne, 2017), antiepileptic medicines commonly given for primary pain (Morrison et al., 2017) and various antidepressant medications (Riediger et al., 2017). Despite this, the biomedical intervention for CP still remains an important part of multidisciplinary management. Therefore, it is important to consider the impact and decision-making processes involved in patients accessing prescribed and non-prescribed medications that aim to reduce pain.

A summary of the requirements and reasons for the proposed journal for publication of these chapters are detailed in the Appendix (Appendix 1).

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Chapter 1 - Systematic Review

Title

A systematic review and narrative synthesis of qualitative evidence exploring chronic pain patients' views of psychologically informed pain management programmes

Abstract

Research relating to Pain Management Programmes (PMPs) has found there to be heterogeneity in the definition, dose and how the effectiveness of these interventions is measured. This review aimed to synthesise qualitative evidence of chronic pain (CP) patients' perspectives of psychologically informed PMPs. Electronic searches of CINAHL, PsychINFO, PubMed and Web of Science were completed, including published and grey literature. The review included articles that identified the PMP intervention as including two or more disciplines, one of which was required to be a qualified psychologist or therapist, and involved in-depth qualitative data from the patients' perspectives about their experience. The articles included were quality assessed using the Critical Appraisal Skills Programme qualitative checklist. Five overarching themes were identified across articles and synthesised: 1) Group processes, 2) Group structure and recommendations 3) Previous experiences of treatment 4) Facilitators and barriers to change 5) Improved communication and relationships. Key findings were that many patients found benefit in being part of a group, a positive shift in their relationship with themselves, others (including friends and family, and clinicians) and pain itself. There was also a consideration of wider social factors and a 'readiness' as factors that influenced outcome. Healthcare professionals should be aware of the CP patient' individual narratives and where they are at on their pain journey when collaboratively considering interventions for pain management at assessment stage. PMPs may also benefit from the inclusion of CP patient's social networks to help facilitate wider systemic change.

Introduction

Definition and efficacy of pain management programmes (PMPs)

The National Institute for Clinical Excellence (NICE, 2021) publishes guidance on pharmacological and non-pharmacological strategies for managing chronic primary pain conditions. The guidance defines PMPs as "*any intervention that has 2 or more components, including a physical and a psychological component, delivered by trained people, with some interaction/coordination between the 2 components*" (NICE, 2021, p.40)

The guidance considered evidence purporting to PMPs effectiveness and suggest that treatment delivered separately, using unidisciplinary approaches, is recommended, with interdisciplinary approaches such as PMPs, being less effective. As a result, the committee did not recommend PMPs for the management of chronic primary pain. In part, this was due to the definition of a pain management programme being inconsistent, a heterogenous population of CP diagnoses and presentations being treated, and little evidence to suggest clinical outcomes were significant compared with usual care. These recommendations were met with scrutiny from professionals in the field, particularly for the exclusion of highly relevant and contradictory evidence available (Eccleston et al., 2021; Faculty of Pain Medicine, 2021a).

The British Pain Society (BPS, 2019a) drafted guidance on PMPs suggesting that interdisciplinary, group-based interventions can help patients normalise their experiences, maximise learning through peer support and be cost effective, whilst acknowledging that some treatment may be better suited on an individual basis. The BPS also responded to the NICE guidance published in 2021, finding it to have not incorporating stakeholder feedback of 'standards of care', a reductionist view of chronic primary pain conditions, and sweeping guidance of withdrawing medications deemed ineffective (BPS, 2021). Furthermore, the evidence base considered in evaluating PMP interventions appears to be wholly quantitative

in nature, perhaps indicating a further lack of wider stakeholder's perspectives, including those of patients, pertaining to this intervention.

A posited benefit of PMPs is the application of a biopsychosocial approach, which conceptualises how the experience of pain is filtered through the biological, psychological and social contexts (Cheatle, 2016) and how this perpetuates the negative impact CP has on individuals. PMPs are uniquely set up to assess and manage chronic pain using this heuristic approach (Gatchel et al., 2018). This contrasts with the outdated and reductionist biomedical approach (Gatchel et al., 2014), with the biopsychosocial approach shifting the focus of treatment of CP from pharmacologically managing symptoms to improving quality of life by managing the widespread impact of CP conditions (Hylands-White, Duarte & Raphael, 2016). A mapping review determined that interventions for fibromyalgia, coined as either multi- or interdisciplinary, should be considered as two ends of the same continuum (Giusti, Castelnuovo & Molinari, 2017) when attempting to conceptualise this for future studies. They considered that both interventions tailored their approach to the presenting difficulties of the individual suffering with CP. However, they also found a heterogeneity in the disciplines involved, reflecting earlier presentations of PMP definitions, and other research (Wilson, 2017; Elbers et al., 2022). For the purpose of this review the term multidisciplinary will be used to refer to multiple discipline's involvement, including an interdisciplinary approach.

PMPs differ nationally in their resources, staffing and intensity and, therefore, may provide varying levels of support for CP populations (Faculty of Pain Medicine, 2021b). The BPS published guidance highlighting how PMPs can be delivered on an individual or group level, and can vary in programme intensity and duration (BPS, 2019a). For the purpose of this study and the considered benefit of peer support, the review will consider PMPs facilitated as a group. The key difference is the programme is delivered by a

multidisciplinary team of professionals to support patients. The guidance suggests that PMPs should include various disciplines such as, medical doctors specialising in pain, psychologists, physiotherapists, occupational therapists, nurses and pharmacists. Although varying in definition, PMPs effectiveness has been reported through various studies and reviews.

Effectiveness of multidisciplinary PMPS

Heterogeneity: The issue of measuring effectiveness

When considering the evidence base and research pertaining to the effectiveness of PMP, benefits have been reported for physical and psychological functioning (Wilson, 2017). Research has considered the 'dose' effect or treatment hours of PMPs and the impact this has on effect. Guzman et al. (2001) suggest that more intensive programmes are more effective than less intensive programmes. However, this review has been scrutinised, arguing not only that there was a vast different number of hours within what was defined as a 'high' and 'low' intensity programme, but also the content and disciplines involved complicating the results further (Waterschoot et al., 2014). Waterschoot et al. (2014) also carried out a review and considered that multidisciplinary PMP to be an effective intervention when considering outcomes of disability and quality of life when compared with other treatments, including unidisciplinary interventions. A review considering the long-term benefits of various PMPs (Elber et al., 2022) found that physical and psychological functioning are maintained over time. However, the issue of heterogeneity relating to programme structures and their measures was also noted in this review. Other research suggests that the benefits of PMPs, such as reduced emotional distress, may be maintained initially (4 weeks) following the intervention but may return and increase after longer periods of time (6 months-1 year) (Oslund et al., 2009). Despite the long-term impact being uncertain, the benefits can have wider implications of returning to work, reduced use of health care services and pain medications (van Hooff et al., 2011). Research also suggests

that psychosocial and clinical variables, such as pain and physical functioning prior to treatment, are key predictors of whether PMPs will be an effective intervention when considering outcome measures (de Rooij et al., 2013; Lewis & Bean, 2021). However, the considerable heterogeneity in dose, definition of PMPs and outcomes measures used to measure their effectiveness (Wilson, 2017) continue to be a criticism of the research being carried out (Kaiser et al., 2014). Consequently, these limitations may hinder synthesis of results and efforts to provide clear understanding of the PMP and patient characteristics most likely to result in an effective intervention.

Psychologically informed PMPs

The role of psychology in PMPs (BPS, 2019a) and the management of CP (NICE, 2021) is integral in addressing the insidious impact of CP syndromes. Various psychological approaches underpin multidisciplinary PMPs, with Cognitive Behavioural Therapy (CBT) being an extensively utilised and researched approach to pain management (Eccleston, Morley & Williams, 2013). CBT is firmly rooted in cognitive theory and attempts to address the way in which thoughts and behaviour interact by using cognitive and behavioural techniques to overcome predominantly mental health difficulties (Beck, 1979). CBT attempts to address perceptions of pain on various levels and develop coping strategies to manage the associated psychological distress, thus help cope with their pain condition (Ehde, Dillworth & Turner, 2014). According to research and reviews, CBT is posited as an effective approach to the management of CP (McCracken and Turk, 2002; Prothero et al., 2018; Williams et al., 2020). However, there does remain some evidence to suggest that not all CP patients respond positively to CBT (Kerns & Rosenberg, 2000; Cheng & Cheng, 2019). Williams et al.'s (2020) Cochrane Review also considered Acceptance and Commitment Therapy (ACT) and its effectiveness in treating CP.

ACT can be considered a form of CBT based on psychological flexibility, which refers to being conscious of the present moment, thoughts and feelings associated with this and a persistence in changing behaviour in line with goals and values (Hayes et al., 2011). It differs from CBT by drawing on Relational Framework Theory (Hayes et al., 2001), which suggests that we learn to relate to stimuli in our environment through arbitrary cues and events and the development of language to understand and relate to these stimuli. It is beyond the scope of this essay to consider the theoretical underpinnings and clinical application of ACT more widely, however, there are detailed reviews considering its application and effectiveness for a broad range of diagnoses and presenting difficulties (Gloster et al., 2020; Soo et al., 2011; Wynne et al., 2019) Research has reported a large benefit for ACT at the end of treatment and follow-up (Williams et al., 2020). However, the review also notes the limited number, quality and precision of reporting in the studies included in this review. Similar results have also been found in systematic reviews (Hann & McCracken, 2014; Simpson, Mars & Esteves, 2017; de Graaf et al., 2021) suggesting the efficacy of ACT as a treatment for CP, with much of the research being small in size, indicating significant risk of bias, and of low to moderate quality, with uncertainties as to whether the effect can be sustained (Du et al., 2021).

Although CBT and ACT have been included extensively in reviews, there is a wide variety of psychological approaches to PMPs that have shown potential, such as compassion- (Kirby, 2016; Malpas et al., 2022; Penlington, 2018) and mindfulness- (Chiesa and Serretti, 2011; Cusens et al., 2019) based, and solution focused (Simm et al., 2013; Simm and Barker, 2017) interventions, with the research suggesting more evidence could support their use. However, the vast number of psychological approaches also contributes to the heterogeneous nature of these interventions and thus complicates the wider field of research and pertaining to the effectiveness of these interventions and how this is measured.

Outcomes Domains and PMPs

Hann & McCracken's (2014) review found that to a large extent the outcome domains in research were in line with those recommended by Initiative on Methods, Measurement and Pain Assessment in Clinical Trials (IMMPACT) (Turk et al., 2003). Turk et al. (2003) recommend six domains to be measured to determine the efficacy and effectiveness of CP interventions; Pain, physical functioning, emotional functioning, participant rating of global improvement, symptoms and adverse events, and participants disposition. The authors of these recommend that these domains be *considered* when determining the effectiveness of an intervention and not that clinical significance be achieved for all domains to establish its efficacy. These domains can be used in clinical settings to measure outcomes for patients accessing various approaches to psychologically informed PMPs, inform commissioning and cost-effectiveness (BPS, 2019b). The BPS (2019b) propose various robust outcomes measures appropriate to pain management covering several of the IMMPACT domains and whilst these may represent a gold standard of measurements, they represent how to measure *clinically significant* change versus *meaningful* change.

Despite the encouraging support for PMPs and their effectiveness as a CP intervention, there appear to be limitations in how these are measured due to the heterogeneity of dose, disciplines, approaches, and outcomes. Therefore, the first aim of this review is to consider a particular PMP that is defined as multidisciplinary, involving a qualified psychologist or therapist and collate patient stakeholder's perspectives as to what is considered an effective and efficient psychologically-informed PMPs where quantitative reviews may be lacking. By doing so, the review provides a unique perspective and contributes to a quantitative evidence base that struggles to provide a clear picture of what an effective and efficient PMP entails (Elbers et al., 2022). The qualitative nature of the review also provides an opportunity to capture a broader understanding of outcomes from patients that are not constrained by quantitative measures or outcomes. Thus, the second aim of the study is to capture what patients consider to be key

outcomes of attending a PMP, which in turn can inform broader qualitative patient-reported outcome domains that might be considered for PMPs despite dose, disciplines involved or approach being used. Furthermore, by providing the perspectives of patients' lived experiences, the review highlights the importance of service user involvement in service development.

Method

The study protocol was registered on PROSPERO [CRD42022374819]. PRISMA guidance (Page et al., 2020) was used to guide the reporting of the review and associated checklist completed (Appendix 2).

Eligibility Criteria

The criteria and search terms were developed using the SPIDER (Sample, Phenomenon of Interest, Design, Evaluation and Research Types) search strategy (Cooke et al., 2012), which has been shown to be more efficient and specific when considering qualitative research questions than alternatives such as PICO (Population, Intervention, Comparison, Outcome) (Cooke et al., 2012; Methley et al.,2014).

Sample

Related search terms: *(Patient* OR service user* or individual*) AND (chronic pain OR persistent pain OR long term pain OR long-term pain)***.*** Adults (over 18 years of age) with a CP diagnosis that has deemed them appropriate for a PMP. Participants should be attending or have attended a pain management programme at the time of the study. Participants who are receiving a pain management intervention for pain-related conditions other than CP, e.g. cancer, will not be included. Studies focusing on pain management programmes for children or young people (under the age of 18), or specific non-CP populations e.g. veterans were not included. There was no upper limit to CP as defined by NICE (2021) guidance and so participants will be included with no age limit.

Phenomenon of interest

Related search terms: *(pain management program* OR PMP OR pain clinic) AND (psycholog* OR psychologically informed OR psych* therap*)*. Pain management programmes were defined as having at least two components or disciplines that have some interaction or co-ordination in supporting the management of CP condition (NICE, 2021). Initially, searches attempted to capture research comprising ACT-based pain management programmes, however a scarcity of qualitative research led to widening these search terms. Pain management programmes that were "psychologically informed" were then considered. This was determined by the involvement of a qualified psychologist or therapist as part of the intervention and will report on the therapeutic approach underpinning the pain management programme intervention. Interventions involving only 1:1 or unidisciplinary interventions, were not included

Design

Related search terms: *(Qualitative)*. Qualitative studies were included in this study that elicited patients' views and experiences of PMPs in depth. The methods that were included encompassed interviews and focus groups as these generate data through discussions and conversations in particular depth (McGrath et al., 2019; Nyumba et al, 2018).

Evaluation

Related search terms: *(attitudes OR perception* OR perspective* OR experience* OR evaluat*)*. The review attempted to capture qualitative studies reporting on the experiences and perceptions of participants attending psychologically informed PMPs. This would help to determine what aspects participants may have considered a strength of limitation of the PMP they attended.

Research Type

Related search terms: *(Qualitative),* Mixed method studies were considered if it included interviews or focus groups and reported the whole sample's qualitative responses. Quantitative studies, and other systematic or scoping reviews were excluded. Study protocol and proposal were also not considered appropriate for inclusion. In addition to commercially published evidence, grey literature such as theses and dissertations, was also considered in the review where it was identified in the database searches.

Search Strategy

The search terms were generated through a number of scoping searches using EBSCO. The terms were refined, optimised and finalised alongside the research team. The following databases were searched: CINAHL and APA Psychinfo (using EBSCO), PubMed and Web of Science. These databases were selected as reviews have identified their efficient coverage of articles (Bramer et al., 2017), relevance to the review topic and representation of a wide range of disciplines. Studies were restricted to English language due to limitations of the reviewing team. No restrictions were placed on dates for studies.

The finalised terms used for searches across all databases were as follows:

(Patient* OR service user* or individual*) AND (psycholog* OR psychologically informed OR psych* therap*) AND (pain management program* OR PMP) AND (chronic pain OR persistent pain OR long term pain OR long-term pain) AND (attitude* OR perception* OR perspective* OR experience* OR evaluat*) AND (qualitative)

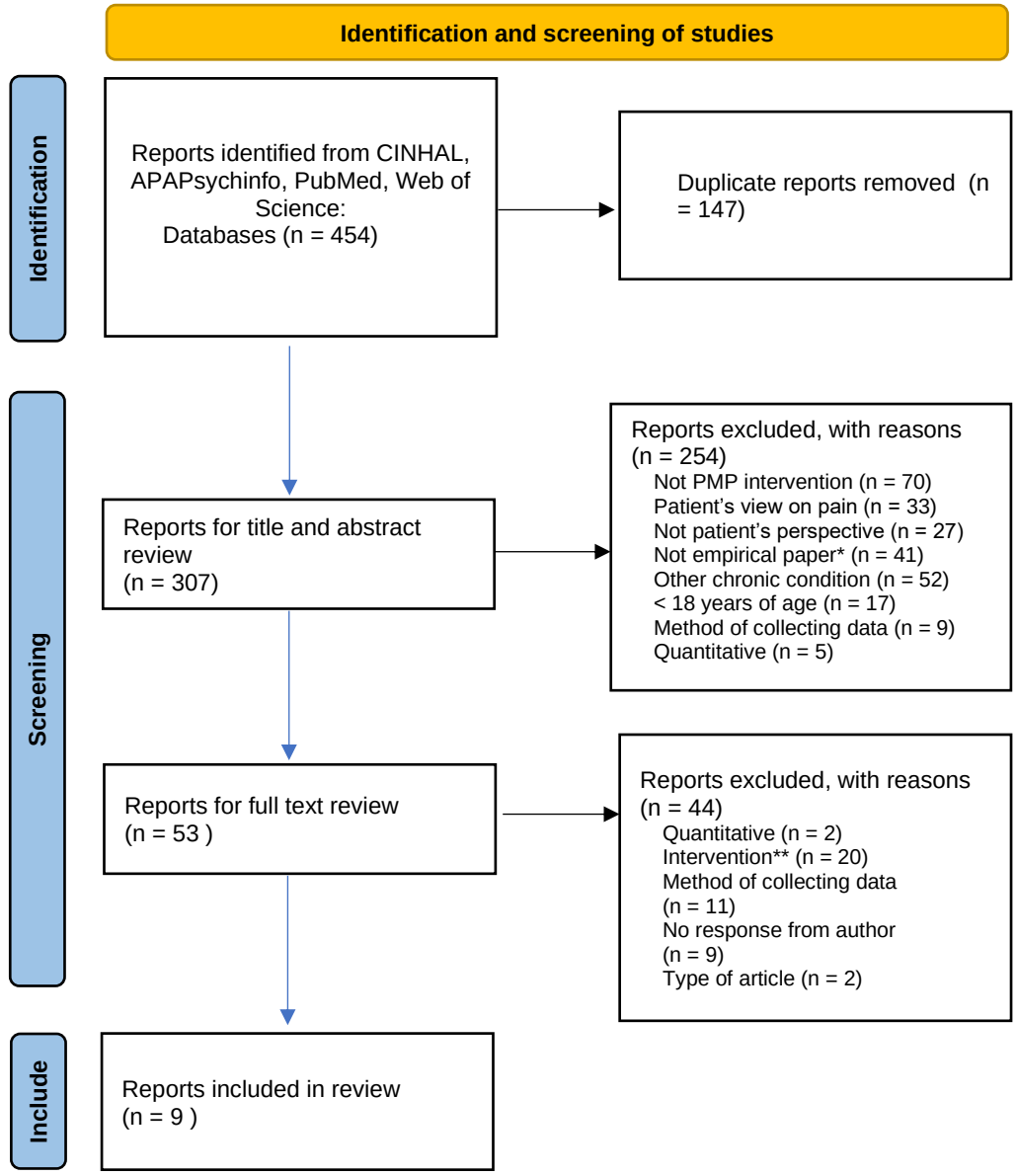
The same terms were used across all databases to ensure consistency in all searches. Individual search results for each database are available in the Appendix (Appendix 3, Appendix 4, Appendix 5, Appendix 6).

Data selection

Database search results were transferred to Endnote (Version 20) and grouped in to respective database searches. Following the consolidation of searches on to Endnote, duplicates were deleted using the feature on Endnote programme, this was checked for error by cross referencing the deleted box with full list of articles. Articles were then manually deleted for duplicates (Appendix 7). The remaining articles were then transferred to Rayyan (www.rayyan.ai), a web-based tool which supports the reviewing process by collating all papers and abstracts and enables remote sharing with other reviewers, which was particularly beneficial for the predominantly remote nature of the current review process. The process involved two researchers (CM and RW) who independently reviewed titles, abstracts and full texts on Rayyan and after each stage they were exported back to Endnote for consistency (Appendix 8). As the author of the reviews, CM reviewed 100% of titles and abstracts with RW as an independent, peer-reviewer reviewed 20% of titles and abstracts. A third reviewer (NF), who was part of the research team conducting the reviews, was consulted where discrepancies occurred between CM and RW's reviewing.

Figure 1

Study selection process



*Papers included; conference, systematic review, feasibility study, protocol.
**Interventions included; unidiscipline interventions, comparing PMP with other intervention, not psychologically informed.

Data extraction

The next step, following the full text screens, involved identifying basic information, which was extracted and placed in to a Word document. The researcher-developed table included identifiable details of prospective studies including; Author, Year, Country, Qualitative Approach, Analysis, Sample, Intervention, Psychological Approach and Key Themes. Corresponding authors were contacted for further clarification or detail (N=9) where details

pertaining to inclusion and exclusion criteria were unclear, particularly in relation to disciplines involved. If no response was received, the article was excluded. The identifiable details and key themes within the included articles are presented in Table 1.

Risk of bias/quality assessment

Once the full article screen had been completed, the remaining studies were assessed for quality using the Qualitative Studies Checklist, Critical Appraisal Skills Programme (CASP, 2018) (Appendix 9). The CASP checklist for qualitative studies is the most commonly used and effective tools for determining research bias (Long et al., 2020; Galdas, 2017). The checklist prompts the reviewer to complete a total of 10 questions; 9 questions requiring a 'yes', 'can't tell', or 'no' answer and the final question providing more qualitative reflections on the value of the research. Each question provides a prompt to the reviewer to consider when attempting to ask the question. The tools are not designed to be scored but are a way of opening up discussion about the article. Therefore, a quality score is not assigned to any of the articles. A table containing each article included and corresponding answers to each question can be found in Table 2. Responses to Question 10 '*How valuable is the research?'* is not included in the table but is explored further in the 'results' section.

Strategy for data synthesis

A narrative synthesis of studies supported an iterative process and is commonly used in developing an understanding of heterogenous literature and qualitative studies (Popay, 2006; Ryan, 2013). Ryan (2013) outlines steps to guide the process of a narrative synthesis, 1) identifying conceptual theory and model to understand how the intervention works, why and for whom; 2) initial synthesis of findings of included studies; 3) explore relationships within and between studies; 4) consider and assess robustness of the synthesis. These stages were adopted for the purpose of this review and described in more detail below. Popay (2006) also

advise on how to conduct a narrative synthesis using various tools and techniques, these are also identified below.

The first step was to identify a conceptual model that helped consider how PMPs function as an intervention in the context of healthcare services and provide support for CP. As described in the introduction, the biopsychosocial model helps conceptualise the intervention and underpinned how the results of the review are conceptualised.

The second step involved becoming familiar with the included articles and summarise their findings and themes, this was collated in to tabular format (Table 2).

The third step went beyond this and explored the similarities and differences within and between each of the studies. In order to do this, the reviewer adopted various techniques and tools as outlined in Popay's (2006) guidance. Initially, the data was colour coded and placed in a table whilst systematically reading the studies and helped visually consider similarities and differences. This table was developed further as themes between studies were identified. Reviewers then met to discuss these emerging themes and discrepancies, resulting in the reported themes. These themes were then written up in narrative form to provide an overview of these themes and how they might display similarities or differences.

Lastly, the reviewer critically considered the robustness of the synthesis and any limitations of the process or articles included.

Table 1.

Summary of articles and key themes of included articles

Author/ Country	Year	Sample	Method	Analysis/ Framework	Intervention	Psychological Approach	Key Themes
Ainsley et al /UK	2021	Facial Pain 11pts, (5 male, 6 female)	Focus Groups (2)	Thematic Analysis (constructionist perspective)	Group Facial Pain Management Programme (FPMP) (4hrs p/w, 8ws). 5 Disciplines (Psych, PT, OT, Dr)	CBT/ACT	Identified a positive experience of being in a group and shifts in psychological wellbeing and behavioural change. They also recommended more 1:1 time with peers and psychology and alterations to future programmes to improve concentration.
Arfuch et al /Spain	2022	Fibromyalgia (FMS) 10pts (female)	In-depth interviews (6 telephone, 4 face-to-face)	Thematic Analysis (hermeneutic phenomenological perspective)	Group Multicomponent Intervention Programme (MCI) (2hrs p/w, 12 ws) 4 Disciplines (Psych, PT, N, Dr)	CBT	Identified some aspects of being in a group as positive, whilst others found this difficult. The intervention improved sense of forgiveness and dealing with guilt relating to their CP condition. Consideration of wider social factors e.g. health and gender inequalities.

Booth et al /UK	2022	Chronic pain (reports various diagnoses) 13pts (10 female, 3 male)	Focus Groups (3)	Abductive Analysis (Theoretical Framework of Acceptability, TFA)	Group Virtual Pain Management Programme (vPMP) (20hrs p/w, 3ws) 4 Disciplines (Psych, PT, OT, N)	CBT	Built positive relationships with peers and HCPs. They described benefits and limitations of virtual PMP. Sense of PMP coming to an end was difficult for some. Recommendations for future PMPs considered dosage of PMP and use of word acceptance in title of PMP.
Casey et al /Ireland	2020	Chronic pain (not reported diagnoses) 11pts (7 female, 4 males)	Focus groups (4)	Thematic Analysis	Group Pain Management Programme (3½hrs p/w, 8ws) 2 Disciplines (Psych, PT)	ACT	Participants varied in reaction to the term ‘acceptance’. Acceptance was seen as a continuum rather than an end goal. Pain beliefs were pivotal to either facilitating or limiting acceptance. Peer support in the group was valued. Values helpful in facilitating change.
Casey et al /Ireland	2019	Chronic pain (reports various diagnoses) 26pts (14 female, 12 male)	Focus groups (5)	Interpretive Phenomenological Analysis	Group Pain Management Programme (3½hrs p/w, 8ws) 2 Disciplines (Psych, PT)	ACT	Considered ‘acceptance’ as a journey and dynamic. For some acceptance was linked with sense of loss. Some were considered ambivalent to acceptance. For some a history of failed attempts at curing chronic pain helped them to let go of this pursuit. There was also a sense of perceived

							injustice and abandonment by HCPs during this pursuit of a cure.
Egan et al /Ireland	2017	Chronic pain (reports various diagnoses) 16pts (12 female, 4 male)	Focus groups (4)	Content Analysis	Group Pain Management Programme (18hrs p/w, 4ws) 5 Disciplines (Psych, PT, OT, N, Dr)	CBT	Found meeting others with CP and involving family validating. Sense of feeling believed whilst on PMP. Attributed changes to coping, acceptance and understanding of pin to PMP. Found others' lack of understanding a barrier to acceptance. Recommended follow ups for future patients, requirement of cognitive shift to fully engage and sharing of knowledge with family and friends.
Harrison /UK	2012	Chronic pain (reports various diagnoses) 12 pts (9 female, 3 male)	Semi-structured interviews (face-to-face)	Thematic Analysis (critical realism)	Group Pain Management Programme (3½hrs p/w, 8ws) 3 Disciplines (Psych, N, OT)	ACT	Pts identified pre-programme expectations of being hopeful or hopeless, considering historical failed interventions and being misunderstood or judged. They identified requiring a readiness for change. They considered their relationship with pain and wider societal views impacting acceptance. Some the group as validating and HCPs as accepting, whilst others struggled with the group

							setting. Social skills helped to reintegrate to society.
Mathias et al /UK	2014	Chronic pain (reports various diagnoses) 6pts (female)	Semi-structured interviews	Interpretive Phenomenological Analysis	Group Pain Management Programme (6hrs p/w, 8s) 3 Disciplines (Psych, PT, N)	ACT	Felt validated by others in the group. Psychoeducation helped feel understood and validated by healthcare professionals (HCPs). Shift to acceptance of pain compared to pain and pursuit of cure dominating life prior to PMP. Increased confidence during/post PMP and more positive sense of self. All themes related to change due to PMP providing sense of control, acceptance and new sense of self.
Thompson et al /UK	2018	Chronic pain (reports various diagnoses) 104pts (68 female, 36 male)	Qualitative themes drawn from feedback sessions during PMP.	Thematic Analysis (codebook)	Group Pain Rehabilitation Programme (11hrs p/w, 4s) 4 Disciplines (Psych, PT, N, Dr)	ACT	Improved relationships with self and 'internal events'. Majority of groups found values and awareness to be key aspects of PMP. Improved relationship with pain. Aprroaches to activity and specific activities were also considered important part of PMP. Relationships with others and communication was key in getting most out of PMP.

Results

The four database searches returned 454 results. After duplicates had been removed 307 articles remained. These were then screened systematically for by their title and abstract resulting in 53 full-text reviews to determine their eligibility for inclusion in the review. During the screening phase of the review, RW peer-reviewed 20% at each stage. There were some discrepancies that were discussed and agreed upon between RW and CM and did not require mediation from third reviewer, NF. As a result of the reviewing process, 44 articles were excluded and a total of 9 articles were included in the review (Figure 1). As the main author was a co-author of one of the included studies (Ainsley et al., 2022), it was agreed that RW would peer-review this as part of the 20% of quality appraisal of included studies in an attempt to reduce bias.

Study Characteristics

All articles were commercially published with one exception being an unpublished thesis (Harrison, 2012). A total of 209 participants made up the combined sample from all included articles, (Range= 6-104, Mean= 23), consisting of male (N= 67) and female (N= 142) participants. The majority of samples consisted of both male and females (Ainsley et al, 2021; Booth et al. 2022; Casey et al.; 2020, Casey et al. 2019; Egan et al., 2017; Harrison, 2017; Thompson et al., 2018) although few other articles' samples consisting of only females (Arfuch et al. 2022; Mathias et al, 2014). The CP diagnoses varied widely, with the majority of articles reporting heterogenous sample with various CP diagnoses. (Ainsley et al., 2021; Booth et al., 2022; Casey et al., 2019; Egan et al., 2019, Harrison, 2012, Mathias et al., 2014; Thompson et al., 2018), one article's sample focused on FMS (Arfuch et al., 2022), and the remaining article is assumed to be heterogeneous (Casey et al., 2020). The majority of research was carried out in the UK (Ainsley et al., 2021; Booth et al., 2022; Harrison, 2012; Mathias et al., 2014;

Thompson et al., 2018), three of the articles were from Ireland (Casey et al., 2020; Casey et al., 2019; Egan et al., 2017), and the remaining article was from Spain (Arfuch, et al., 2022).

The largest sample of 104 participants was made up of 16 groups of participants providing feedback during a PMP regarding what they valued from the programme (Thompson et al, 2018). This was included in the study as it represented what was considered a focus group, whereby the conversation was recorded and key phrases were identified and agreed upon in relation to their experience of the PMP they were attending. However, this was not explicitly defined in this way in the article. The other studies all reported having taken a semi- or structured approach to their method through either focus groups (Ainsley et al., 2021; Booth et al., 2022; Casey et al., 2020; Casey et al., 2019; Egan et al, 2017) or semi-structured or in-depth interviews (Arfuch et al, 2022; Harrison et al., 2012; Mathias, 2014).

All the articles reported on the type of analysis of the data, and all but two (Casey et al., 2020; Thompson et al., 2018) declared their theoretical approach. There was some convergence in the type of analysis and a noted divergence across articles reporting their theoretical approach across the articles. Over half of articles used a form of thematic analysis (TA) and varied in their theoretical approach, using; constructionist (Ainsley et al., 2021), hermeneutic phenomenological (Arfuch et al., 2021), and critical realist (Harrison, 2012) perspectives. The remaining articles analysed their data using IPA (Casey et al., 2019; Mathias et al., 2014), Content Analysis (Egan et al., 2017), and Abductive Analysis (Booth et al., 2022).

All articles considered the effectiveness of a multidisciplinary intervention for the treatment of CP condition(s) but used various terms to refer to this. The number of hours the PMP was facilitated per week (Range= 2-20; Mean= 7.9, Mode= 3.5), and duration of PMP in weeks (Range= 4-12; Mean= 7, Mode= 8) varied widely. This variation is also represented in the overall time of programmes in hours (Range= 24-72; Mean= 40; Mode= 28). A vast difference was also identified in the number of disciplines involved in facilitating the programmes and

varying combinations. As defined by the inclusion criteria, articles were characterised by having input from a psychologist or therapist and at least one other discipline. The other disciplines reported in delivering the PMPs were; Physiotherapy, which featured in all interventions; Nurse or Nurse specialist featured in five (Arfuch et al., 2022; Booth et al., 2022; Egan et al., 2017; Harrison, 2012; Mathias et al. 2014); Occupational Therapy in four (Ainsley et al., 2021; Booth et al., 2022; Egan et al., 2017; and Harrison, 2012); and Medical Doctor in four (Ainsley et al., 2021; Arfuch et al., 2022; Egan et al, 2017; Thompson et al., 2018).

All but one of the articles (Booth et al., 2022) were face-to-face interventions. Booth et al.'s (2022) study explored participants' perspectives of a virtually delivered PMP. Although research suggests that participants prefer face-to-face versus remotely delivered PMPs (Cranen et al., 2012), Williams et al. (2022) argue that more research is required to consider both of these interventions and patient's satisfaction of them. Therefore, the inclusion of this paper might help determine divergence and convergence in terms of themes identified that could help contribute to this field of research.

Just over half of the articles reported that the psychologically informed approach to the PMP was ACT (Casey et al., 2020; Casey et al., 2019; Harrison, 2012; Mathias et al.,2014; Thompson et al., 2018), the remaining reported a CBT approach (Arfuch et al., 2022; Booth et al., 2022; Egan et al., 2017), with the exception of one (Ainsley et al., 2021) reporting it used a blend of both CBT and ACT.

Quality Appraisal

The CASP (2018) qualitative checklist was used to open up discussions about the articles and the response to each question is represented in Table 2.

Table 2.
Quality Appraisal – Responses to the Qualitative Studies Checklist, CASP (2018)

Authors	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9
Ainsley et al. (2021)	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes
Arfuch et al. (2022)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Booth et al. (2022)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes
Casey et al. (2020)	Yes	Yes	Yes	Yes	Yes	No	Can't tell	Yes	Yes
Casey et al. (2019)	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes
Egan et al. (2017)	Yes	Yes	Yes	Yes	Yes	No	Can't tell	Yes	Yes
Harrison (2012)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Mathias et al. (2014)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Thompson et al. (2018)	Yes	Yes	Yes	Yes	Can't tell	Yes	No	Yes	Yes

Note: Q1 Was there a clear statement of the aims of the research?; Q2 Is a qualitative methodology appropriate?; Q3 Was the research design appropriate to address the aims of the research?; Q4 Was the recruitment strategy appropriate to the aims of the research?; Q5 Was the data collected in a way that addressed the research issue?; Q6 Has the relationship between research and participants been adequately considered?; Q7 Have ethical issues been taken into consideration?; Q8 Was the data analysis sufficiently rigorous?; Q9 Is there a clear statement of findings?

Overall, articles present strengths in articulating the aims and adopting an appropriate qualitative methodology to address these aims. The aims of exploring participants' perspectives of attending a psychologically-informed PMP was met by identifying CP patients either during or after their attendance. All studies provided explicit reasoning behind their research design and how this addressed the aims of the study. The data collection for each study was also detailed explicitly using structured means of collecting data e.g. interviews or focus groups, with the exception of one study (Thompson et al., 2018).

A limitation of three of the research articles (Booth et al., 2022; Casey et al., 2020; Casey et al., 2019) was little consideration of the relationship between the researchers and the

participants. There were vague details of researchers tasked with interviewing (Casey et al., 2020) and recruiting (Booth et al., 2022; Egan et al., 2017) and processes adopted attempting to reduce bias. However, there was little evidence of other considerations of the researchers' position, particularly in the relation to bias during interpretation of data.

As discussed, Casey et al., (2020) and Thompson et al. (2018) both report analysing their data using TA. However, they did not consider their theoretical position. Although TA is not tied to any particular theoretical framework, it is important for the theoretical position to be clear in its reporting in order to represent the positioning of the author and how they had approached and interpreted the data (Braun & Clark, 2006). Despite this, both authors provided an in-depth breakdown of how their analysis was conducted.

For over half the articles, there were minimal (Ainsley et al., 2021; Casey et al., 2020; Casey et al., 2019; Egan et al., 2017) to no discussions (Thompson et al., 2018) relating to ethical considerations. The former four articles with minimal considerations stated the ethical approval and reference number and little else. Thompson et al. (2018) did not reference any ethical approval or considerations. Reviews considering how ethics is reported in research has reported a failing in describing how consent has been achieved (Wu et al., 2019) and addressing broader discussions relating to ethical considerations, choosing to report of ethical approval and that informed consent had been obtained (Stolt et al., 2022). However, this may not indicate a lack of consideration or poor-quality research but merely the limitations placed on authors to adhere to publication requirements (Long et al., 2020).

Despite Thompson et al.'s (2018) apparent limitations and lack of specificity relating to method and details surrounding ethics, they provide comprehensive reflections on their position as a researcher and considered their relationship with the participants. They also detail their approach to mixed methods analysis, which produced themes convergent with the other articles in the review. Research also suggests that large qualitative data may require a

quantitative tool for analysis (Roberts, Dowell & Nie, 2019; Braun & Clarke, 2019). Therefore, Thompson et al.'s (2018) article was considered appropriate for inclusion.

Data Synthesis

The narrative synthesis collated the articles and identified overarching themes considered between the articles. Five themes were identified; 1) 'Group processes'; 2) 'Programme structure and recommendations'; 3) 'Previous experiences of treatment'; 4) 'Facilitators and barriers to change'; and 5) 'Improved communication and relationships'. Each of these themes will be considered in turn.

Table 3

Prevalence of overarching themes across articles

Authors	Group Processes	Group structure and recommendations	Previous experiences of treatment	Facilitators and barriers to change	Improved communication and relationships
Ainsley et al. (2021)	✓	✓		✓	✓
Arfuch et al. (2022)	✓		✓		✓
Booth et al. (2022)	✓	✓	✓		✓
Casey et al. (2020)	✓		✓	✓	
Casey et al. (2019)			✓	✓	✓
Egan et al. (2017)	✓	✓		✓	✓
Harrison (2012)	✓		✓	✓	✓
Mathias et al. (2014)	✓		✓		✓
Thompson et al. (2018)				✓	✓

Group Processes

A key finding between seven studies was the notion of how the group environment impacted on the intervention. They posit beneficial (Ainsley et al., 2021; Arfuch et al., 2022; Booth et

al., 2022; Casey et al., 2020; Egan et al., 2017; Harrison, 2012; Mathias et al., 2014) and limiting (Ainsley et al., 2021; Arfuch et al., 2022; Booth et al., 2022; Harrison et al., 2012) factors relating to the treatment of their CP condition.

There was a sense across all studies positing positive group processes, particularly a sense of empathy and being supported by the group. When sharing they were met with validation and legitimisation, which contrasted from previous experiences with family, friends and HCPs. A sense of togetherness was evident in the majority of these studies. The advantages relating to meeting others who experienced similar adversities was considered beneficial both face-to-face and virtually, particularly meeting in informal settings without HCPs present.

In contrast, some studies identified that the group was not conducive with sharing more sensitive information (Ainsley et al., 2021; Arfuch et al., 2022; Booth et al., 2022; Harrison, 2012). Some participants considered there not to be enough time with HCPs, 1:1, to address these sensitive thoughts, feelings and emotions that they perceived as difficult to broach in a group setting (Ainsley et al., 2021). This was particularly compounded by a PMP being facilitated virtually whereby they felt unable to have informal discussions with HCPs as they might have done face-to-face (Booth et al., 2022). In one study (Harrison, 2012), there appeared to be a dynamic of comparing oneself or in some cases feeling intimidated by certain individuals or the size and number of people in the group.

Group structure and recommendations

Three studies (Ainsley et al., 2021; Booth et al., 2022; Egan et al., 2017) reported that participants made recommendations for future PMPs based on their experience of attending the respective programme.

The theme makes reference to participants requiring more informal time with peers to develop social connections outside of the sessions. These studies also considered participants' requests for shorter days and longer duration of the PMP to support with concentration and

engagement. Further to this, and beyond the immediate programme, a request for further support, follow up sessions and refreshers were considered to be beneficial after having received intense support from PMP. One article in particular (Booth et al., 2022) reported concerns of feeling abandoned once the programme had finished. A sense of being abandoned over the course of their treatment, was an experience shared and reported by many other studies and relates closely to the following theme.

Previous experiences of treatment

An overarching theme considered in six studies was of CP patients' experiences of treatment they experienced prior to PMP leaving them feeling abandoned, invalidated and not understood (Arfuch et al., 2022; Booth et al., 2022; Casey et al., 2019; Casey et al., 2020; Harrison, 2012; Mathias et al., 2014). This influenced their perception of PMP before they engaged with the treatment, feeling sceptical of and hopeless in the context of their previous experiences and the journey leading up to receiving a PMP as an intervention. There appeared to be a fear of this being perpetuated in the PMP due to perceived invalidation from HCPs and family and friends in the past. Some studies (Casey, 2019; Mathias et al. 2014), also linked this to being in the context of participants' pursuit of finding a cure or a solution to their CP condition. Consequently, leaving them to feel powerless to affect change and take control or self-manage their condition. Conversely, it was also reported that a history of failed attempts also encouraged them to engage with PMP out of desperation (Harrison, 2012) and for some, these failed attempts contributing to a shift in belief and acceptance of there being no cure (Casey, 2019).

Facilitators and barriers to change

The majority of studies identified themes of facilitators (Ainsley, et al., 2021; Casey et al., 2020; Egan et al., 2017; Thompson et al., 2018) and barriers (Egan et al., 2017; Casey et al.,

2019; Casey et al., 2020; Harrison, 2012) to CP patients to achieving meaningful change whilst on a programme.

PMPs helped identifying values and meaningful goals, which in turn, helped to facilitate change. In order to do this, it was considered being in the present moment supported the consideration of values and what would be a meaningful goal to improving quality of life. Thompson et al. (2018) identified that by accepting setbacks might happen and how they can be opportunities to learn, this can help to set goals that are achievable. There appeared to be a sense that stepping back and having space and time to consider value and meaningful goals was important to affect change and improve wellbeing. A specific change identified in two studies (Ainsley et al., 2021; Egan et al. 2017) by participants was the reduction in usage, dependency and reliance on medication was considered a positive outcome of the PMP.

This theme also reports barriers participants identified to achieving goals whilst on PMP. They describe difficulties relating to the concept of acceptance and living well with pain. For some participants this evoked quite strong emotions of loss, defeat and giving up. There were connotations of an ongoing fight with pain (Harrison, 2012) and by accepting pain they are actively surrendering to pain and submitting to it. For others, this appeared wider than internal factors, suggesting that a lack of acceptance from friends, family and wider society posed an external barrier to acceptance of their CP condition.

Perhaps an important contribution to this theme identified in three articles (Egan et al., 2017; Casey et al., 2019; Harrison, 2012), was that some participants posit that in order to benefit and fully engage in a PMP and affect change, a readiness or shift towards acceptance is required prior to or during the PMP. One study (Harrison, 2012) reported that readiness increased over the course of the PMP.

Improved communication and relationships

Eight of the nine articles (Ainsley et al., 2021; Arfuch et al., 2022; Booth et al., 2022; Casey et al., 2020; Egan et al., 2017; Harrison, 2012; Mathias et al., 2014; Thompson et al., 2018) contributed to an overarching theme of improvements in communication with friends and family, and becoming more social as a result of the PMP. There also appeared to be a reported improvement in relationships with HCPs, themselves and pain.

The PMP appeared to improve communication in close relationships with friends and family and a reintegration to socialising within and outside the group intervention. As a result, the studies posit an alleviation of isolation, development of social skills and assertiveness. Ainsley et al.'s (2021) study also suggests that this linked and had a positive impact psychologically.

The studies also suggest an improvement in relationships with clinicians, which links in somewhat with a previous themes and contrasts with previous experiences. The studies reported that participants felt believed and validated, and listened to without judgement enabling them to build more positive relationships with clinicians than they perhaps had done previously. A study (Mathias et al., 2014) found that psychoeducation and developing a shared understanding helped participants feel understood and supported by HCPs.

An improvement in the relationship with the self was also observed in these studies. Describing how they identified a more positive sense of self when comparing themselves to before attending PMP (Mathias et al., 2014), and being accepting of this 'new self' (Egan et al., 2017) with a willingness to continue to maintain and change future self (Casey et al., 2019). Studies went on to describe certain attributes in themselves that they had developed over the course of the PMP that contributed to this new sense of self. There were reports of learning self-forgiveness in order to live well with pain and free from guilt (Arfuch et al., 2022) and being kinder to themselves (Thompson et al., 2018). There was also a shift in prioritising themselves and acting in their own best interest (Thompson et al., 2018). Ainsley et al.'s (2021)

participants describe the PMP being a chance for self-reflection and developing skills of acceptance and self- compassion. As suggested in one study (Mathias et al., 2014), positive change was attributed to the sense of control the strategies learnt on the PMP provided and so could go some way to explaining how this shift in sense of self occurred.

Three studies also suggested a shift in the way in which participants related to their pain condition following the PMP (Harrison, 2012; Mathias et al., 2014; Thompson et al., 2018). These articles suggest a shift to no longer fighting with pain or struggling less with pain. This allowed them to feel more empowered and allow themselves to experience and live well with CP.

Discussion

To our knowledge, this is the first review to systematically consider psychologically-informed PMPs from CP patients' perspectives. The review can add to the current research and reviews relating to PMPs where a synthesis of qualitative evidence is lacking, and provide a unique perspective from patient stakeholders concerning the effectiveness and key outcomes of PMPs. The review has done this by identifying what participants considered to be the salient features of a PMP, particularly aspects they found to be effective and efficient, and how this affected meaningful change and outcomes.

The importance and improvement of social relationships

Participants referred to positive influences, particularly stemming from the group nature of the intervention. This appeared to provide a supportive, validating and normalising environment for many of the participants taking part in various PMPs. When considering outcomes of individual versus group, research has considered there to be little difference in outcomes for CP (Keefe et al., 2002; Thorn & Kudkda, 2006). Despite this, social support has been shown to reduce pain intensity, improve mood and functioning (Deyo, 2015), particularly in multidisciplinary CP interventions (Oraison & Kennedy, 2021). Further to this, PMPs

provided an opportunity for friends and/or family to be invited to be part of the intervention (Ainlsey et al., 2021; Egan et al., 2017; Harrison, 2012), which indicated a positive wider, systemic impact of the intervention beyond social connection within the group. For those interventions that did not indicate direct involvement of social networks, there still appeared to be a benefit in communication with others (Casey et al., 2019; Thompson et al., 2018), and a recommendation that PMPs should involve them (Arfuch et al., 2022). Providing a space in the treatment of CP for social networks can provide an opportunity for additional support, experiencing a sense of community and gaining new insights in to CP and coping strategies for family and friends (Lemmens et al., 2005). Black and Lobo (2008) considered the concept of family resilience and identified that communication was a key factor and trait. Thus, by re-establishing communication between CP patients and their close social networks, it might begin to improve the understanding of how they respond to the condition (Walsh, 2015), the impact it has had, and build social support and resilience.

The importance and improvement of relationships with systems

There also appeared to be an improvement in relationships with clinicians, which shifted away from and linked with historical experiences of feeling abandoned and invalidated by the systems around them, including HCPs. Prior to attending the PMP, a pursuit of a cure appeared to be a common experience for CP patients, suggesting the dominant biomedical approach of pain being a fixable problem and reflects the values embedded in society (Eccleston, 2016). This may posit a link between contextual factors influencing HCPs approaches and patients' perspectives of the support provided. However, it may be reductionist to suggest that HCPs and/or social others being validating are the only factors leaving patients feeling invalidated. There may be more consideration of each patients' needs, particularly from a psychological perspective (Edlund et al., 2017). Edlund et al., (2017) found that patients who experienced heightened invalidation also experienced heightened pain interference and negative affect, they

also found that this impacted on outcomes following pain management intervention and effective communication. Nicola et al. (2021) highlight the importance of pain-invalidation occurring on various levels; the self, within social networks and between HCPs. In turn, the invalidating-self might be a representation of internalised stigma (Perugino et al., 2022), whereby hegemonic narratives suggesting pain is curable, combined with ongoing failed attempts or solutions to achieve this, could leave patients internalising this narrative and thus invalidating and dismissing their suffering. The key findings in this review of a positive shift in relationships between clinicians, themselves and pain itself may indicate a key impact of PMPs. Research has shown that HCPs lack of interest, empathy and communication, and lack of integrated multidisciplinary interventions are perceived barriers to effective pain management (Hadi et al., 2017). Therefore, by adopting and implementing a biopsychosocial approach through multidisciplinary PMP approaches to treating CP, this may go some way to reducing and combatting social and internal stigma and may also be something to consider when determining the outcomes of a PMP; potentially contributing to reduction of stigma.

The importance of being 'ready' for change

The notion of limited societal understanding or stigmatisation of CP can also cause a barrier to accessing treatment (Perugino et al., 2022), which is also reported in this review. Despite this, some participants considered factors that enabled change, particularly a 'readiness' for change being a key factor in whether participants fully engaged and benefitted from the intervention. Knight et al (2019) reported similar findings with reasons patients might be excluded from a programme at assessment involving not being ready for a PMP, which they defined as seeking pain reduction and that other intervention for pain management was deemed more suitable. Thus, assessing readiness for a PMP, or self-management approach overall, as suggested by Knight et al. (2019), may be required an extended assessment to explore a PMP approach further, offering various formats (e.g. online), and intensity to match the patient's

needs. In the included studies, participants also made explicit recommendations as to what they would consider to benefit the PMP they attended. These were dependent on their particular experiences and setup of the programme they attended. Despite the heterogeneity in PMPs, there were key recommendation across the articles such as; consideration of daily intensity of programmes having an impact on concentration and engagement and a requirement of support post-PMP, despite some offering follow-up sessions. These may be important considerations for future development or developing services to consider the appropriateness of varying degrees of intensity of programmes based on the degree to which the impact of pain has on their physical and social functioning, and psychological wellbeing. By developing a clear understanding of a patients' narrative and pain journey at the point of assessment, professionals can gain a clear understanding of whether a PMP will be an effective and appropriate intervention.

Limitations

A limitation of the articles included in this review are that the samples are heterogenous, particularly in relation to their pain diagnoses. The majority of studies report on PMPs do not specify a targeted pain diagnosis, with the exception of one article that focused on FMS.

There was also a diverse range of formats to PMPs in terms of duration and frequency, which might also impact a patients' perspective of the PMP they attended. This does not necessarily reflect a limitation of the methodology of the review, but is more indicative of the heterogenous ways in which PMPs are commissioned within the UK and between countries. There were efforts to identify a sample of PMPs that were psychologically-informed and defined by the involvement of a psychologist, which other reviews have failed to do (Waterschoot et al., 2014). It is also important to note that CP patients' perspectives were taken a different time points, prior or after attending a PMP, and these time points are not reported in this review. Given the evidence base's uncertainty around their effectiveness over time, it may

impact how patients' report their experience of a PMP. These may be important considerations for research in the future seeking to consider qualitatively and quantitatively the perceived or clinical effectiveness of PMPs.

The inclusion of CBT and ACT based interventions may have been representative of the broader literature focusing on these approaches. However, there is little representation of other psychological approaches. This was due in part to authors not responding to queries relating to disciplines involved in the interventions when it was unclear in the paper. As a result, the perspectives of participants is limited to these two approaches, which in turn could impact the language used by participants when responding in the studies.

The consideration for the risk of bias for some studies was also considered a limitation, due a lack of reporting of methodological considerations such as; researchers' relationship with patients, and/or theoretical positioning being addressed, and ethical considerations. It is also important the reviewer's bias in interpreting the authors' interpretations of qualitative research.

Clinical implications

PMP interventions may benefit from considering CP patients' history of treatment at assessment stage as this appears to be pivotal in determining whether invalidation and stigma might impact their overall view of their CP treatment journey. Toye et al.'s (2021) meta-ethnography conceptualised this journey as a 'healing' journey and not one that had a destination. They posit CP interventions require valuing patients' stories, encouraging kindness, a connection with a meaningful sense of self and their social world, their future, in order to support CP patients holistically. Therefore, earlier experiences of contact with healthcare system might be important factors to consider when faced with what might be considered disengagement, resistance to change or poor outcomes. HCPs may benefit from exploring the patients' narratives relating to their relationship with themselves and their CP condition and developing a shared understanding or formulation of this. This may also go some

way to begin a process of destigmatising CP and validating patients' experiences. Further to this, implementing and promoting a biopsychosocial approach in a multidisciplinary PMP can also support this understanding, education and rebuilding of relationships with the healthcare system, where they might be strained.

Research has posited that the wider social context where patients experience disbelief and stigma can result in loss of relationships, isolation and emotional distress (Newton et al., 2013). This was a key finding of this review where participants reported benefiting from the group nature of the PMP, contributing to a sense of validation and normalisation, as well as an opportunity to socialise and build relationships with others with similar experiences. The notion of building relationships might also extend to the inclusion of social networks in to a pain management programme. Many participants either found benefit in or considered the prospective benefit of including those they had close relationships with. Therefore, future considerations for PMPs might be to allocate time within the programme to include friends, family and social networks, and to consider protected time to develop peer relationships outside structured PMP sessions to support this.

When considering outcomes, perhaps the importance of 'patient rating of global improvement' as an outcome domain, as recommended by Turk et al. (2003), may be one to consider clinically and for future research, building on the current research and themes drawn from participants' perspectives of PMPs and their benefits found in developing these relationships and how we as clinicians develop more robust and adaptable outcomes measures to measure this.

The review also highlighted a sense of readiness for change that was considered to be a key facilitator to engaging and benefitting fully from the PMP. The notion of readiness might be addressed through the aforementioned shared understanding of the patients' narrative. These findings posit similar processes to those identified in Stages of Change model (DiClemente and

Prochaska, 1982). This has been researched within a CP population and considered to be a potential to predict outcomes for those accessing multidisciplinary CP interventions by identifying the particular stage at which someone might be at (Jensen et al, 2000). Going beyond this, clinicians may benefit from developing a shared understanding of a person's motivation or stage of change and could be introduced as a person-centred qualitative measure of patient outcome for this intervention.

Future research

Future research might consider the heterogeneity of PMPs and what appears to be the most effective combination of disciplines involved, duration and intensity of intervention. Research might consider the impact of outcomes relating to intensity of programme both in short term and long term. There might also be scope to consider patients' perspectives of individual disciplines and what each contributes to the intervention. Patients' perspectives or comparison studies might also consider the effectiveness of PMPs versus 1:1 therapeutic interventions. This may require further understanding of variables involved in the effectiveness of PMP, such as social support, quality of relationships with others and self, and validation, as highlighted in this review.

Further consideration may be given to a variety of psychological approaches outside CBT and ACT, such as compassion- and mindfulness-based, and solution focused interventions. Perhaps considering the differing language used in qualitative data dependent on the PMP approach as to what constitutes meaningful change to patients, e.g., motivation to change, acceptance of living well with pain. Considering the IMMPACT (Turk et al., 2003) domain of 'patient rating of global improvement' and how best to measure this outcome quantitatively or qualitatively, despite the approach being used.

As identified in this review, PMPs differ in the population of pain diagnosis and type of CP they attempt to treat. Perhaps further investigation in to how PMP interventions are supporting

CP patients whose suffering transcends medical diagnosis and is compounded by wider social factors compounding social and/or internalised stigma. There appears to be a sense of a meaningful change in relationships through 'connection' or 'reconnection' with themselves and others and this could warrant further exploration. Perhaps a sense of 'time' being given for them to be heard or understood might play a part and that future research could consider what skills help to foster this meaningful change.

Similarly, research may also seek to focus on what is considered 'readiness' for change and the factors involved in considering, shifting towards, and achieving this, and where CP patients might be that best informs how much they benefit or engage in a PMP.

Conclusion

The synthesis of the qualitative literature concerning patients' perspectives of psychologically-informed PMPs suggests that patients found a group intervention validating and normalising, and found benefits of improved relationships with themselves, those in their social network, professionals and with their pain itself. The effectiveness of PMPs appeared to be influenced by a number of factors such as their beliefs about pain, past experiences of interventions, seeking a cure, and their perceived readiness for a PMP intervention. Although the format, dose and disciplines involved in PMPs differ widely, there appeared to be common benefits of remedying internalised social views of CP through the inclusion of social networks in the intervention and professionals open to learning and understanding CP patient's narratives. Thus, clinicians should be aware of a patients' pain narrative and the journey that has shaped their understanding of pain when considering interventions for pain management, such as a PMP.

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Chapter 2 – Empirical Paper

Title

An investigation of chronic pain patients that have taken or considered taking cannabidiol (CBD) to aid their chronic pain condition

Abstract

Background: CBD products are available without prescription and marketed to help chronic pain (CP), NHS pain clinics in the UK do not utilise these products nor does the research suggest benefit. Despite this, CP patients may wish to trial CBD and research about their experiences is lacking. Therefore, this study aims to capture a UK sample of CP patients' perspectives of taking or considering taking CBD for their CP condition. It is important to consider what factors are involved leading up to and taking CBD in order to support professionals' understanding of decision-making and how best to approach discussions with CP patients in the future. **Methods:** We conducted 12 in-depth, semi-structured interviews with participants with CP to explore the facilitators and barriers to taking CBD and their experiences of discussing this with healthcare professionals. We adopted a thematic approach with a theoretical positioning of critical realism in order to identify themes of, the mechanisms involved in, and how context can influence the decision-making process. **Results:** Participants identified the perceived benefits and side effects of CBD in comparison with prescribed medications. They also identified a generational and cultural shift towards acceptance of cannabis-based products but continued to observe wider related social stigma. For some, interactions and discussions with healthcare professionals regarding CBD and treatment in general were perceived as negative. As a result, some viewed taking CBD as a form of taking control over their treatment and pain management. **Conclusion:** This study identified the various psychological, relational and wider social factors involved in deciding whether to take

or continue taking CBD. By professionals taking the time to consider these factors, patients may benefit through validation, sense of being believed or heard, and may contribute to the breaking down of stigma.

Introduction

Cannabis based products for chronic pain

Many studies have focused on the medical benefits and the interactions of neurochemicals influenced by various potencies and combinations of cannabinoids (CBD/Tetrahydrocannabinol (THC)). Finn et al. (2021) suggest a disparity between preclinical and clinical trials for cannabis-based products. The latter often involves heterogenous methods of intervention and product strength, combinations and administrative approaches, thus, making it difficult to determine the efficacy and adverse effects of CBD alone (Boyaji et al, 2020; Urtis et al., 2020). Finn et al. (2021) also suggest that due to CP patients already being prescribed various analgesics, it is difficult to separate the effects of these products from the newly introduced cannabis-based medicines. This is reflected in the British Pain Society's (2019) review of their position on cannabis-based medicines for CP, whereby it is noted that more high-quality research is required before it can be considered. As a result, clinicians working in pain services have limited guidance on cannabis-based products.

Research has provided evidence supporting the use of various cannabis-based/CBD products for varying chronic physical health conditions and their symptoms (de Carvalho Reis et al., 2020; Costiniuk & Jenabian, 2019; Maroon & Bost, 2018). It is also important to note that many studies carried out are in a variety of different countries, all of which have different legislation relating to cannabinoids between each other and the UK. Currently in the UK, some products have been approved for prescription for patients undergoing chemotherapy for cancer for antiemetic properties, for patients diagnosed with Multiple Sclerosis to help reduce symptoms of spasticity, and for severe treatment-resistant epilepsy (NICE, 2021). Evidence

also suggests that medical cannabis can be prescribed for and has shown to be a course of treatment for musculoskeletal and neuropathic pain in people living with HIV (NICE, 2021; Mills et al., 2022), but not for patients diagnosed with a CP condition (NICE, 2021; British Pain Society, 2018; Royal College of Physicians, 2018). There is a call for more evidence supporting CBD use for CP before it is considered as a line of treatment (Hill et al., 2017; Boyaji et al., 2020).

The research investigating the medical use of cannabis is somewhat polarised (Woelfl et al., 2020). Studies have suggested positive effects for pain management (Rahn & Hohmann, 2009; Whiting et al., 2015), and there is also evidence considering how cannabinoids could be used to reduce the use of opioid based treatments for CP (Hassan et al., 2020; Capano et al., 2020). Despite this there is also extensive evidence relating to the adverse side effects of cannabinoids (Wildes et al., 2020). NICE (NICE, 2019) produced guidance for the use of cannabis-based products, recommending against their use in CP conditions. However, the review of research conducted by NICE concluded that almost all the research considering cannabis-based medicines contained a combination of THC and CBD. This reflects findings of other research (Finn et al, 2021) suggesting heterogenous potencies and products being used to determine effectiveness in managing CP. As a result, these may produce varying adverse effects being generalised to *all* products. Argueta et al.'s (2020) review of research focusing on CBD products specifically, showed limited but promising clinical results for CBD and CP, with a call for more research in the area of CBD-specific products and their benefits/limitations.

Couch (2020) found that 1.4 million people in the UK use illicit cannabis for medicinal purposes. This may be where the lines between illegal and medicinal cannabis cross and their relationship becomes 'grey'. Nutt et al. (2020) consider the challenges and benefits to prescribing cannabis-based medicines in the UK and posit that the evidence tends to be lacking in patient-reported outcomes and lived experience of taking cannabis for medicinal purposes.

By exploring beyond the randomised control trials to pharmacoepidemiology, many individuals could benefit from regulated and better research products such as the reduction of opioid medication use in CP populations (Nutt et al., 2020).

Boehnke et al.'s studies (Boehnke et al., 2016; Boehnke et al., 2019a) both found that medical cannabis users substituted this for their opioid medication prescribed for their CP condition, with users reporting improved symptom management and reduced side effects. Research in this area reports similar reasons for using these products and replicates the reduction in opioid and other prescription medication (e.g. benzodiazepines, antidepressants) use for CP (Lucas & Walsh, 2017; Reiman et al., 2017; Corroon et al., 2017; Schilling et al. 2021). These studies are conducted in countries where medical cannabis is legal to prescribe, therefore, these products vary widely in their potency and combination of CBD and THC. There also appears to various terminology to describe these products, dependent on the country's legal standing on these products. However, when considering CBD specifically for its opioid-use reducing benefits, research suggests it could show promise (De Almeida & Devi, 2020). Capano et al.'s study (2020), posit that by introducing CBD in to CP patients' medication regimen, over half (53%) were able to reduce or eliminate their opioid use, and almost all reported an improvement in their quality of life. Despite this, more research is called on to consider the benefits of cannabis-based medicines and their benefit in supporting patients to reduce opioid use (Köstenberger et al., 2022).

As there are no pharmaceutical CBD products prescribed for CP in the UK, it is difficult to determine their efficacy for the condition as a result of this, patients with a primary diagnosis of a CP condition are left with accessing CBD products from retailers, rather than medical professionals. The CBD products available in the UK vary hugely in their potency, product type, administration route and their regulation. A recent YouGov survey (Ibbetson, 2019) reports that a proportion of UK CP sufferers are exploring the use of CBD for their CP issues,

with 11% of people in the UK have taken CBD products, of which 61% use the products for medicinal purposes, with pain relief the primary use (71%). Further to this, 38% of respondents also use CBD products to treat anxiety and depression. This survey suggests that CP patients are using CBD to manage their CP condition for a myriad of reasons but does not address the complexity of managing a condition that has a biopsychosocial impact.

Factors involved in coping and managing chronic pain

Due to the psychological impact CP can have on patients' wellbeing and overall sense of self, it is important to consider how psychological theory may help understand how patients' make decisions relating to their treatment and how they manage their CP condition. This may also provide insight when applied to patients seeking various, alternative ways of managing outside typical interventions.

Treatment decision-making

Psychosocial explanations of appraisal of chronic conditions and treatment decision making have helped conceptualise these complex behaviours e.g. treatment choices and engagement/adherence. The Common-Sense Model of Self-Regulation (Leventhal et al., 1984) suggests that internal (e.g., cognitive representations of an illness) and external (e.g., healthcare professionals) factors influence decision making regarding treatment and the appraisal of these behaviours/coping strategies.

The process of shared decision making (SDM) places importance on the patient-healthcare professional relationship. Kaldjian (2017) suggests that SDM creates a dialogue allowing patients to identify treatments that align with their value-based goals alongside the healthcare professionals' knowledge and recommendations based on evidence. However, Matthias and Henry (2022) argue that there are vast treatment options for CP making it an iterative approach, thus making SDM unfeasible in some cases. They also suggest that SDM does not account for when fundamental differences in patient and health care professional's views of CP and how

to overcome disagreements. The impact these disagreements can have on patients' relationships with clinicians and trust in the wider healthcare system (Henry & Matthias, 2018) could have deleterious effects.

Whilst these theories help to understand processes involved in decision making, they may well be limited to how CP patients perceive treatment choices. A vast number of patients suffering with CP consider the management of this to be inadequate (Breivik et al, 2006; Hadi et al, 2017). Consequently, patients may respond to ongoing pain in desperation and attempt to seek forms of treatment outside the realm of prescribed medicines (Chatterjee, 2021). Applying this type of understanding may help to understand the processes involved in patients' decision making related to CBD.

Coping and management

Sturgeon and Zautra's (2010) 'Psychological Resilience' (PR) model suggests that some CP patients are able to foster and adopt resilient ways of coping. They describe the importance of interactions between stable, internal or 'trait' resources; and social dynamic, or 'state' resource mechanisms in developing resilience and adapting to a life with CP. In turn, those individuals who develop resilience may adopt a greater number of coping strategies such as seeking social support, greater self-efficacy in their ability to manage pain, thus having increased capacity to implement coping strategies. Another mediating factor posited by the model is the responsiveness of a person's social world as a mechanism for reinforcing resilient ways of thinking and behaving.

The concept of psychological flexibility (PF) has been considered within literature to be a resilience factor in the management of CP (Gentili et al., 2019). McCraken & Morley (2014) highlight the integrative nature of this conceptual framework, suggesting that both cognitive and contextual processes are key in developing coping behaviours. PF can be defined by the extent to which an individual can adapt to environmental and situational changes, utilise

resources, develop the ability to shift perspective and balance competing demands (Kashdan & Rottenberg, 2010). There are a number of key dimensions related to PF; Awareness, Acceptance and Engagement (McCraken, Yu & Vowles, 2022) and can result in individuals being more willing and open to experiencing internal and external discomfort (Faulkner et al., 2020).

Access to treatment

Lévesque, Harris & Russell (2013) propose that access to health care and treatment is guided by the patients accessing the services, the cultural and social context in which the individuals and services are based, and the characteristics of the health care systems and providers. They conceptualise five dimensions to accessibility to services (Accessibility, acceptability, availability and accommodation, affordability, and appropriateness), they also propose five corresponding abilities of the person accessing the services (Ability to perceive, seek, reach, pay and engage). A qualitative study in Australia (Hopkins et al. 2020) considered these domains to treatment for CP patients suggesting they experience such internal and external barriers when accessing treatment. They report that patients experience their GP as a gatekeeper, finding their treatment was out of their control and services were not always appropriate. As a result, the patients made attempts to take control of their own pain management and overall wellbeing. Although, caution should be taken when generalising these findings outside the context and country they were gathered from.

These theories may go some way to understanding CP patients' decision-making processes and how they cope, manage and access treatment for their conditions. A common theme identified in these theories is the interaction between the individual's internal ability to cope and access services and treatment and the social, cultural and institutional context in which they are seeking and these services are provided. These are important considerations when

considered CP patients decision making and their choices of how they manage their CP condition when considering health care provided interventions and alternatives.

Chronic Pain and cannabis-based products: Qualitative research

Much of the qualitative research surrounding cannabis-related products has focused on clinicians' perspectives (Isaac, Saini & Chaar, 2016; Jacobs et al., 2019; Cooke et al., 2019; Narouze et al., 2020) many of which suggest concerns around side effects and lack of understanding of the effectiveness of these products. There have been several studies relating to patient perspectives (Cooke et al., 2019) but not specifically their experience of using CBD products as this current study does. As a result, there has been a call for more research to gain the patient perspectives of the safety profile of cannabis-based products for CP (Manz et al., 2020), which this study also addresses. A recent study carried out by Luque et al. (2021) adopted a similar methodology to the current study by exploring decision making and patients' perspectives on using medical cannabis. However, the study included various potencies and compounds of products and was conducted in USA, in a state that prescribed medicinal cannabis, which differs greatly from the legislative situation in the UK.

A number of studies have attempted to explore patients' decision-making regarding cannabis/cannabis-based medicines (Boehnke et al., 2019b; Luque et al., 2021). These have provided further understanding regarding demographics, administration routes and reasons for taking medicines (e.g. pain, anxiety and sleep), and due to existing medications having limited effect on pain relief (Boehnke et al, 2021). Boehnke et al.'s (2019b) study showed responses from a survey suggesting that participants used different routes of administration of cannabis-based products (e.g. vaping, edibles, creams etc.) for different symptoms. Although these studies are from the patient's perspective, they are limited to a quantitative methodology and to the geographical area in which they are studied.

Aims

The current study aims to explore the use of CBD products in the context of a UK CP sample. Using qualitative methods, the study will provide a deeper understanding of the benefits and/or barriers participants face when considering CBD products as a treatment option. The aim is to contribute to a growing body of evidence regarding CBD and CP and provide another dimension to the research by gathering participants' perspectives on this form of treatment.

Objectives

The main objectives of the study were to explore:

1. Participants' decision-making process in taking and considering taking CBD for their CP condition
2. The benefits participants report as having experienced from taking the CBD products and whether these are taken for pain or other pain related difficulties e.g. sleep, mood etc.
3. Any barriers to taking CBD products
4. Participants' experiences and perspectives of talking to clinicians in pain services about CBD use for CP.

Method

Participant recruitment and sampling

Paticipants were recruited from two Pain Management Service sites in the North West, referred to as 'Site 1', a tertiary pain management programme service, and 'Site 2', a secondary pain clinic service. The recruitment strategy differed in both sites due to differing systems being in place at each Trust.

Site 1 – had an established ethically approved 'Registry' of participants who had provided prior consent to be contacted about research and for their details to be used for research

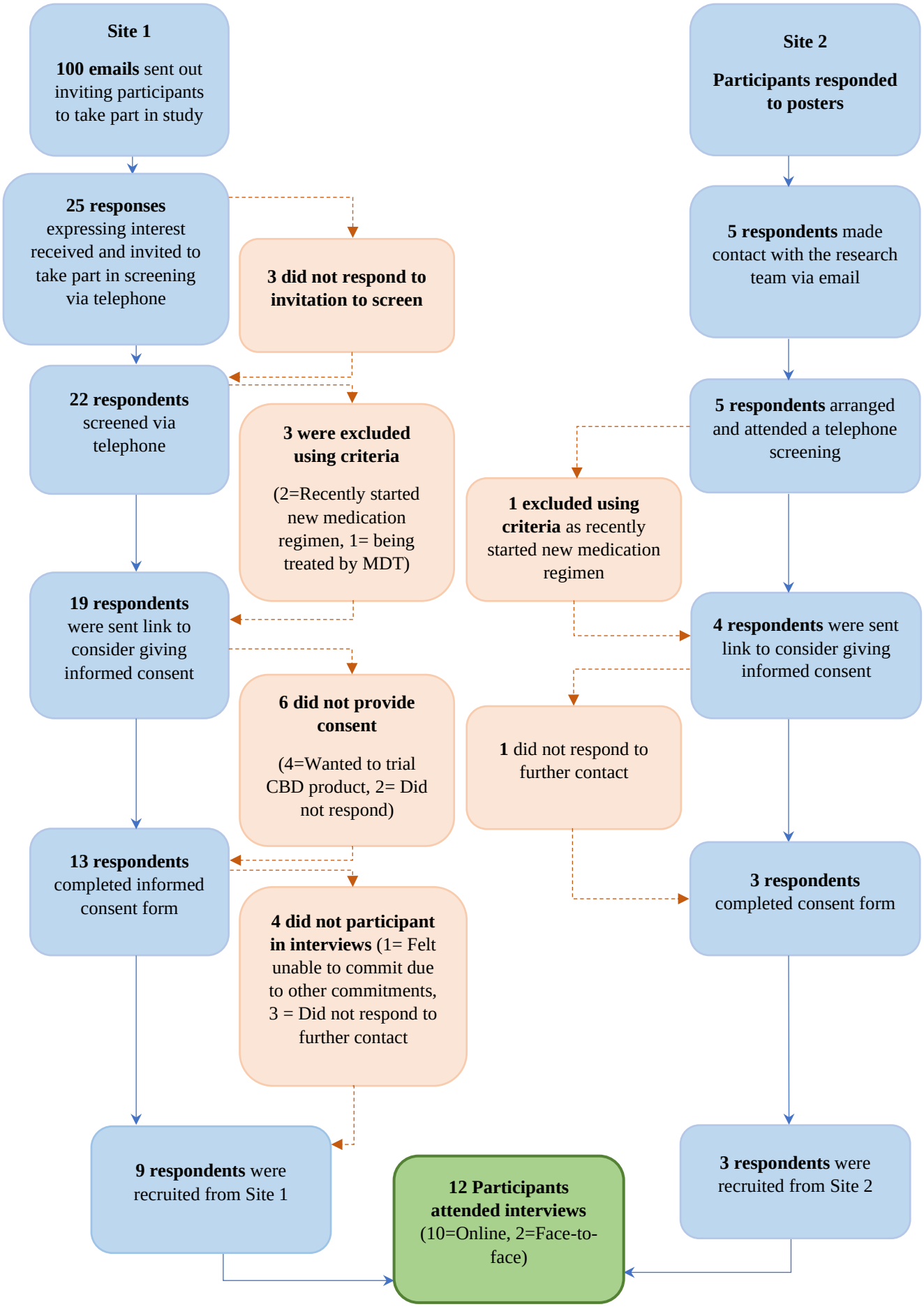
purposes. Advertisements were also used in the pain services' waiting area (Appendix 10). Following NHS ethical approval (Appendix 11) and agreement from the Trust's Research and Development department, participants were contacted via email/telephone and provided with comprehensive information about the study (Appendix 12) and the inclusion/exclusion criteria.

Site 2 – this site did not have a system where participants had provided prior consent to be contact regarding research. Therefore, advertisements (Appendix 10) were posted in public areas e.g. waiting rooms where CP patients access services, inviting participants to contact the research team directly. This will indicate their consent to be contacted for the purpose of discussing and inviting participants to participate in the interviews.

For participants from both sites, consent to take part in an online or face-to-face interview was obtained via completion of an online consent form (Appendix 13) using Qualtrics (https://www.qualtrics.com). Once this had been received, participants were contacted to arrange an interview and to answer any further questions they might have.

A recruitment flowchart (Figure 1) demonstrates the numbers of participants recruited from respective sites. The flowchart also outlines reasons why participants may not have wanted to take part or may have been excluded from the study.

Figure 1
Recruitment Flowchart
Inclusion / Exclusion Criteria



Inclusion criteria comprised people a CP diagnosis, who have considered taking or who have taken CBD products (within the past 18 months) for the purpose of aiding the management CP. Exclusion criteria comprised people who has taken or considered taking CBD >18 months ago, anyone being actively treated by the multidisciplinary pain management team (Site 1 and/or 2), started new medication regimen for the management of their CP recently (<1 month), and/or using any other illicit substance, including cannabis or CBD products containing THC the legal level (≥0.2%) (Advisory Council on the Misuse of Drugs, 2021).

By including participants who had both taken and considered taking CBD products for their CP condition, the research allowed the exploration of a broad lived experience of CBD in the CP population and an opportunity to consider factors that might be barriers and/or enablers to taking CBD. There is little research pertaining to the time period in which CBD becomes effective, however, research has made a distinction between length of time taking cannabis-based products, including CBD, and the influence this has on perceived benefits for CP, product administration route and preference (Boehkne, 2019.) Boehnke et al. make a distinction between 'novice' (<1year) and 'experienced' (>1year) users of these products. Therefore, the current study attempts to capture what might be considered both short- and long-term users of CBD products. The exclusion of CP patients engaging in treatment or having had a change in medication was to reduce interference with clinical treatment and/or adjustment to new medications.

Ethical considerations

Ethics approval was granted by Health and Care Research Wales (22/WA/0252). Participants were given break opportunities, to allow them time to manage discomfort from sitting for prolonged periods of time. Considerations were also given to the question content, especially regarding those regarding CBD use. Although CBD is legal, stigma may still remain

and participants were made aware that they could withdraw at any time. A protocol was in place should any risk of harm to themselves or others be expressed (Appendix 14).

Participants

Demographic information was collated (Table 1) for the purpose of reporting the representation of the CP population in the sample. Participants were also identified during the interview as to whether they had taken or considering taking CBD (Table 2). A number of participants (N=3) reported to meet criteria for having taken CBD in the last 18 months, had stopped taking products in this period, but continued to consider taking CBD. These participants were identified as having taken CBD in the last 18 months and provided a unique perspective on CBD.

Table 1

Pseudonyms and Self-reported Demographic Information

Pseudonym	Sex	Age	Taken or Considered
P1	F	64	Taken
P2	F	62	Considered
P3	M	54	Considered
P4	F	27	Taken
P5	F	71	Considered
P6	F	48	Considered
P7	F	35	Considered
P8	M	N/A	Considered
P9	F	30	Taken*
P11	F	39	Taken*
P12	F	68	Taken
P15	M	55	Taken*

*Participants who had taken CBD within the last 18 months, stopped and were considering taking CBD again in the future.

Methodological approach

A qualitative methodology, using interviews was considered appropriate for this study to provide an opportunity for researchers to explore participants unique experiences in-depth (McGrath et al., 2019). There is limited guidance on sample size, however, qualitative research for psychology studies of this size suggests 10-20 participants (Braun & Clarke, 2016). There is little evidence to suggest whether particular traits or relevant factors relate specifically to CP patients taking CBD. Therefore, an explorative approach using thematic analysis was deemed most appropriate, with no specific diagnosis excluded. Other approaches were considered but not deemed appropriate as they require a more homogenous sample (e.g. IPA, Smith, Flowers, & Larkin, 2009).

Guidance for Thematic Analysis (TA) suggests that sample size cannot wholly be identified prior to analysis as meaning is generated through interpretation (Braun and Clarke, 2019). The importance of qualitative research reaching ‘saturation’, where the research fails to produce any more themes has been explored (Guest et al. 2006; Ando et al., 2014), can guide the number

of participants required for qualitative research. As a result of reaching saturation, as agreed by researchers, 12 participants were recruited for this study.

For the purpose of this study, TA was rooted in a critical realist epistemological and ontological framework. Wiltshire and Ronkainen (2021) consider polarising TA approaches in a binary sense could limit the potential benefits of lending from both positivist and constructivist approaches. They suggest that by using a realist approach researchers can generate an understanding of what is being observed in the data, what is unobserved but inferred, and what wider unobserved powers or mechanisms might be at play to generate a phenomenon (Bhaskar, 1978). Therefore, using a synergy of approaches from both Braun and Clarke (2006) and Wiltshire and Ronakainen (2021), researchers developed a better understanding of the meaning-making of participants (Wiling, 2012) and were able to consider the wider mechanisms at play influencing the phenomena of considering or taking CBD for a CP condition.

Procedure

The semi-structured interviews were based on an interview schedule (Appendix 15) to allow for open exploration of participants' perspectives whilst ensuring study aims were met. The questions included in the interview schedule were developed between all researchers and involved a process of extensively reviewing relevant literature, drawing on the team's combined academic and clinical experience of working with a CP population, and formulating and testing the interview guide within the research team. This was reflective of guidance set out for developing research guides (Kallio et al., 2016), which provide guidance on developing an inter-reliable interview schedule based on a systematic methodological review. They describe various inter-related phases that include: (1) identifying the prerequisites for using semi-structured interviews; (2) retrieving and using previous knowledge; (3) formulating the

preliminary semi-structured interview guide; (4) pilot testing the interview guide; and (5) presenting the complete semi-structured interview guide.

These in-depth semi-structured interviews lasted between 46-73 minutes (M=57 minutes). Participants were asked initially if they had taken or considered taking CBD for their CP condition to help shape the opening question. More specific questions relating to the objectives of the study were explored such as what led them to take or consider taking CBD, barriers and benefits experienced or considered, and whether discussions with healthcare professionals had taken place. Participants were offered a break 30 minutes in to the interview to stretch or manage any discomfort they might be experiencing.

Nine interviews were conducted via videoconferencing and two interviews were face-to-face. Clinic rooms on respective sites were used to conduct face-to-face interviews. Each participant received a £10 Amazon voucher for their participation in the interviews. Due to an error, a recording was deleted before it had been transcribed. However, the participant (P7) agreed to take part in a second interview and were reimbursed for their time.

Two of the interviews were transcribed by the primary researcher (CM) and the rest were transcribed by external transcribers as recommended and approved by University of Liverpool. For those externally transcribed, a confidentiality agreement was signed by the transcribing service to ensure confidentiality. Those transcribed by external transcribers were checked for accuracy by CM. All participants' information was anonymised and the recording was destroyed after transcriptions had been checked for accuracy.

A reflective summary details the position of the primary researcher and how the interview process may have impacted on data analysis and interpretation (Appendix 16).

Data analysis

It is important for qualitative research such as thematic analysis to be conducted with rigour (Nowell et al., 2017) and trustworthiness (Nyirenda et al., 2020). Therefore, the study's

interviews were analysed using Braun & Clarke's (2006) approach to Thematic Analysis (TA). Braun and Clarke provide a structured approach to TA (Table 3), which will be adopted to identify and define themes from transcripts of the semi-structured interviews. Braun and Clarke's approach involves an iterative process of familiarisation with the transcripts; leading to generating codes from the data; and in turn producing themes that are reviewed and defined for the final report.

Table 3

Phases of thematic analysis. [Braun & Clarke, 2006, p. 87]

	Phase	Description of the process
1	Familiarising yourself with your data	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas
2	Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code
3	Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme
4	Reviewing themes	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis
5	Defining and naming themes	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6	Producing the report	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

The interviewing researcher (CM) conducted 12 semi-structured interviews and then simultaneously analysed these with a second researcher on the team (PR). Braun and Clarke's (2006) step-by-step approach guided the analysis of the data.

Familiarising with data and generating initial codes

CM became immersed in the interview data by transcribing two interviews, with the other nine being transcribed by an outside agency. These were checked against the audio recordings for accuracy and this also acted as a way of becoming familiar with all transcripts and the data as a whole. After half of the interviews had been transcribed and CM had become familiar with

these, PR took a proportion of these to become familiar with and they met to discuss emerging themes, individually and across participants.

Searching for and reviewing themes

Following the completion of the remainder of interviews and transcripts, CM immersed themselves in the data again by revisiting the previous transcripts and checking for accuracy in the recently completed transcripts. During this time, PR was also invited to consider a proportion of these transcripts and both CM and PR discussed emerging themes once more, ensuring triangulation. By including another researcher in the process of analysis helped to reduce bias of a single researcher's interpretation and increase validity (Denzin, 1978).

Defining and naming themes

Finally, when the final themes had been drawn up, these were discussed with the wider team and agreed upon. Recruitment ceased when saturation of themes was reached by consensus of CM, PR and the wider team.

Participants did not have any relationship or contact with any researcher prior to the interviews. A further reflective summary is available detailed this process and the methods taken to reduce bias (Appendix 16).

Results

A total of 4 overarching main themes were identified, which were derived of 13 subthemes. A visual representation of these themes was developed to present the findings in an accessible way (Figure 2).

Theme 1: Access

Participants expressed their ability to access information from a variety of sources that influenced their decision-making processes. They also considered CBD to be easily accessible from a variety of sources. These sources varied as to what participants considered to be legitimate. Despite this, there seems to be a consensus that information and products were

easily and readily accessible. Despite this, there was also a subtheme relating to barriers to accessing CBD, which varied and was influenced by current and historical factors.

Accessing information

The majority of participants identified that family and friends were a key source of information through related conversations about taking and considering CBD. This information was considered an anecdotally 'trusted' source. Friends and family who had experienced CP or had taken CBD products were also considered reliable sources of information.

> "It was a big deal for me mentally to start on it because a lot of my friends in California and have been using stuff for years and smoking marijuana and all that. It was only because of my son, my faith and trust in my son." (P1, Taken)

> "Another friend of mine damaged his back and he was saying about how he was taking CBD" (P4, Taken).

> "My daughter has got fibromyalgia. And she was taking it for a long time. CBD oil and she reckons it helped her." (P5, Considered)

Similarly, accessing information from the media and the internet were also considered as part of a wider pool of information. These varied widely and highlighted the vast amount of information that is available for CBD and variation in what people might consider to be a trusted source of information.

> "I mean certainly initially when I looked up CBD stuff I looked at scientific papers." (P11, Taken)

> "And then subsequently I read that [newspaper] article, and she had said in her thing, in the article, that it didn't appear to interfere with other medication that she was on. But not to be tempted and exceed the dose." (P12, Taken)

> "…you've got the internet so everything's more available now than it's ever been really, to be honest, to educate yourself if need be" (P15, Taken)

Some participants, however, did not consider the information available online to be sufficient and still wished for more information, particularly from healthcare professionals (HCPs).

They considered HCPs to provide more trustworthy information and advice, and found that information online was either inconclusive or unconvincing.

> "if they could signpost you where to go to get, the brand, what shops definitely sell the right stuff, as long as I knew that, from a health care professional and that probably be where the trust would be better." (P9, Taken).

> "if it was a professional saying, "This is really quite effective for chronic pain," I would probably be more- Or less concerned with the idea of trying it." (P6, Considered)]

> "British Medical Journal is great for me, I use that a lot and I try and look at published papers as opposed to just hearsay on the internet" (P7, Considered)

> "when we kind of tried to look online for corroborating evidence, it was a bit woolly." (P6, Considered)

Accessing CBD products

As with accessing information, participants considered varying degrees of legitimate ways of sourcing CBD. Some participants had worries and concerns about accessing products that were being sold. They made the distinction between someone 'selling' the products and a HCP prescribing them, with the people selling products not having theirs or the person's interest at heart.

> "I don't want to go to Holland & Barrett because they're a chain, and they're there to make profit. They're not there to look after me." (P8, Considered)

> "I am not convinced that every single brand that makes any of the CBD knows exactly what they are doing. They just go "Oh this works and we will sell it to make money." You have got that problem." (P9, Taken)

"if this was going to go to the NHS or, you know, to be rolled out in the medical profession and I don't mean this to be Joe Bloggs on the street selling it, because I don't entertain that personally, I'm waiting for it to come out into, you know, medicine" (P7, Considered)

Whilst others considered accessing CBD products on the high street or online as being safe and legitimate. There also appeared to be a distinction and justification of buying off the high street versus purchasing from sources that might be have connotations of purchasing illicit substances.

"But I do think with the internet it's very easy to find UK-based places that you can buy it from." (P11, Taken)

"The Kind and the other hemp stuff that I'm finding that is helping me is all online through Amazon." (P1, Taken).

"I know some of the health food places sell them. I know Asda has started selling stuff so I'd probably try and, again, go from a recommendation…I don't think I'd speak to the kids on the corner." (P6, Considered).

Participants' responses relating to accessing products varied and appeared to link with worries and concerns about the content of the products. The content of products seemed to reflect the source, paying particular attention to the lack of regulation. Their concerns also linked with perceptions of products being tampered with and not containing what they state they contain, having connotations of illicit substances. Thus, having both harmful physical or legal implications.

"Because I don't want to buy stuff which is coming through the post and it's illegal and then I'm going to get knock on the door by the police" (P2, Taken)

"So- I- I'd kind of like that reassurance, I guess, that if you take CBD oil, it doesn't then show up in your system as a "you've taken an illegal drug substance and you shouldn't be driving." (P6, Considered)

"…the one thing that you do think about when you're taking them is this is unregulated, who knows what's in it, you think there's unlikely to be anything harmful in it, but is there actually anything beneficial in it, who knows." (P11, Taken).

Despite these concerns, all participants expressed how easily they were able to access CBD products online and on the high street. This suggests the ubiquity of CBD products and their availability. The concerns regarding access to CBD products did not appear to be barriers but more considerations in the decision making for people taking and considering taking CBD.

Barriers to accessing CBD

Barriers appeared to be factors that would prevent participants from accessing CBD in the future. There was a sense that some participants were still looking for permission or approval from HCPs before they could consider taking CBD products.

"sometimes you just feel like oh god, I'll umm, I'll just take it, you know and then something stops me and then you know, I don't know, it's approval you are looking for really." (P5, Considered)

"You just- it's just not ethically right for one, so if it's done on a medical- on a resea[rch]- you know, like you're- what we're doing here, then I'm 100% because if it helps [laughs] great, I'll be singing and dancing, you know." (P2, Considered)

Whilst discussing barriers to taking CBD, the majority of participants also considered the expense of the products to be something of a barrier. Discussions centred around the general expense related to CBD and how they may not be able to afford products from the outset or be able to maintain purchasing CBD in the long term.

"I don't know if it's about £40 a box but that's what he gets, you could pay more, the financial thing's probably, if I'd had the money I probably would have tried it myself" (P3, Considered)

"To be fair, getting hold of them is really easy but expensive. Considering it's like £10 for a prescription from the doctors, give or take." (P4, Taken)

"Maybe the barrier- I could only see at the moment, just with the currently climate, is money. It is expensive" (P7, Considered)

Others' concerns related to interactions with the other medications they were taking for either CP or other conditions. Their concerns linked with not having enough information and this having been a barrier to taking CBD in the past and for some continues to be a barrier. This also appeared to link with wanting more information from HCPs.

"I did buy some of the liquid that you put on your tongue. But I never actually took it because I'm on a lot of other medication, and I thought you're dabbling here girl." (P12, Taken)

"I'm always very worried about kind of drug interactions. I do take a lot of painkillers and stuff, and I- I just think when something isn't researched enough, then there's a potential issue" (P6, Considered)

"if it's not regulated then I don't see how you would know what was in it, what the dosage was, how it would react to your body if you're on existing medication" (P7, Considered)

Some participants also considered their state of mind to be something that had stopped them from trying CBD or limited their capacity to recognise any benefit so stopped taking it. This linked with their wellbeing and wanting to be 'in the right head space' due to historical or current difficulties relating to their mental health.

> "Well, the money was the main thing but also state of mind was the main thing... As regards of mental health I haven't been in the right place to try" (P3, Considered)

> "I don't know if I was in the best kind of head space to actually think more logically about it. I think when I am really sore, you're quite apathetic about some things because you're just a bit fed up and a bit pissed off really" (P11, Taken)

The themes relating to 'Access' appeared to be varied in nature with key similarities and differences. The majority of participants agreed that information and physical access to products was readily available. However, there appeared to be various different factors involved their decision-making processes of taking CBD, with some people overcoming concerns and others feeling they were a barrier.

Theme 2: Views of CBD

A theme in the interviews often centred around perceived benefits and side effects of CBD for people who had taken or were considering taking products. These views were about CBD alone and also drew on comparisons with prescribed medications and where they felt CBD sat in relation to these. Participants also discussed the influence of wider social and historical contexts that influence their views of CBD and taking products.

Perceived benefits

Some of the participants who had taken CBD described experiencing some form of pain reduction along with other benefits such as sleep and anxiety. In order to test their hypothesis, some participants took breaks from taking CBD and reported an increase in symptoms. As a result of these benefits, some participants even considered CBD to be essential to the management of their CP condition.

> "So when I took the CBD I actually felt a lot calmer and I am very much an overactive thinker, I have anxiety, I have depression, borderline personality disorder as well and it seemed to, I am trying to find the right word, but it like levelled out that mood swing phase that I go through on a regular basis" (P9, Taken).

"And over time I could feel myself becoming a little bit more like, not as bad as I was but I wasn't great. A little bit more anxious, a little bit more self-conscious. So it must have actually dulled something, made it a little bit more chill." (P4, Taken)

"In a very simplistic way, I feel that if I take them on a regular basis my quality of sleep is better" (P12, Taken)

"I couldn't survive without all these different CBD oil products that I use for my pain" (P1, Taken)

CBD was also considered beneficial when in combination with others strategies, not necessarily attributing CBD as being the sole reason for improvement in management of pain and related symptoms. There was also uncertainty that having used other strategies alongside CBD, whether CBD was actually effective in managing symptoms.

"Whereas if I sort of attribute it to, well if I exercise regularly then it eases 10%, if I take CBD it eases 10%, if I take time for myself it's 10%, and each bit of it is notching it down a little bit and making life a lot more bearable." (P4, Taken)

"I think, 'Right, well is this attributed to the CBD or is it towards the X minimum, you know, the little bit of exercise that I'm doing? Which is contributing to it more?' And I couldn't define if the CBD oil actually really helped" (P15, Taken)

Importantly, many of the participants described feeling as though there had been an impact on functioning and overall quality of life.

"It would be the quality of sleep, and the knock-on effect is if I manage to get a really good night will be six hours. And if I do that, then I can function really well." (P12, Taken)

"If I took all of my medications prescribed for me, I'd be a junkie and I am able to function using the different CBD oil products every day" (P1, Taken)

In some cases, participants described having taken CBD and stopping recently due to the product not living up to expectations. However, they did not believe that their experience would deter them from taking different products or similar products at a different dosage in the future

> "I wouldn't say it's influenced from the previous decision, because I know that there is different strains of CBD you can get different, like I want to say dosages...but you can get different strengths of CBD oil. Now because have done a lot of research into it since the last time I took it" (P9, Taken).

> "This is it, the fact I've still got the capsules at home I think that actually that again would probably be where I would start, and try and take it for a more prolonged period and again see if there's a benefit." (P11, Taken)

> "I mean, I have run out of some of my medication and I'm going to be speaking to the GP...if that's the case then I potentially might look at it again" (P15, Taken)

Perceived side effects

Participants did not report any side effects from taking CBD or had not discussed or reported having accessed information relating to side effects. Side effects that had been considered related to worries about the overwhelmingly positive reviews and acceptance of others leading to a neglect in consideration of side effects. There were also worries relating to not experiencing side effects in the short term, suggesting that there might be long term side effects not yet identified.

> "If it's long term, is that any good? Because that's never been proven either." (P8, Considered)

> "With CBD I mean obviously I believe that there will be side effects based on individual differences, maybe in long term use there might be something" (P9, Taken)

"And I'm wondering are people neglecting any possible long-term side effects of CBD because they're not wanting to besmirch the reputation of the wonder drug you know." (P4, Taken).

Comparisons with other medications

Participants appeared to draw on comparisons to develop their view of and reasons for taking CBD as a product in relation to other forms of treatment, particularly prescribed pharmacological interventions. Some participants considered their prescribed medication to be working and others did not. Despite this difference, they all considered CBD to be an alternative to currently prescribed medication.

"so I think I've tried most prescribed pain meds under the sun...and I think I just thought the fact that I am intolerant of lots of other drugs I thought what else can I take that might help me improve my quality of life like this really." (P11 Taken)

"I have reduced the gabapentin, I am on one now. I don't feel any different...and that is why I wanted to try it [CBD] really" (P5, Considered)

"I don't particularly want to have any less than that in order to manage, so I think if they do continue with the 'We want you to stop taking tapentadol' then trying CBD oil will probably come back into the 'maybe this has to be given a go'"(P6, Considered)

Despite there being mixed views of the effectiveness of prescribed medications, all participants reported the side effects of prescribed and other medications as reducing functioning and engagement with day-to-day activities

"I thought I'm sick and tired of taking pain relief because they don't work, one, they make you feel like a zombie anyway" (P2, Considered)

"I do increase the gabapentin and the amitriptyline. But to get rid of the pain, it has an impact on my cognitive function as well" (P12, Taken).

> "And I was on a medication, just a standard one, wasn't really related to much. And it gave me migraines to the point where once a week I was laying up in bed in the dark with an ice pack on my head." (P4, Taken)

Participants also considered worries relating to the long-term side effects of prescribed medication and the impact this could have and has had on their general physical health and how they might compound pre-existing or comorbid chronic physical health conditions. They also expressed not wishing to take all prescribed medications due to not having a positive perception of medication in general.

> "I'm supposed to take up to 8 ibuprofen a day. I'm suppose to take 5 amitriptiline a day. I take loratodene, antihistamines, calcium, vitamin d...I mean there was no way with one kidney I was going to do that to myself." (P1, Taken)

> "I've never shared as- like I have been able to lately, in the past couple of years, about how the effects are, and then now the doctors and what have you can see, Oh, you're right, that medication has done this to your stomach now, that medication has done this to your bowel now and that medication has caused us to worry about your heart now." (P2, Considered)

CBD was considered by the majority of participants to be an alternative to prescribed medications as it had been reported to produce less side effects. This was for people who had experienced less side effects from taking CBD and was considered a potential benefit by those who were considering taking CBD. Although it was reported that CBD may not produce as much of a pain reductive effect, interviewees appeared to weigh this against reduced side effects and determine a preference for the reduction in side effects to have a more positive impact on their pain management, functioning and overall quality of life.

> "if I take co-codamol I feel it straight away, you feel drowsy, you feel the side effects straight away and I don't like it. I can't recall any of those side effects or anything particularly unpleasant in relation to it at all, no." (P15, Taken)

"I wouldn't be able to do all these things without the CBD oil. I can't live without them, no." (P1, Taken)

"I don't want to mask it with meds...I don't want to rattle for the rest of my life, so I need to get to the cause of the problem, to find the solution, to fix it. So with CBD you are managing the pain without any side effects, potentially, right?" (P7, Considered).

"What's the point in living your life if you're just going to exist to pop a few pills and not experience the world you know...You could say oh yes I want the pain to go, but what good is the pain going if you can't live your life." (P4, Taken)

A further comparison was made with prescribed medication, suggesting that CBD was considered more 'natural' than prescribed, or 'man-made' medications.

"It's not as taboo or it's not- it's stuff which has been, you know, induced chemicals and what have you, it's natural, yes, so that's- that helps." (P2, Considered)

"Yes, I would yes. I would be more willing to, because obviously being natural" (P3, Considered)

"with CBD or like even cannabis in general it's a herb and I know long term there has been research into how it can damage the brain, but it is a natural thing, it's not something we have made." (P9, Considered)

Stigma

Despite the majority of participants having a positive perception of CBD compared to prescribed medication, there still appeared to be a social factor in their concerns surrounding perceptions of CBD and how others might perceive them. There appeared to be a subtheme of CBD being stigmatised with worries or concerns about being judged by others, actual experiences of being judged by others and/or expectations that others might judge.

"I've only ever brought it up the once. And I think part of that is because I didn't want to get frowned upon or have- I guess I do- I worry about the idea that people would go, 'are you just a druggy?'" (P6, Considered)

"Their advice, and also the judgement that they would have of me. Which is silly because I'd be going in and coming out, and I'd never be going in again sort of thing. I don't know." (P12, Taken)

"So it's like, "Hey [parent] I'm taking CBD" and she's there thinking oh great my other child is now taking weed. So she wasn't too impressed" (P4, Taken).

Stigma from others, including professionals and family, appeared to be influenced by its continued affiliation with cannabis as an illicit substance. Past experiences within family systems relating to substance misuse or addiction also contributed to perceived judgement from others.

"I didn't know a great deal about cannabis or CBD it was always something that my mum kind of put an idea in my head, like the traditional views of this is a drug, don't touch it. I won't speak to you if you touch it." (P9, Taken)

"I don't know, I mean- my mind because of when I'm- from when I was a child it's- it's- CBD is known as- it's a drug." (P2, Considered)

"I think CBD, and probably with the link to a lot of people still think oh is it cannabis, and is it actually an illegal drug." (P11, Taken)

However, a number of participants identified that accessing information, self-educating and sharing this with family members helped to reduce stigma

"There are lots of products made from the cannabis plant. So it's education, I think, and raising people's awareness of what products are safe and beneficial" (P12, Taken)

"So the negative side effect basically comes from a preconceived notion of what it is, as soon as a little bit of education comes in she [parent] was like that's fine." (P4, Taken)

> "knowing that cannabis is illegal, that's it, so anything from the cannabis plant people view as being illegal, and it's lack of understanding but there's more understanding now" (P15, Taken).

Generational and cultural shifts

Many of the reported difficulties with families appeared to stem from parents or those from an older generation to them who may have differing views. Some described a recognition of how being socialised to this has contributed to their perception of CBD and continued links with cannabis. They described a generational shift with the 'current generation' as being more 'open' to the idea of alternative medications and forms of treatment. Others described feeling they were in opposition and embracing the shift towards acceptance of alternative medications.

> "As the demographics move, then my generation and the younger ones are a little bit more open to them than perhaps, my mum's generation." (P6, Considered).

> "So I feel like because doctors generally are going to be older than me, and obviously older than anyone younger than me, it is very much like we are fighting with the older generation to just hear us." (P9. Taken)

Despite there being some differing in approaches to the observations of a generational shift, participants that discussed this topic appeared to agree that there had been some form of shift. This shift also appeared on a cultural level too. Almost all participants described how CBD was much more present in recent years, attributing this to a noticeably occurring cultural shift.

> "The more people want it, the more places sell it." (P6, Considered)

> "The whole of the city, the whole of Liverpool- And probably the country, but the whole of the city is changing." (P8, Considered)

"There's lots more now, there is a hell of a lot more, I have seen them in Superdrug, I think I have seen them in Boots and online if you search it, there's a lot of avenues where you can get your hands on CBD oil." (P9, Taken)

The majority of participants also discussed CBD being much more acceptable due to information and products being more acceptable. This also linked with cannabis-related medicines becoming viewed as more medical than recreational. There appeared to be more awareness of cannabis-related products being destigmatised by research being carried out in the area.

"I don't know whether there is just more kind of cultural acceptance of it as well." (P11, Taken)

"I think cannabis products are far more acceptable now" (P12, Taken)

"I think more open-minded about it now and there's a lot more research gone into it and there's a lot more thought about it now" (P2, Considered)

Some participants also commented on a disparity between social and medical views of cannabis-related products, suggesting medical research needs to catch up with the faster shifting social views.

"So I would say health care professionals now, they are living in an old, a different era where we've gone through years and years of testing of one thing, we know this works, why are we throwing money into something else." (P9, Taken)

"So I think there is a- You know, a shift in it in the attitude, but I think the medical professionals and industry- I'd like to see that shift in them, so that there is more legitimate research and guidance on it." (P6, Considered)

Theme 3: Discussions with professionals

Another theme was one of discussion with professionals, which varied between participants. Some participants reported having had positive experiences with professionals. Others, however, had somewhat negative experiences. There was also a sense that professionals were often noncommittal and participants attempted to make sense of the mechanisms behind this. For some participants, an element of 'trust' was required for them to open up to professionals about taking CBD.

Positive interactions

Some of the participants had described having open and honest discussions with professionals about them taking CBD. This appeared to be a validating experience for some.

> "...anything that is not under the NHS he [GP]won't agree to even though he knows I'm doing it whereas my other main consultant is all for me taking it" (P1, Taken)

> "I spoke to one of the GPs I was with,...when we were speaking he was very open to the natural approach, the trying to find ways to heal without medications..." (P7, Considered).

> "So he is aware, I've told him what I'm doing and what I'm taking, and the anecdotal effect that I feel it has had. And he's just said well if it's working for you..., we can't endorse it, there aren't any NICE guidelines on it all" (P12, Taken)

Negative interactions

Other participants experienced feeling dismissed and judged for taking or considering taking CBD. There was also a perception that CBD was still being considered a social taboo by professionals. These experiences led them to be less likely to talk to professionals in the future.

> "I haven't barely spoke to anyone, like I say, when you get shot down, you think that's pointless really asking them... it's like a look of disgust really, don't want to feel belittled by them do you." (P3, Considered)

"It was slightly taboo, and I don't know if that's because of their [HCP] view on it..." (P2, Considered)

"his stance on it was very different to what I've experienced in the past with other medical professionals who just shut it down completely." (P7, Considered).

The sense that professionals were noncommittal in their responses to CBD was also considered in the wider context of their professional status and guidance. Participants appeared to be seeking out the reasons why professionals might not be committed to answering questions about CBD such as it not being within their professional remit.

"I think that does just make it a slightly grey area that a lot of medical professionals understandably don't really want to talk about. They're trying to push evidence-based medicine, but it's very hard when you're basically telling people to buy stuff off the internet." (P11, Taken).

"He was very noncommittal...Now whether that's because CBD oil isn't prescribable, I don't know. But it was a bit of a- There was no real discussion." (P6, Considered)

"...so it is very much about look we have had these on the market for years, we know they work, we know the risks, we know how to identify when those risks are going to happen, so because we know that, we would rather take that risk than take the CBD route." (P9, Taken).

For some participants building up and having trust in a professional is a key factor in whether they would share their use of CBD with them. This might require time and some participants acknowledged that having time to develop trust, understanding and open discussions is not always possible.

"'Oh, here you are, there's the medication, go away.' That's how it's felt like because I know how busy people are whereas others, say, for example, your service is signposted this study whereas other it's not, it's, 'Take a tablet, shut up and get out.'" (P2, Considered)

"But my last practice nurse who took my blood pressure, I told her and she was brilliant. And now if I- If I see her again, I'll ask her about CBD." (P8, Considered)

"I completely see why but I think they're all quite often so limited in time it's very much like come in how are you doing what can we do, next patient. So again I don't think there's always that time to explore everything in as much depth as there potentially could be..." (P11, Taken).

Theme 4: Taking Control

The theme of 'taking control' appeared to relate to various subthemes about trying out various alternative medications when they might not be open for discussion or prescription from HCPs. This control appeared to be part of a wider understanding that current medications were not sufficient in managing their CP condition, therefore, attempts were made through trial and error to determine the effectiveness of alternatives such as CBD. There were also subthemes of communicating their needs to HCPs when they felt they had not been met in the past.

Trial and error

For some participants, it was important for them to take control when considering and taking CBD by accessing information and attempting to take it themselves through a process of trial and error. This was despite concerns and perhaps in response to a lack of information from HCPs. This also appeared to be a recurring approach to other management strategies in an attempt to identify what works best for them as individuals

"I have gone through this for five years now and a lot of it is trial and error. So I know what's good and what isn't good" (P1, Taken)

"You go back to the '70s where it was all like, trial and error, and it still is trial and error. Of course it is. Going back to the CBD, all of us are looking. Not just my disabled mates, all of us are looking for something that'll help us." (P8, Considered).

"I took a small-ish dose and see what effect it has increased your dose, and then I thought well this isn't having much of an effect and gave up on it...But it's just trial and error isn't it." (P11, Taken)

For others, a process of vicarious trial and error occurred, whereby they overcame certain worries and concerns about safety by others having testing and recommended products. This also appeared to vary and link in with types of sources of information and accessibility to products.

"Basically the relief that they got from it, they felt that it worked so it was nothing more than that, well, you know, 'Why don't you try this? This worked for me.' So I just thought, Yes, well, what have I got to lose and- other than try it?" (P15, Taken).

"I'd sooner, where I know it's tried and tested, with my cousin I'd go with that." (P3, Considered).

"But then I probably would go on the one my daughter went on." (P5, Considered)

Advocating For Self

Some participants described having to be your own advocate by doing your own investigations as what HCPs offer is not enough to help support the holistic management of CP. This appears to link with dissonance experienced during discussions with professionals and the patient-clinician relationship.

"you have to be your own advocate when you have CP or a chronic illness or a chronic disease because its not enough just going to a doctor you have to do your own investigative work." (P1, Taken)

"the times I've gone to the doctors and been like I've got this, please I need some help managing it, I'm not here for drugs I'm just here for help. And they'll go, 'oh you've got something completely different, it's not that, where's your medical degree?'". (P4, Taken)

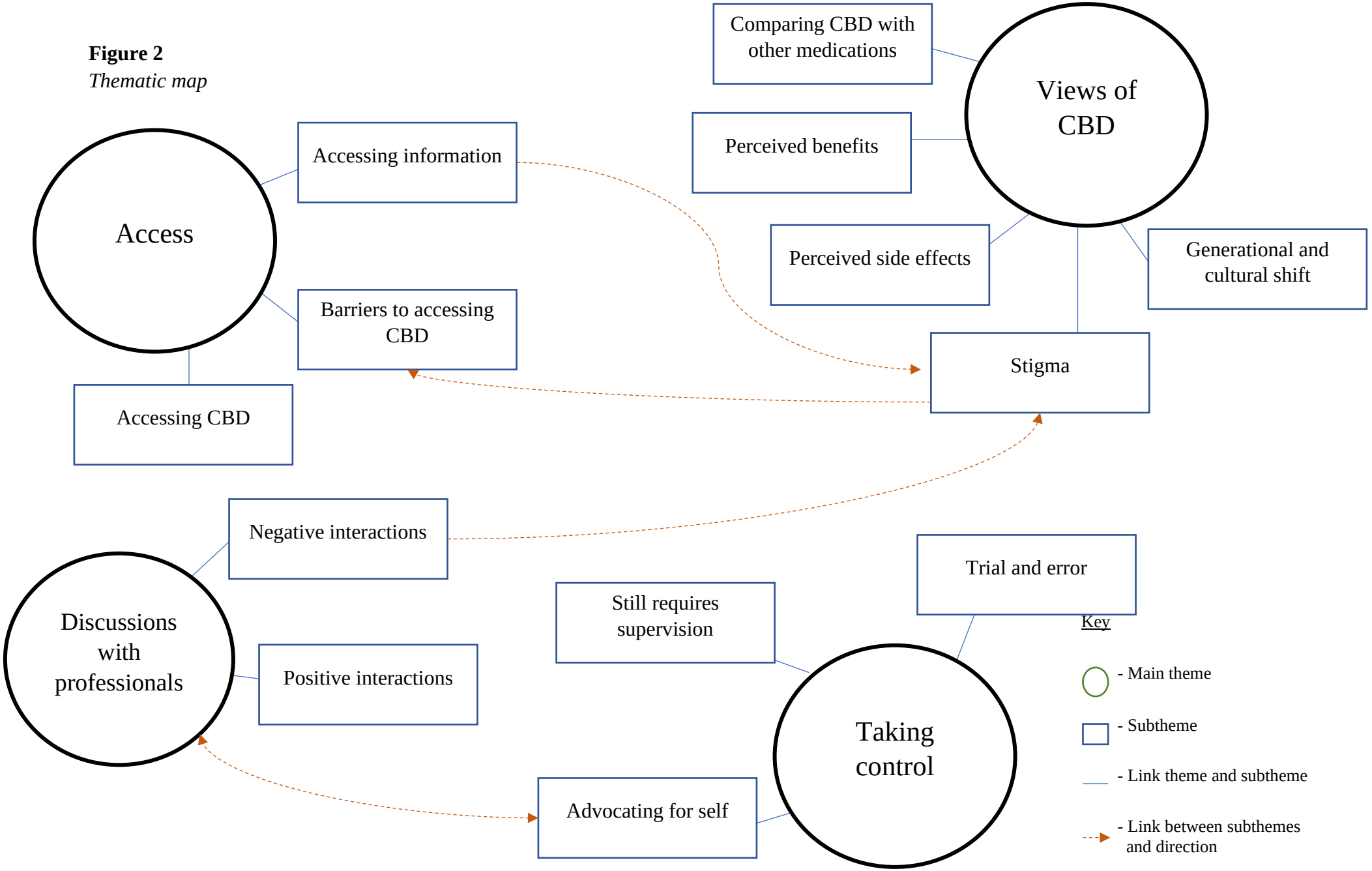
There was also a sense that advocating for yourself at appointments with HCPs was also important in order to get needs met. This also seemed to link with having some control over your own body, particularly when managing your CP condition to give a sense of helping oneself.

> "it's the approach you take with medical professionals because a lot of people- a lot of people are frightened to talk to doctors about things and ask very sort of blunt questions whereas I'm not...like 'don't just write me a prescription and expect me to take it, I'm not putting my trust in you like that, you have to justify why you're doing that.'"(P7, Considered)

> "'Well, we'd like you to, you shouldn't take it because this, that, and the other.' And I said, well, you know, I would- quite forthright and tell someone it's, you know, it's my body, I'd make decisions- it's no different, you know, all the other drugs have side effects what, you know, I've looked in it'" (P15, Taken).

Despite the strong message from a number of participants about taking control and making decisions about taking CBD with or without the support of HCPs, some participants did not agree. These participants still considered the supervision of HCPs a requirement before they took CBD e.g. through research clinical trials.

Figure 2
Thematic map



Discussion

The study sought to explore the decision-making process around either taking or consider taking CBD in a sample of CP patients, whether they had experienced or considered benefits or barriers to taking CBD, and their experiences of talking with HCPs. The results have highlighted several main themes and corresponding subthemes summarised in the table below:

Table 4

Summary of themes and related subthemes

Main Theme	Subthemes
Access	Accessing information
	Accessing CBD
	Barriers to accessing CBD
Views of CBD	Perceived benefits
	Perceived side effects
	Comparing CBD with other medications
	Stigma
	Generational and cultural shift
Discussions with professionals	Positive interactions
	Negative interactions
Taking control	Trial and error
	Advocating for self
	Still requires some supervision

The findings will be discussed and conceptualised alongside research and theory, considering implications for clinical practice, the strengths and limitations of the study and make suggestions for direction of future research.

A key finding in the data relates to how decision-making relating to CBD involves its comparison to prescribed medications. All participants reported side effects of prescribed medications having a negative impact on their day-to-day functioning. This appeared to be a key mechanism in their continued use and consideration of alternatives, such as CBD. Horne and Wellman (1999) suggest a ‘Necessity-Concern Framework’ (NCF) whereby patients weigh up ‘necessity’ and ‘concerns’ about taking medications for long-term health conditions, with

particular concerns relating to dependence and long-term side effects (Horne et al., 2013). Similarly, research suggests CP patient's beliefs, concerns and perceived side effects of prescribed medication are predictive of medication nonadherence (Rosser et al., 2011), increased emotional distress and disability (McCracken, Hoskins & Eccleston, 2006) and reduced functioning (Martel et al., 2015). The current study contributes to these findings relating to medication beliefs being a mechanism in participants' decision making when it comes to considering CBD. Although participants reported reduced analgesic effects compared with prescribed medication, they also reported fewer side effects resulting in improved functioning, engagement with day-to-day activities, and quality of life. For participants who were considering CBD, the perceived reduction in side effects was a key factor in their continued consideration of taking CBD.

Rosser et al. (2011) found that a third of CP patients reported feeling they were not adequately informed about their prescribed medication by the prescribing clinician bringing about a 'mistrust' of HCPs managing their medication. Furthermore, medication can act as a mediator in the patient-doctor relationship and upon agreed adjustment can act as a mechanism for collaboration in the relationship (Durif-Bruckert, Roux & Rousset, 2015). Similar findings in this study related to the theme of 'Discussions with professionals' when discussing CBD. Participants who had a positive experience considered this to be open and honest and had found these discussions beneficial. However, others had felt dismissed or received non-committal answers. In line with other research, there appeared to be an element of trust in the patient-HCP relationship when disclosing taking or considering taking CBD.

Participants considered the position of the HCP and barriers to facilitating discussions about CBD, such as; limited time and capacity to engage in discussions about pain management, and official guidance. They also considered their own position of being a burden and previous

experiences of feeling dismissed as barriers to broaching the subject. Parsons et al.'s (2007) systematic review found similar results whereby patients had felt dismissed by clinicians and perceived themselves to pose a great demand on practitioners' resources. Research pertaining to CP patients' experiences of feeling dismissed or disbelieved by others, including HCPs and friends and family, posits this causing actual and perceived stigma, isolation, and emotional distress (Upshur, Bacigalupe & Luckmann, 2010; Newton et al., 2013; Braeuninger-Weimer, Anjarwalla, Pincus, 2019; Koesling & Bozzaro, 2021). Whilst participants conveyed feelings of dismissal relating to their CP condition in general and CBD-related discussions, explanations for this appeared to go beyond the dyadic patient-clinician relationship and considered contextual concerns such as time-limits, professional guidance and stigma contributing to these barriers.

Participant views of CBD appeared to be shaped by negative and stigmatising societal attitudes. Stigma occurs through the implementation of social power in identifying an 'other' and disapproving, rejecting, excluding (Naushad et al., 2018), and discriminating against the characterised difference of this othered group or person (Goffman, 1963). Stigma experienced by CP patients can have a profound impact on their relationships with friends, family and peers (Earnshaw, Quinn & Crystal, 2011), healthcare professionals (Cohen et al, 2011) and can lead to a large proportion of patients to internalise stigma (Waugh, Byrne & Nicholas, 2014). In the context of this research, participants discussed stigma related to CBD and how this can be perceived as a barrier, making particular reference to its continued links with cannabis and social perceptions of this as an illicit substance. Participants also considered negative interactions with healthcare professionals to compound stigma. A recent qualitative study (Hulaihel et al., 2021) based in Israel, suggests that 'felt' stigma towards taking legalised medical cannabis was as a result of cultural and social contexts. This current study provides a

UK-based sample of CP patients' perspectives of cannabis-related products that are legal for purchase. Participants acknowledged a perceived shift in their social and cultural context, with CBD becoming more acceptable and accessible online and on the high street. It also highlighted a potential disparity between social and medical or healthcare shifts and perceptions of CBD. These shifts were attributed to recent and more acceptable generational views of cannabis-related products. Access to information also appeared to be a mechanism in supporting them to overcome internalised stigma and educating others about CBD.

Some participants made a distinction between the selling and prescribing of medications. There appeared to be negative connotations of acquisition of illicit substances and related risks when purchasing medications outside healthcare services. This related to the notion that trust in HCP and healthcare to provide medication or products that are 'safe' and contain what they claim to. For many participants who were considering taking CBD, reservations related to the lack of approval from HCPs, and it not being prescribed, as a barrier. Geest, Whyte & Hardon (1996) posit that a 'prescription' represents a means of communication and conveys power and social control. They describe how a prescription connotes a validation or recognition of a patient's complaint and their attempt to help or support. This could support an understanding of the current data regarding participants' preference for HCPs to prescribe CBD a form of recognition of what works and what might work for them, and their struggles related to their CP condition. A contributing barrier to accessing CBD was one of affordability, which may also contribute to a desire for CBD to be prescribed.

Power can be an intrinsic part of the relationship between patient and clinician (Eccleston, Amanda & Rogers, 1997; Kristiansson et al., 2011; Greville-Harris et al., 2015). Participants responses indicated a theme of 'taking control' suggesting that control or power may be taken in order to manage their CP condition. The concept of Health Locus of Control (HLOC)

(Wallston, Wallston, & DeVellis, 1978), an extension of Levenson's Locus of Control (1974), could help to conceptualise this view and how CBD might factor in to this process of taking control. HLOC conceptualises and defines internal locus of control (IHLOC) as health outcomes being within their control and predominantly influenced by one's own behaviour. In contrast, Chance (CHLOC) and Powerful others locus of control (PHLOC) are principally due to either chance factors (e.g. luck) or other people (e.g. clinicians). Research posits that increased IHLOC and self-efficacy in CP patients can lead to a reported improvement in frequency and intensity of pain (Pellino & Wards, 1998, Zuercher-Huerlimann et al., 2019), more effective coping strategies (Haythornthwaite et al., 1998) and improved pain rehabilitation outcomes (Keedy et al., 2014). CBD appeared to represent a way in which participants might attempt to adopt a more IHLOC compared to what might be perceived as a PHLOC with prescribed medication. This was apparent in the interaction between the theme of 'Discussions with professionals' and subtheme 'Advocating for self', whereby participants found that discussions with professionals influenced and was influenced by their decision to advocate for themselves in various healthcare settings in order to have more control of their treatment. This also appears to highlight the importance of power dynamics in the patient-clinician relationship and the influence this can have on decision making processes and treatment.

Further to this, patients adopting a more IHLOC might be considered to be taking a more active role in their pain management, developing a sense of autonomy and moving away from what might be considered a 'cure'. By doing so, these patients may be seen as attempting to build resilience to the impact CP has on their lives and wellbeing. The Psychological Resilience (PR) model (Sturgeon & Zaurtra, 2010) helps conceptualise how trait resources and state mechanisms can support the development of resilience to pain. In the context of this

framework, in response to pain and/or vulnerability traits e.g. negative psychological impact of CP, and mechanisms e.g. loss of control, negative interactions with professionals or others, CBD might be considered a coping behaviour or response. Consequently, this study suggests a perceived greater sense of control or efficacy in managing their pain, increased engagement in valued activities due to reduced pain and side effects, and a return to what might be considered reduced stress, and adapting to a life *with* pain. It also suggests the notion of more acceptance in CP patient's social world and positive responsiveness to CBD could be considered a mechanism for reinforcing its use as a management strategy. Conversely, participants described a preference for overall functioning and quality of life, compared to pain reduction, connoting a sense of relinquishing control of pain. By developing a sense of internalised control, participants may also be conveying a state of psychological flexibility (McCraken & Morley, 2014) by being more open and willing to experience the discomfort brought on by pain. Participants demonstrated *awareness* of their suffering, *acceptance* that their condition is chronic and untreatable with medication, and *engagement* with their values and living a life well with pain.

The themes identified also highlight the uniqueness of CBD as a product compared to other medications accessed for pain management. Participants discussed the legitimacy of various sources of information and ways in which they access products. This appeared to differ from other forms of over-the-counter medication that might be accessible from a pharmacy or professional. CBD was also explicitly compared with prescribed medication as having less side effects and the potential benefit of improving quality of life.

Clinical implications

Table 5

Summary of clinical implications

Implications to consider
The patient-clinician relationship in the treatment decision making process
Increasing HCPs understanding of CBD and confidence in facilitating open discussions about these products
The wider social and cultural context shift towards 'safer' medications
The clinicians' role in reducing stigma and gaining a better understanding of patients' needs

The study highlights the importance of the patient-clinician relationship in supporting a patient in their decision-making process when it comes to CP treatment. This research also supports the notion that the professional's role of supporting the patient in making decisions can help to develop a more internal locus of control for the patient, which in turn should contribute to their sense of self-efficacy in managing their condition.

The research could support HCPs, healthcare services and systems in understanding the position of CP patients relating to CBD. By increasing understanding of CBD and related products for professionals could consequently increase their confidence in facilitating open and honest discussions about prescribed and alternative medications they are taking or are considering taking. By having these open discussions with CP patients, healthcare professionals may begin to break down stigma felt by patients. This could be achieved by building trust and ensuring patients are left feeling believed, understood and validated in relation to taking CBD and their wider lived experience of their CP condition.

The study may also support HCPs and the systems in which they work to be aware of the wider social and cultural shifts relating to cannabis-related products and how these discussions may become more common in the future. This may be particularly significant given the notion of substituting prescribed medications, like opioids, with cannabis-based products to better manage their CP condition.

The study also raises awareness for clinicians to consider non-reported factors and the potential role of psychologists to support reducing stigma around attempts to manage pain via non-prescribed methods and are potentially not reported. By encouraging this, we can begin to gain a better understanding of patients' journeys and current needs.

Strengths and limitations

To the researchers' knowledge, this is the first qualitative study to consider UK patients' perspective of taking and considering taking CBD for their CP condition. The research will contribute to the understanding of participants' perspectives of CBD unique to the context of the UK. This was achieved by using thematic analysis as an explorative approach to interpreting participants' perspectives and bolstered by using critical realism as a way of enhancing this understanding by considering healthcare systems and wider social and cultural influences. CBD itself, is also a unique product as; in the context of CP services, it is not prescribed; nationally, it is not regulated; and internationally, it is afforded little clinical research. Despite this, there is evidence to suggest that these products are still taken by the CP population with little exploration, and this study goes someway to doing that. By taking in to account participants' lived experience of taking cannabis-based medicines for their CP condition in the UK, where data is lacking (Nutt et al., 2020), it also provides further evidence to suggest patients' decision to substitute prescribed medications with these types of products.

A limitation of the research may be that the sample was heterogenous and does not represent the whole demographic range of the CP population. Although unable to report on self-reported diagnoses, participants may have comorbid diagnoses that CBD products are prescribed for and so might influence their view of taking or considering taking these products. However, as an explorative study with participants recruited from two sites a range of experiences, of ages, diagnoses and considerations has provided a breadth of experiences and has drawn several common themes that could underpin future research. A further limitation may be that some participants had engaged in various interventions that could have influenced their perception of pain, sense of control and psychological flexibility. As highlighted in the data, CBD was not the only contributing factor in the management of their pain and various other strategies employed alongside the products were of benefit. Participants who had engaged in the recruitment process may also represent a small proportion of CP patients willing to engage and discuss CBD. Therefore, the responses may have been biased positively towards CBD. Due to limited regulation of CBD products in the UK, it is difficult to determine the content and whether other components were contained that might impact participants perception of their efficacy. Information pertaining to other medications participants were in receipt of was not reported, which may also have some bearing on their responses. These will be important considerations for future research.

Future research

Table 6

Summary of future research

Future research to consider
A consolidation of CBD and CP research
The impact of CBD on secondary symptoms of pain e.g. sleep, mood etc.
The characteristics of CP patients taking CBD
The opioid reducing effects of CBD and potential benefits

This study suggests that a consolidation of the evidence and literature pertaining to CBD's effectiveness for the management of CP is warranted. In turn, this could support clinicians understanding and consequently patients' understanding from a clinical healthcare perspective. It is important for clinical research to consider the wider cultural and social context in which it sits and the potential benefits for quality of life, as identified in this paper. Future research may want to consider the factors involved in an improved quality of life for CP population when taking CBD e.g. sleep, mood etc. However, caution may also be advised when approaching such products affirmatively and acknowledgement of the challenges that may be faced along the way.

Many of the participants attending interview advocated for more clinical trials and expressed their interest in taking part to support this understanding in the future. An extension of the qualitative research could provide more in-depth understanding of the beliefs and perspectives of medication in this population to understand the mechanisms leading to taking and considering taking CBD. Perhaps a unique population to consider would be those who have

taken CBD in the past, stopped and continue to consider taking CBD in the future. Quantitative research could also consider whether characteristics of diagnosis, multiple pain sites, comorbidities, psychometrics, functioning or outcome of previous medical interventions related with accessing or considering accessing CBD for their CP condition. This may help to consider whether certain patients may require more support to consider treatment options for their pain condition.

A particular area of interest may also be to explore the notion that patients may substitute prescribed medications with cannabis-based products, like CBD. Future research could consider the extent of this further, perhaps the reasons patients might do this, and what medications they are specifically substituting. Further clinical research is required to consider whether there is also a long-term benefit to substituting prescribed medications, such as potential opioid-sparing effects (Campbell et al., 2018), and whether cannabis-based products might offer a 'safer' alternative.

Conclusion

This study provides unique insights in to the decision-making processes of taking and considering taking CBD for a CP condition. To the knowledge of the researchers, this is the first qualitative research to address this topic in the UK, highlighting and contributing to a gap in research considering CP patients' perspectives of CBD. The rich data collected identifies the importance of participants' medication beliefs, communication between patient and clinician, and the influence of stigma in the decision-making process. The consideration of these factors may also be crucial when supporting patients to improve their sense of control, resilience and psychological flexibility and consequently live a life well with pain. Future work should support HCPs and patients to understand the effectiveness of CBD as a strategy to support the

management of CP and thus foster an openness for these discussions to flourish and be commonplace in clinical settings in the future. It may also be of benefit to explore the potential reduction in opioid, or prescription medication-taking associated with taking as an alternative CBD.

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Appendix

Appendix 1

Overview of proposed requirements and suitability for publication

Title: The European Journal of Pain

Requirements: The journal does not specify an overall word count or formatting style. However, some requirements e.g. Introduction (500 words) and Discussion (1500 words), were not met for purpose of thesis submission.

Suitability: The European Journal of Pain publishes high quality research relating to the subject of chronic pain reaching a broad international audience. Whilst exploring journals, it was apparent that the journal publishes a multitude of qualitative papers concerning patients' perspectives.

For further information on The European Journal of Pain's submission requirements please see the website: https://onlinelibrary.wiley.com/page/journal/15322149/homepage/forauthors.html#Manuscript_Structure_and_Word_Count_

Appendix 2

PRISMA Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	12
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	12
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	13-18
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	17-18
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	18-20
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	20-21
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	20-21
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	21-23
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	22-24
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	25-32
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	25-32
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	23 & 32-33
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	N/A
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	25-29
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	23-24

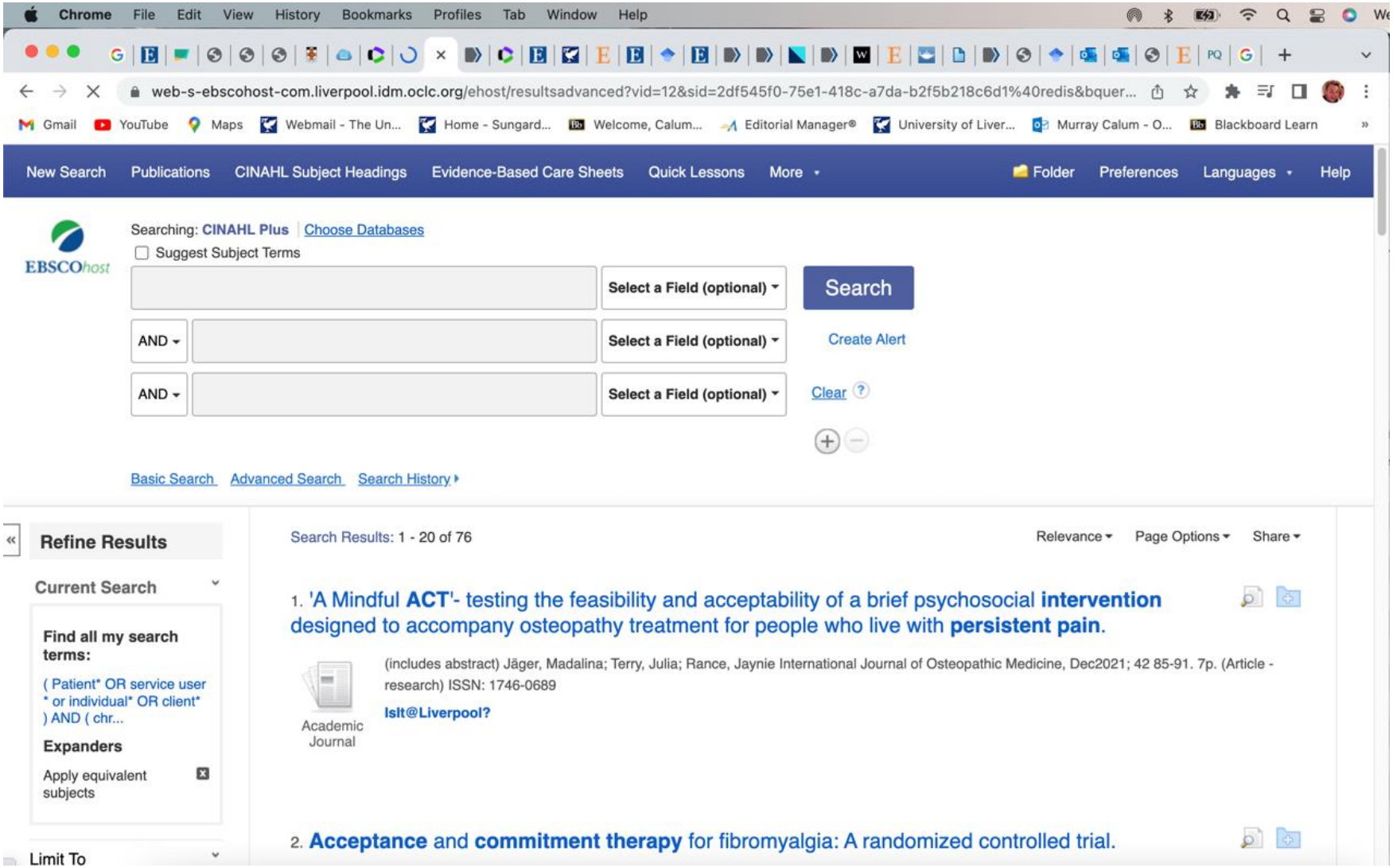
Section and Topic	Item #	Checklist item	Location where item is reported
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	23-24
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	23-24
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	23-24 & 30-32
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	33-25
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	23
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	32-35

RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	21-22
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	22
Study characteristics	17	Cite each included study and present its characteristics.	25-29 & 30-32
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	33-35
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	35
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	35-40
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	35-40
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	35-40
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	35-40
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	23
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	32-35
DISCUSSION			

Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	40-43
	23b	Discuss any limitations of the evidence included in the review.	43-44
	23c	Discuss any limitations of the review processes used.	43-44
	23d	Discuss implications of the results for practice, policy, and future research.	44-45
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	18
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	18
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	18
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	N/A
Competing interests	26	Declare any competing interests of review authors.	N/A
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	N/A

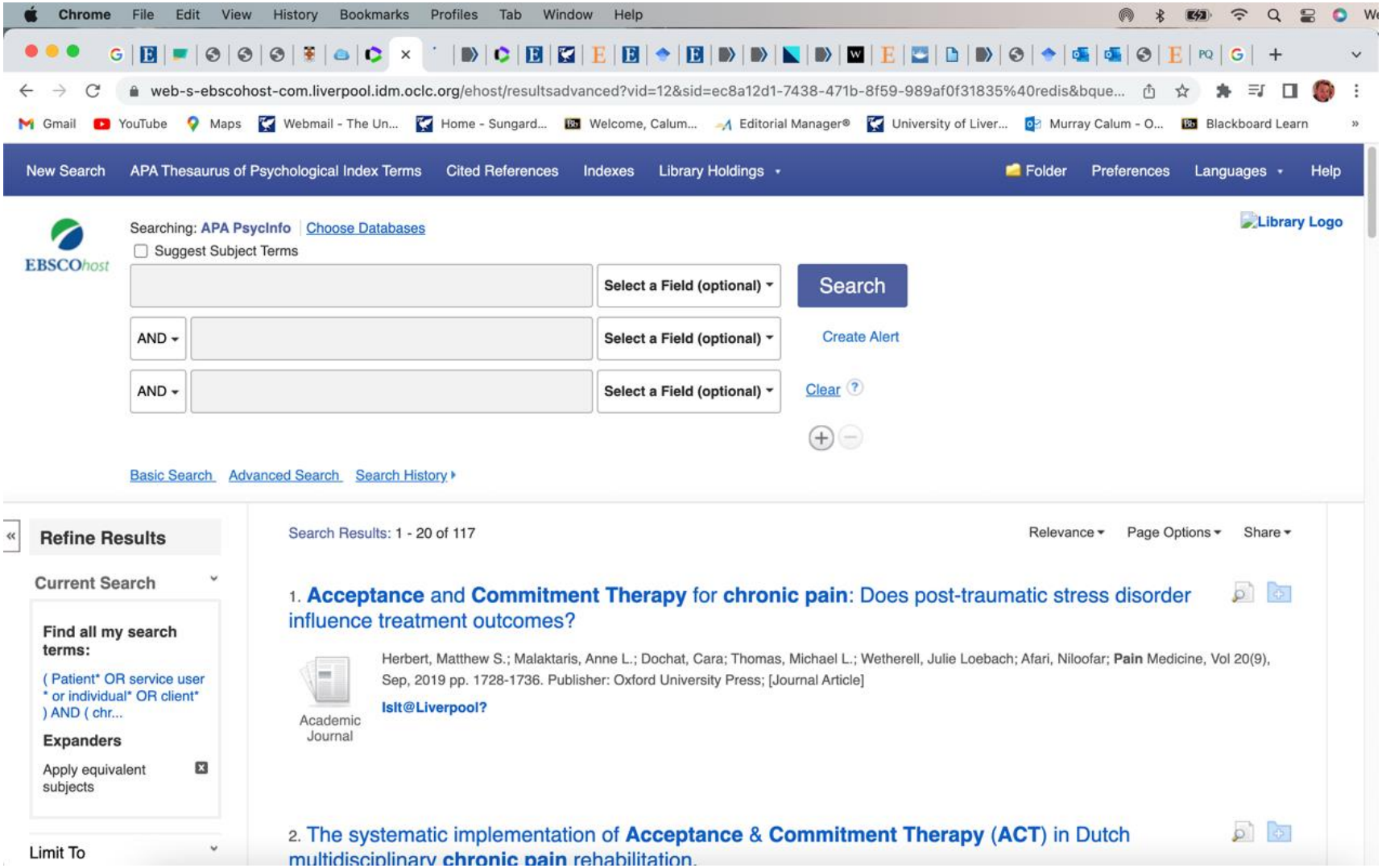
Appendix 3

CINAHL Database Results Screenshot



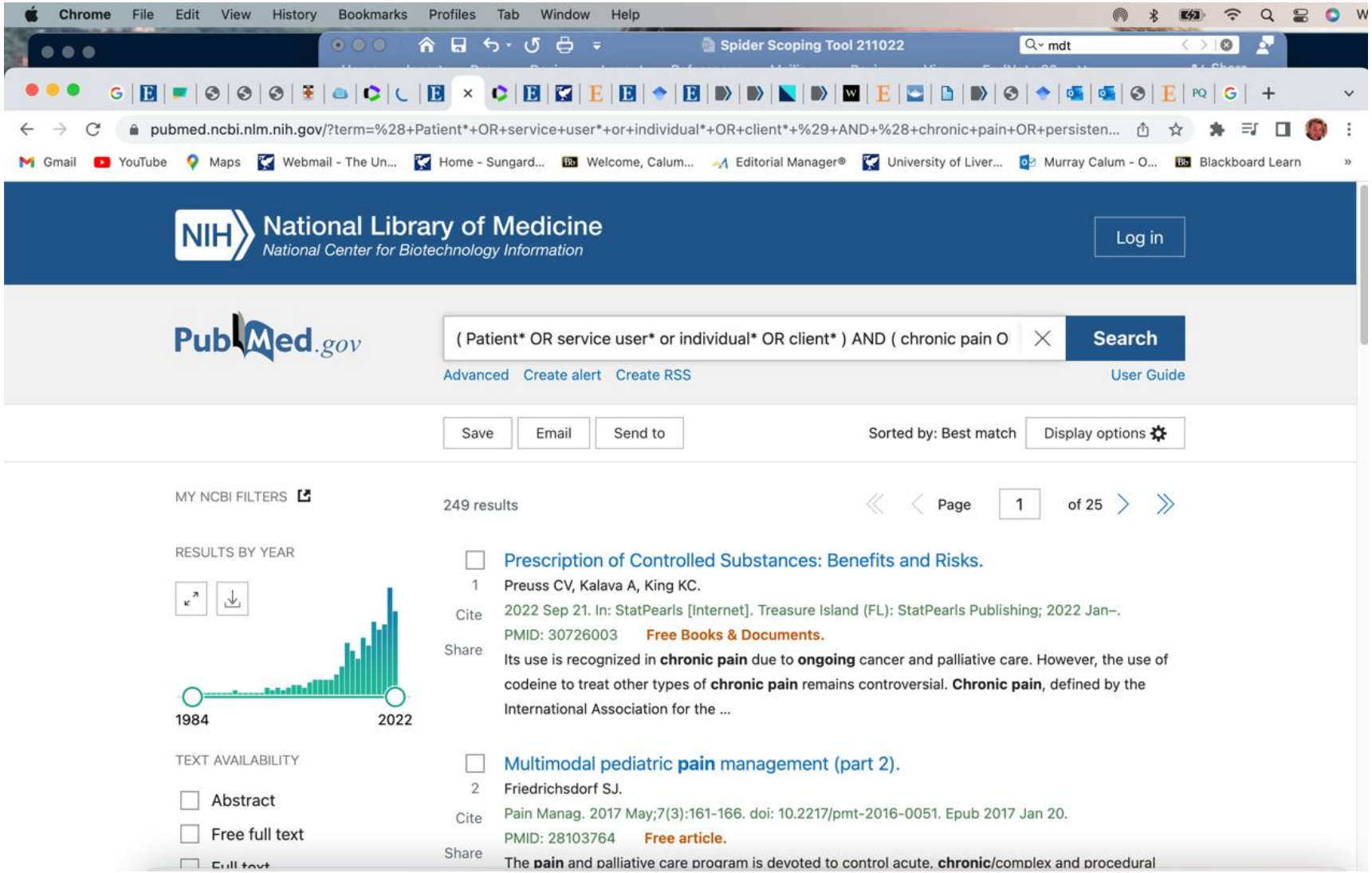
Appendix 4

APA Psychinfo Database Results Screenshot



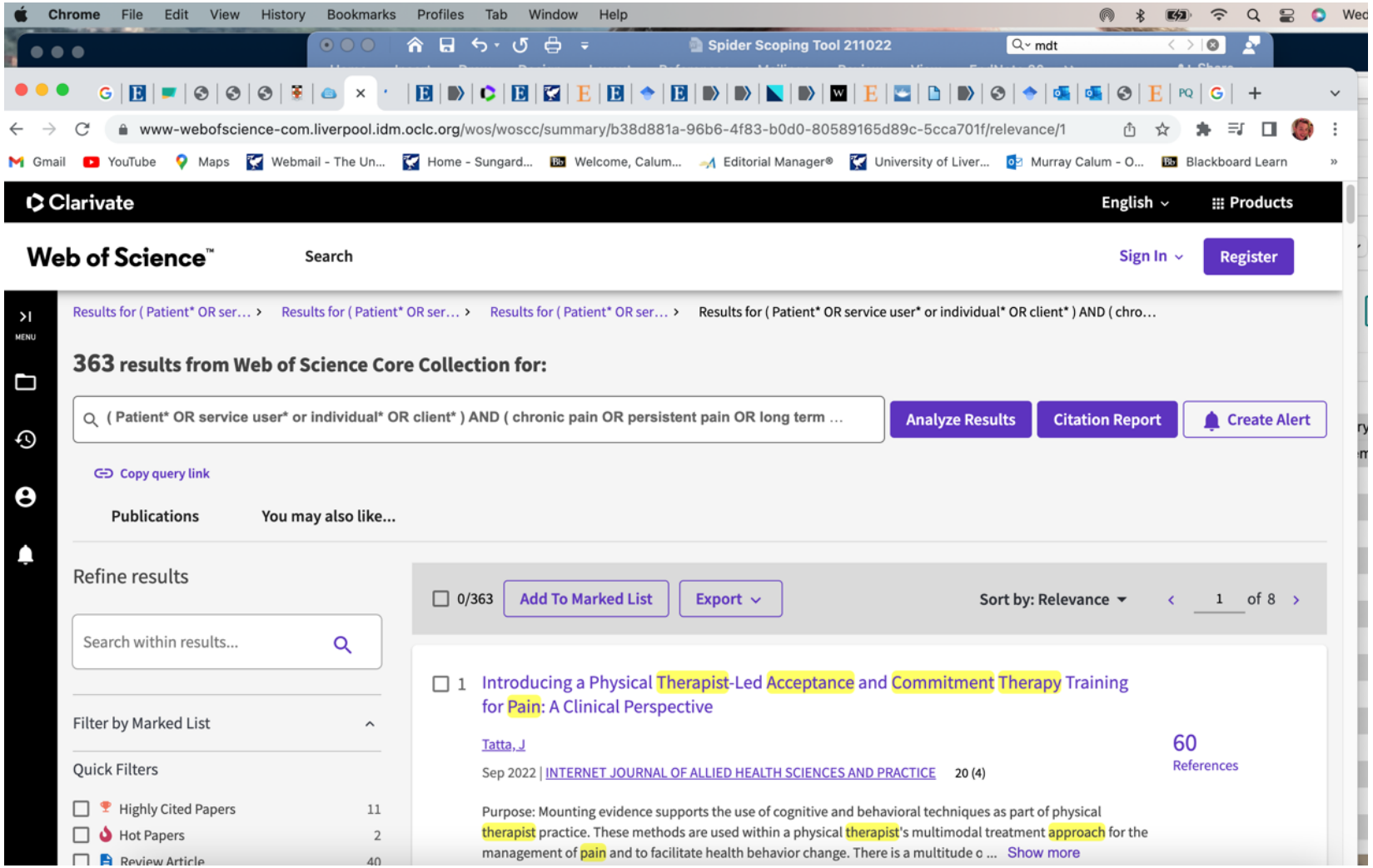
Appendix 5

PubMed Database Results Screenshot



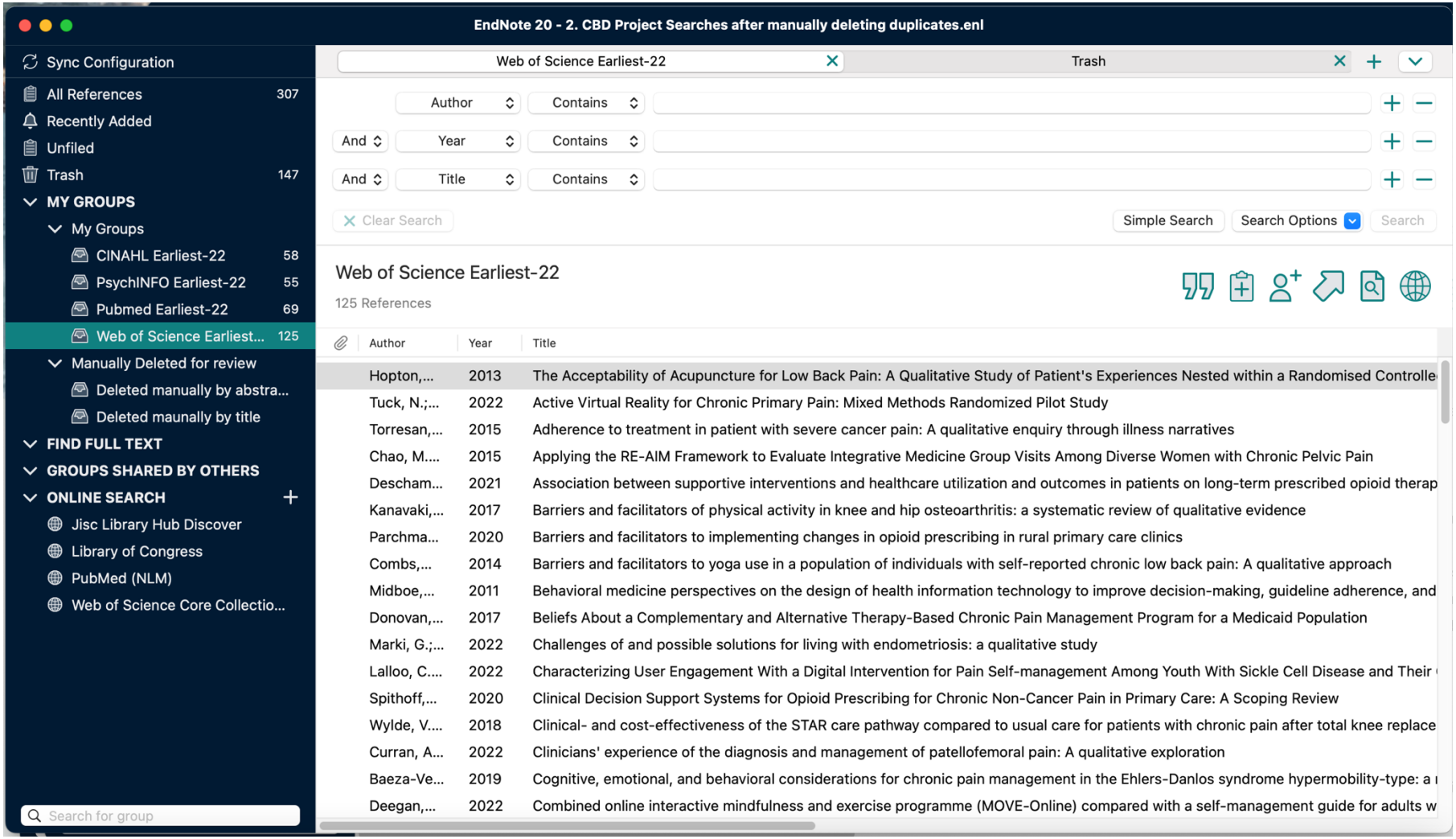
Appendix 6

Web of Science Database Results Screenshot



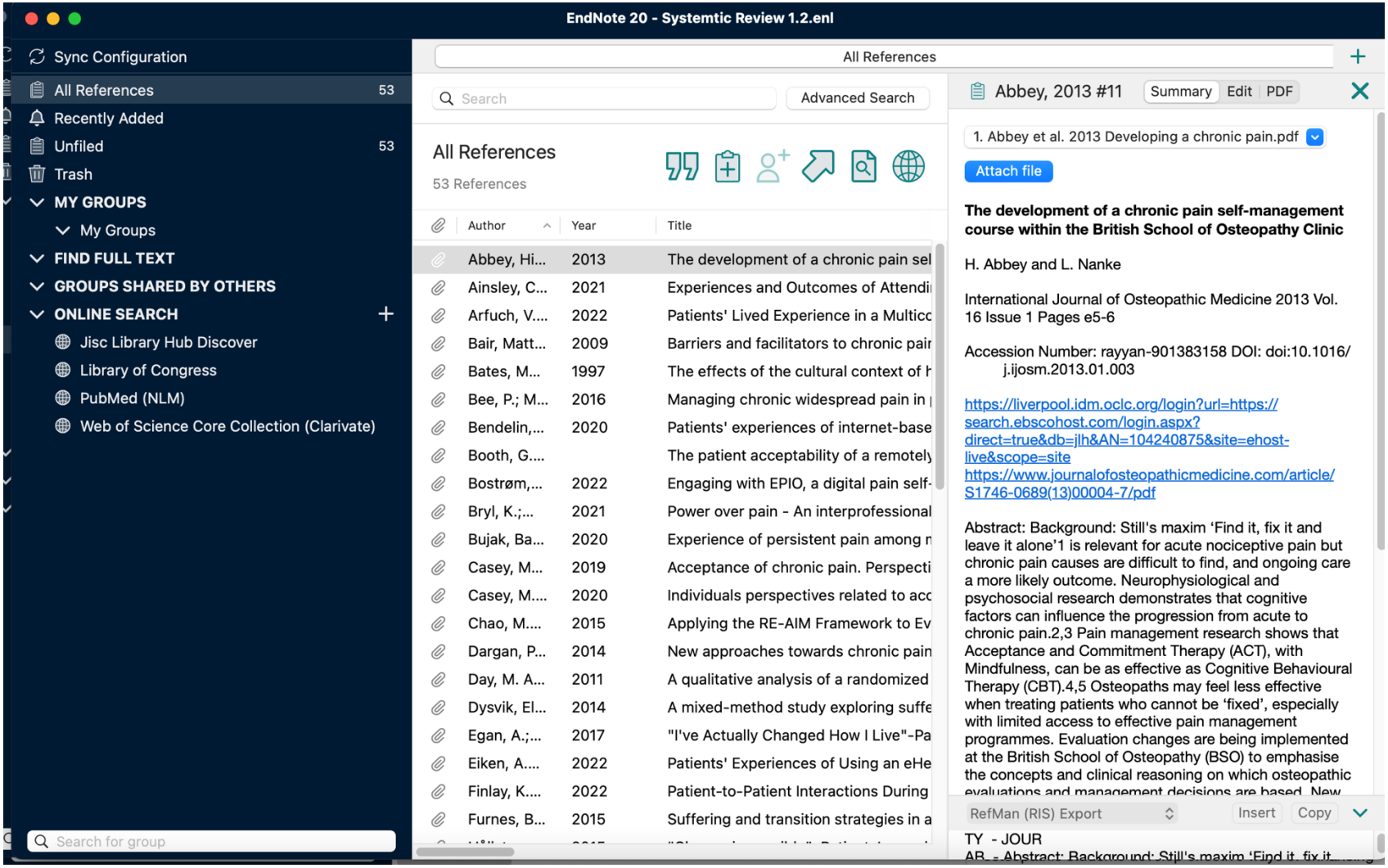
Appendix 7

Endnote Screenshot: After duplicates deleted



Appendix 8

Endnote Screenshot: After titles and abstracts deleted



Appendix 9

Critical Appraisal Skills Programme – Qualitative Checklist

CASP
Critical Appraisal Skills Programme

www.casp-uk.net
info@casp-uk.net
Summertown Pavilion, Middle Way Oxford OX2 7LG

CASP Checklist: 10 questions to help you make sense of a **Qualitative** research

How to use this appraisal tool: Three broad issues need to be considered when appraising a qualitative study:

- Are the results of the study valid? (Section A)
- What are the results? (Section B)
- Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is "yes", it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a "yes", "no" or "can't tell" to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

About: These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA 'Users' guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

Referencing: we recommend using the Harvard style citation, i.e.: *Critical Appraisal Skills Programme (2018). CASP (insert name of checklist i.e. Qualitative) Checklist. [online] Available at: URL. Accessed: Date Accessed.*

CASP
Critical Appraisal Skills Programme

Mathias et al 2014 Individual experiences of an acceptance-based pain management programme: An interpretative phenomenological analysis

Paper for appraisal and reference:

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

Yes ☐ Can't Tell ☐ No ☐

HINT: Consider
- what was the goal of the research
- why it was thought important
- its relevance

Comments:

2. Is a qualitative methodology appropriate?

Yes ☐ Can't Tell ☐ No ☐

HINT: Consider
- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal

Comments:

Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?

Yes ☐ Can't Tell ☐ No ☐

HINT: Consider
- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments:

CASP
Critical Appraisal Skills Programme

4. Was the recruitment strategy appropriate to the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

Comments:

5. Was the data collected in a way that addressed the research issue?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the setting for the data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
- If methods were modified during the study. If so, has the researcher explained how and why
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data

Comments:

CASP
Critical Appraisal Skills Programme

6. Has the relationship between researcher and participants been adequately considered?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Comments:

Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

Comments:

CASP
Critical Appraisal Skills Programme

8. Was the data analysis sufficiently rigorous?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Comments:

9. Is there a clear statement of findings?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider whether
- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Comments:

CASP
Critical Appraisal Skills Programme

Section C: Will the results help locally?

10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Comments:

Appendix 10

Research advertisement

12-8-22, Version 1.4

CHRONIC PAIN AND CBD

HAVE YOU TAKEN, OR CONSIDERED TAKING CBD (CANNABIDIOL) FOR YOUR CHRONIC PAIN CONDITION?

IF SO, WE WOULD LIKE TO HEAR FROM YOU!

Why?

- Many people **use CBD** products e.g. oil, gummies, creams etc. to help manage their chronic pain conditions There is limited research to help us understand the perspectives of patients and this study aims to explore that.
- Interviews with patients will explore this topic by discussing the **types of products** people use, **why they use them/don't use them**, and experiences of discussions about **CBD**.
- We hope to explore **patients' perspectives** on this subject and share them with healthcare professionals so they can better understand this from different viewpoints.

Who can take part?

The project is looking for people who...

- **Are aged 18+**
- Have a **chronic pain condition**
- Have **taken or considered taking CBD**

What is involved?

If you are eligible and willing to take part, you will be invited to a **60-90 minute interview** with one of our researchers. This will either be face-to-face or online using videoconferencing e.g. Zoom, Microsoft teams etc.

How can I take part?

Please contact the researcher using the following email address **calum.murray@liverpool.ac.uk** for further information. We will then arrange a time to speak to you on the phone and provide you with more details about the study.

Thank you for taking the time to read this poster and consider your involvement in this study.

Reimbursement

Each participant will receive a **£10 Amazon Voucher** for their participation in the interview.

Appendix 11

Ethical Approval Letter

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Dr Nick Fallon
Department of Psychology
University of Liverpool Eleanor Rathbone Building
Bedford Street South
L69 7ZAN/A

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

29 August 2022

Dear Dr Fallon

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**An investigation of chronic pain patients that have taken, or considered taking, CBD to aid their chronic pain condition**
IRAS project ID:	**309410**
Protocol number:	**UoL001690**
REC reference:	**22/WA/0252**
Sponsor	**Spark, Liverpool Health Partners**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **309410**. Please quote this on all correspondence.

Yours sincerely,
Gurmel Bhachu

Approvals Manager

Email: HCRW.approvals@wales.nhs.uk

Copy to: *Miss Karen Wilding*

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Copies of materials calling attention of potential participants to the research [Research Poster]	1.4	12 August 2022
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance Certificate]	1.0	01 August 2022
Interview schedules or topic guides for participants [Interview Schedule]	1.3	12 August 2022
IRAS Application Form [IRAS_Form_13072022]		13 July 2022
Letter from sponsor [Letter from Sponsor]	1	21 April 2022
Organisation Information Document [Organisation Information Document]	1.4	22 August 2022
Organisation Information Document [Organisation Information Document Broadgreen]	1.3	22 August 2022
Other [Response to REC]	1	22 August 2022
Other [Participant Debrief Sheet]	1.3	22 August 2022
Other [Adverse Events Protocol]	1.2	12 August 2022
Other [Response to REC]	1.0	16 August 2022
Participant consent form [Participant Consent Form]	1.3	22 August 2022
Participant information sheet (PIS) [Participant Information Sheet]	1.4	22 August 2022
Research protocol or project proposal [Protocol]	1.5	22 August 2022
Schedule of Events or SoECAT [Schedule of Events Walton Centre]	1	22 August 2022
Schedule of Events or SoECAT [Schedule of Events Broadgreen]	1	22 August 2022
Summary CV for Chief Investigator (CI) [Chief Investigator CV]	1	24 June 2022
Summary CV for student [Student CV]	1.0	06 July 2022
Summary CV for supervisor (student research) [Supervisors Research CV]	1.0	08 July 2022
Summary CV for supervisor (student research) [Supervisors Research CV]	1.0	02 July 2022
Summary CV for supervisor (student research) [Supervisors Research CV]	1.0	20 June 2022

IRAS project ID	309410

Information to support study set up

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	Expectations related to confirmation of capacity and capability	Agreement to be used	Funding arrangements	Oversight expectations	HR Good Practice Resource Pack expectations
There are two site types Site Type 1 – will identify participants via a poster in the waiting room Site Type 2 –will identify participants from a database	Research activities should not commence at participating NHS organisations in England or Wales prior to their formal confirmation of capacity and capability to deliver the study in accordance with the contracting expectations detailed.	An Organisation Information Document has been submitted and the sponsor is not requesting and does not expect any other agreement to be used with participating NHS organisations of this type	The sponsor has detailed its proposals with respect to whether any study funding will be provided to participating NHS organisations of this type in the relevant Organisational Information Document. This should be read in conjunction with the relevant Schedule of Events/SoECAT which details the cost implications of the study for	In line with HRA/HCRW expectations a Local Collaborator should be appointed at participating NHS organisations of this type.	Where an external individual who does not already hold an NHS employment contract will be conducting any of the research activities that will be undertaken at this site type then they would be expected to hold an Honorary Research Contract. External staff holding pre-existing NHS employment contracts should obtain a Letter of Access. This should be issued on the basis of a Research Passport (if university employed) or an NHS to NHS confirmation of pre-engagement checks letter (if NHS employed). These should confirm Occupational Health Clearance.

			participating NHS organisations.		These should confirm standard DBS checks

Other information to aid study set-up and delivery

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.
The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio

Appendix 11

Participant Information Sheet

NHS Liverpool University Hospitals NHS Foundation Trust

UNIVERSITY OF LIVERPOOL

NHS The Walton Centre NHS Foundation Trust

Information Sheet 22-08-22 Version 1.4

Research Study Title:
An investigation of chronic pain patients that have taken, or considered taking, CBD to aid their chronic pain condition

You are being invited to take part in a research study. The study will form part of the Trainee's (Calum Murray) research project for their qualification in Doctorate of Clinical Psychology at the University of Liverpool.

Before you decide it is important for you to understand why the research is being done and what participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Do ask us if there is anything that is not clear or if you would like more information. Please take time to decide whether or not you wish to take part.

Why are we doing the research?
The aim of the study is to understand the benefits and barriers that influence decision-making about whether to take Cannabidiol (commonly known as CBD) products for Chronic Pain from the perspective of chronic pain patients. There is little research focusing on patients' perspectives and this research is an opportunity to capture this. We would also like to hear what types of products are being used, and whether you have spoken to clinicians involved in your care about taking CBD.

Can I be involved?
You can get involved if:

- You **have** considered or tried CBD products to help manage your chronic pain condition in the last 18 months.
- You **are not** currently undergoing a pain management programme for your chronic pain condition (you can still take part if under the care of a pain clinic)
- You **are not** currently undergoing a new change (within the last 4 months) in medication for your chronic pain condition
- You **are not** currently using any illegal substances (e.g. marijuana, heroin etc.)

What will happen to me if I take part?
After you have expressed interest in wanting to take part, you will be given the opportunity to discuss the study in more depth and ask any questions you might have. You will then be provided with a link, where you can access information about the study and have time to consider your involvement. If you agree to take part, you will be able to give your consent

using the same link. The consent forms will be stored electronically on an encrypted file at the University of Liverpool which can only be accessed by the Chief Investigator (Dr Nick Fallon) and Trainee (Calum Murray).

If you agree to take part and give your consent, we will contact you to arrange a single 1:1 interview, either remotely via video call software (e.g. Zoom) or face-to-face. The latter option with take place on hospital sites in the Liverpool area. The interview will be conducted by Calum Murray (Trainee), will be recorded and last between 60-90minutes. The focus of the interview will relate to your experiences of considering and/or taking CBD products for your chronic pain condition.

NB We will note your preference of how you would like the interview to take place, either face-to-face or remote interview. However, any restrictions in place due to COVID-19 pandemic will take precedence and may dictate the way in which interviews are facilitated and what can be offered.

You will be offered an opportunity to reflect on the discussions and offered support if you felt distressed by any of the discussions. You will be able to withdraw from the study at any time until the data has been analysed. After this time, which will be 2 weeks from the interview date, we will be unable to withdraw you from the study.

Can I leave the study at any time?
It is up to you to decide whether or not you take part in the study. If you do decide to take part after you have read this, you will be asked to agree and sign a consent form. However, if you change your mind, you can withdraw at any time up until the data has been analysed without giving a reason.

What will happen to the recording of my interview?
The audio recordings of your activities made during this research will be transcribed (copied to an anonymous text file) to be used for analysis. The data collected will be written up for a Doctoral Thesis in Clinical Psychology and eventually published in a journal. Your data will be completely anonymous and you will not be identifiable for any of these publications. The original recording files will be destroyed after the interviews have been transcribed. No other use will be made of them without your written permission, and no one outside the study will be allowed access to the original recordings.

What are the possible disadvantages or risks of taking part?
We will be talking about a potentially sensitive topic and understand that this may be uncomfortable or cause distress.

For example, we will be asking questions relating to your decision-making relating to CBD products, what you are taking and why, the benefits or barriers to taking them and whether you have spoken to healthcare professionals about taking them. If you believe this content may cause distress, please consider whether this study is appropriate for you before consenting to taking part.

If you are experiencing any distress, researchers will support you to access the appropriate local services and support.

What are the possible benefits of taking part?
Your participation will make a significant contribution to a limited area of research in capturing chronic pain patients' perspectives on this growing issue. Many people who engage in this type of research find that it gives them a chance to talk openly about their experiences which can be positive.

What if something goes wrong?
If you have a concern about any aspect of this study, you should ask to speak to the researchers (details below) who will do their best to answer any questions. If you wish to seek advice or reassurance about your own health, then we recommend that you should contact your General Practitioner (GP). If you remain unhappy and wish to complain formally about the research, you can do this by contacting the local NHS Patient Services Team:

Walton Centre Site
PALS Team based at The Walton Centre NHS Foundation Trust, Lower Lane, Fazakerley, Liverpool, Merseyside, L9 7LJ. You can telephone them on **0151 525 3611**.

Royal Liverpool and Broadgreen Hospital Site
PACT Team based at The Royal Liverpool and Broadgreen Hospital Trust, Thomas Dr, Liverpool L14 3LB. You can telephone them on **0151 706 4903**.

Will my taking part in this study be kept confidential?
All the information that we collect about during the course of the research will be kept strictly confidential. You will not be able to be identified in any following reports of publications. If you agree to take part, you will be assigned a unique number to protect your identity, with your personally identifiable information being stored on an encrypted database. The database will be password protected and will only be accessible to the Chief Investigator (Dr Nick Fallon) and the Trainee carrying out the research (details below) in order to identify you should you wish to withdraw before the data is analysed.

Demographic information (your age, gender and ethnicity) will be collected to understand who has taken part in the study and report this and contact details will be collected in order to arrange interviews and send results of the study out when it is complete. This information will be stored in a locked cabinet at the University of Liverpool. This only be accessed by the Chief Investigator (Dr Nick Fallon) or the Trainee (Calum Murray) should you request being contacted about the research after the study. This will be destroyed after the study has finished.

NB Everything you talk about in the interviews will be confidential. However, if we are concerned for your wellbeing or that of someone else, it is our duty of care to contact the relevant authority or your GP. If this is the case, we will pause the interview to discuss the reasons for this and what information will need to be shared with others in order to keep you and others safe.

How will we use information about you?

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

- Name
- Age
- Ethnicity
- Contact details

People will use this information to do the research or to check your records to make sure that the research is being done properly. 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.

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
- by sending an email to [insert email], or
- by ringing us on 0151 556 6131

What will happen to the results of the research study?

The study is due to end in September 2023 after which time the results will be published online and freely accessible to the public. Should you indicate a wish to be receive a copy of the result of the study please let us know and we can send these to you. You will not be identified in any report or publication using this data.

Who is organising and funding the research?

The University of Liverpool is sponsoring this research as part fulfilment of Calum Murray's Doctorate in Clinical Psychology course. Calum is running the study with support from Dr Katie Herron, Dr Graeme Fitzpatrick and Dr Nick Fallon.

Who has reviewed the study?
All research in the NHS is looked at by an independent group of people called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given a favourable opinion by [insert REC details and contact information here]

If any issues remain unclear, please do not hesitate to contact the study team who will happily explain any details or answer any questions you may have about the study.

You can contact the study team via:
Calum Murray, Trainee Clinical Psychologist
0151 794 5530
[email address]

Katie Herron, Clinical Psychologist (Supervisor)
0151 556 6131

Nick Fallon, Chief Investigator
0151 795 7332

Thank you for taking the time to read this information sheet, we hope that is has been helpful in enabling you to decide if you would like to participate in the study. If you would like to participate, please click next to bring you to the consent page.

Appendix 13

Consent Form

NHS Liverpool University Hospitals NHS Foundation Trust

UNIVERSITY OF LIVERPOOL

NHS The Walton Centre NHS Foundation Trust

Participant Consent Form, 22-08-22, Version 1.3

Participant number: _____

Title of Project: *An investigation of chronic pain patients that have taken, or considered taking, CBD to aid their chronic pain condition*

Chief investigator: Dr. Nick Fallon

1. I confirm that I have read and understand the 'Participant Information Sheet [Version and date]' for the above study. I have had an opportunity to consider the information, ask questions and I have had these answered satisfactorily. ☐
2. I understand that taking part in the study involves completing an online or face-to-face interview taking around 60-90 minutes. ☐
3. I understand that my participation is voluntary and that I am free to withdraw at any time up until two weeks after the interview without giving any reason, without my medical care or legal rights being affected. In addition, I understand that I am free to decline to answer any particular questions or question. ☐
4. I agree for my identifiable information to be stored on a secure electronic database for the purpose of recruitment and will be removed following study completion. ☐
5. I agree for interview recordings to be stored on a safely encrypted file for the purpose of transcribing that will only be accessible to researchers on the project. In addition, I understand that the recording will be destroyed once transcribed. ☐
6. I understand that the transcription will remain anonymous and be used solely for the purpose of analysis and publication for this study ☐
7. I am aware that my GP or relevant authorities will be contacted should the researcher be concerned about my wellbeing or that of someone else ☐
8. I agree to participate in this study ☐

If you are satisfied with these and agree to take part, please click 'Yes' confirming that you understand the participant information and consent form and that you consent for your responses to be used in this project. This will then take you to the next page.

On the next page you will be asked to provide some personal information which will be stored on the system for 7 days. This will allow for researchers to take the information and store it securely and if you are eligible, will be in touch shortly to arrange an interview.

A copy of this consent form will be made for you, one will be made to keep on file at the research site and another will be made for your medical records.

NB This document should be filed in the on-site file and the participant's medical records.

Appendix 14

Adverse Events Protocol

Adverse Events Protocol Version, 12-08-22, Version 1.2

Participants are pre-warned of the potential sensitive nature of the topic and should they become distressed, they are able to withdraw at any time from the interview. In the unlikely event a participant becomes distressed during the interview, we will adopt the following distress protocol:

1. The interview is immediately terminated by the researcher and recording device switched off.

   If this is being done **face-to-face**, the participant will be asked to remain in the room whilst they are distressed.

   If this is being done **online**, the participant will be asked to stay on the call. We aim to ensure that participants are not left in a distressed state.

2. Participants are encouraged to contact their GP to support a referral to the appropriate service (e.g. mental health service, psychological therapies, social services). If necessary, the researcher can also contact the patient's GP and hospital liaison mental health team or safeguarding team if appropriate.

3. If participants consent, a follow-up call will be made 2-3 days following the interview to ensure the participant is no longer distressed and check on their general wellbeing following the interview.

4. Should a participant disclose sensitive information, they are directed to contact appropriate support services. Prior to participation participants will be aware of our duty of care to contact GP or relevant authority in the event that we are concerned for their wellbeing

5. Contact clinical supervisor from relevant site for further support if required.

6. All adverse events should be reported as soon as possible to the Chief investigator and Clinical supervisor on site. This should also be recorded along with steps taken and outcome in a log on site, which can be accessed by the Chief investigator and Clinical supervisor.

If in considerable distress, consider following <u>support services:</u>

- GP
- Hospital onsite mental health liaison or safeguarding team – A&E Department. These can be found onsite at both Broadgreen Hospital and Aintree Hospital.

Further support services can be found on the next page:

Support Services

Other support services are also available should participants wish to contact them for further support

Chronic Pain Services

Pain UK – has a list of charities for general and specific chronic pain conditions.

https://painuk.org/

Pain Concern – provide information and resources on chronic pain and also offer an email and telephone support service.

help@painconcern.org.uk
0300 123 0789

The Chronic Pain Policy Coalition (CPPC) – forum of professional, members of parliament and patient who operate on policy level to develop improved strategy for chronic pain services and associated conditions.
paincoalition.org.uk

Health Talk – Resources on managing chronic pain and videos of patients who have lived experience of chronic pain conditions.

https://healthtalk.org/chronic-pain/overview

Pain Relief Foundation UK – a foundation that funds research to raise awareness of chronic pain. They organise fundraising events and talks from those experiencing and working in the field of chronic pain.

https://painrelieffoundation.org.uk/

Action on Pain – provides resources and information on managing pain and a telephone/email service to contact their volunteers.

0345 6031593

painline@action-on-pain.co.uk

Psychological support

NHS Talking Therapies website – information on services for people seeking psychological support.

https://www.nhs.uk/mental-health/talking-therapies-medicine-treatments/talking-therapies-and-counselling/nhs-talking-therapies/

Improving Access to Psychological Therapies (IAPT) service finder – this website can be helpful in locating the local IAPT or psychological support service in someone's area.

https://www.nhs.uk/service-search/other-services/

The Samaritans – service that can be accessed 24/7. The service can be contacted via phone, or email. There are other ways of contacting and resources on the website to support with wellbeing.

116 123

https://www.samaritans.org/how-we-can-help/contact-samaritan/

Appendix 15

Interview Schedule

Interview Schedule, 12-08-22, Version 1.3

Researcher explanation: *Thank you for taking the time to attend the interview today and for agreeing to talk about your experiences. I am going to ask you a few questions about your experiences of taking, or considering taking, CBD for your chronic pain condition. The interview will last around 60 to 90 minutes and I will offer you an optional break when we are around 30 minutes in to the discussion.*

Do you have any questions before we start? [Answer questions]

Are you happy to begin? [Address any issues]

Questions:

1) *Firstly, could you tell me a bit about what led you to start/stop, or consider taking CBD products?*
2) *What CBD products do you take and why?*
3) *What benefits of taking CBD products for chronic pain have you experienced or considered?*

Researcher prompt: *Would you like to take a break now as we are around halfway through the questions?*

4) *What side effects of taking CBD products for chronic pain have you experienced or considered?*
5) *What barriers have you experienced to taking CBD products?*

Prompting questions:

- *Have you experienced any barriers to accessing CBD products? And why do you think that is?*

- *Have you experienced negative views from others regarding taking CBD products? And why do you think that is?*

6) What is your experience of talking about taking CBD products with a healthcare professional?

   Prompting questions:

   - *Have you experienced barriers to talking about CBD products in pain services?*

Researcher closing interview: *Thank you for your time discussing this topic today, that concludes the interview.*

Do you have any questions about what has been discussed today? [Answer Questions]

Do you have any concerns or worries after what has been discussed? [Address concerns]

Are you happy for what has been said to be used in the research? [Record answer].

We will be anonymising your data to ensure that there is no identifiable information that could identify you in anyway. I would like to remind you that you are free to withdraw from the study in the next two weeks. If you wish you to withdraw, please contact a member of the research team.

Before we finish, would you like to be contacted about the publication of the research and receive a link? Please provide details of how you would like to receive this.

Thank you again for your time today.

Appendix 16

Reflections

Reflections

Positionality of the primary researcher

My position as a trainee clinical psychologist is only part of my identity and my past and present experiences will influence the way in which I have interpreted the interviews and experiences of the participants I interviewed for this study.

I do suffer from a lower back pain and this positions me as someone who is biased to wanting to support the chronic pain population in some way. Although this does not impact on my day-to-day life on a regular basis, there are concerns for the future that this might worsen and I may need to access the support of services and medications. I do not take or have ever taken CBD products for this or any other purpose. Therefore, there was little personal experience to draw upon in that respect. However, my professional experiences of working in chronic pain services in the past and past experiences of talking about these products undoubtedly had an impact and shaped my interpretation of the participants responses.

During recruitment to the study, I was on placement at one of the sites (Site 1). There was a conflict of interest as someone eligible for the study had been contacted and were also flagged as someone appropriate for potential 1:1 therapeutic work in my clinical capacity. After discussion with the clinical team, and supervisors, it was deemed appropriate to conduct the research interview and then approach the person following this for 1:1 clinical work. This posed a unique challenge in that my clinical and researcher role as a trainee were in conflict. This was made clear to the participant and they were happy to proceed with the interview. This represented a key challenge potentially faced by practitioners conducting research in a clinical setting and how to overcome this.

As a team, we considered a broad range of experiences; participants who had taken and considered taking CBD. We considered how dichotomising the sample might influence our interpretation of results, however, we felt it was important to represent how the sample varied. Whilst it does not capture the entire spectrum of decision-making processes, it was agreed that it provided a way to represent the similarities and differences of those participants who had either taken or consider taking CBD. We kept this in mind whilst considering.

Reflections on analysis and process

Conducting interviews

Therapist vs. Researcher

During the interviews, it was important for me to take a neutral stance as a researcher. However, this in itself was a challenge from the outset. Many of the participants described being distressed by their chronic pain (CP) condition and the impact it has had and continues to have on their lives.

'I had a horrendous head injury and accident seven years ago, which changed my life. I am now classed as disabled and medically retired from Barclays Bank and I've been prescribed copious amounts of traditional medications and pain medications' (P1)

'I'm trying, every day's different but I want to try and better my life, get myself back on track, get myself back into work. I've got a young son, I mean that's basically really it. I want to try, I'm at a late stage in my life I've got a nine year old son, so it's hard going to watch him play football and spending time, the weather doesn't help and then you start throbbing.' (P3).

These stories were often quite emotive and influenced how I conducted the interviews, attempting to provide empathy as well as following a topic guide. Much of the training in clinical psychology is focused on the clinical skills and this was something I found quite conflicting.

However, as the process went on, it felt that the participants were able to share their stories in a different way. This felt much more open and without clinical restriction. It allowed for their narrative to be heard outside the confines of addressing a particular mental health or clinically defined problem.

Supporting vs. Exploring

Similarly, whilst discussing these products, many of the participants asked my advice and my thoughts on whether they should be taking them. This posed an interesting friction between my role as a researcher, exploring their experiences, and what I could offer as support.

"*I'd trust you obviously with your knowledge and if you suggested something I'm happy to try any of it.*" (P3)

This was similar to the previous reflection, where I felt conflicted in my role as researcher and therapist, however, this went a bit deeper. The reasons being that the content of the interviews tended to focus on a theme that they felt 'dismissed' or received 'non-committal' answers from professionals when posing these questions. As a result, I was conflicted between attempting to avoid perpetuating this experience with the knowledge I had gained from the research and literature, and remaining neutral and exploring this question with them. It also made me question how participants viewed me; as a researcher or a healthcare professional.

As the interviews progressed, however, this became a useful question and led on to rich discussions about their experiences of talking with professionals and what they were looking for in posing those questions to professionals and myself. It also helped to consider themes relating to the importance of professionals and my position as *both* research and healthcare professional conducting the research.

Interpreting the data and themes

I used opportunities to discuss the themes are various points with my research team, particularly PR. I attempted to reduce bias by introducing PR at two keys points in my interpretation of the data; 'Familiarising with data and generating initial codes' and 'Searching for and reviewing themes'. This helped to consider my position at these two points and consider the themes in relation to this. I included the research team in its entirety for the remaining stage of 'Defining and naming themes'. PR chose the transcripts to read and identified a mix of participants who had either taken and considered taking CBD to ensure a representative sample.

Familiarising with data and generating initial codes

I began reading the transcripts in more detail after all interviews had been conducted to ensure the data was considered as a whole. Firstly, I listened to the transcripts I was transcribing (P1 and P4) and this helped to immerse myself back in to these interviews. Once these had been transcribed, RP read the same transcripts to and we met on 6.2.23 via MS Teams to discuss the initial codes that were emerging in the data. We identified that

participants received a vast amount of information from various sources and they appeared to actively appraisal this information, considering a way of educating themselves. There also appeared to be a sense of legitimisation of these sources and this varied in terms of what they 'trusted', with an emphasis on professionals being key. We also noted that there was a sense of 'taking control' over their own body and pain management, where tradition, prescribed medications had not been successful. Following this, I received the remaining transcripts from the transcription service and checked these for accuracy, which also enabled me to re-immerse myself in the remaining interviews.

During the course of this step, I found myself looking too far beyond the data and looking at themes. Discussions with RP helped to refocus my attention on the aims of the study and not to go beyond this or overreach as a project. I often found myself being drawn to the emotive nature of the participants responses and these discussions supported me to take a step back from this and consider the data as it was presented in the transcripts. My experience of the interviews also helped to shape the emphasis of some points, particularly the way in which participants were conveying the patient-clinician relationship.

Searching for and reviewing themes

Whilst listening to the remaining interviews and checking for accuracy, I made notes of codes that seemed to appear across the interviews. Following this, I re-read all the transcripts and began to piece together some of the emerging themes. At this point, PR read two more of the transcripts (P2 and P3) and we met to discuss this on 21.2.23 via MS Teams. We began to discuss an identified theme of how information was accessed and trusted by participants, as well as how they considered accessing products. CBD appeared to be compared favourably to prescribed medications, and we noted some of the reasons for this such as; 'reduced side effects' and 'increased quality of life'. An emerging sense that there were cultural and social factors involved in the decision process of taking CBD was also discussed. I felt drawn towards wanting to explore this in depth, relating to broader institutions, however, PR was able to refocus our attention on the data.

We also used Wiltshire and Ronkainen's (2021) description of critical realism to begin to consider; things that are noticed by the researcher, things that really exist but are not noticed by the researcher, and things that are not observable but are causal powers and have potential to influence participants' decision making. This helped to conceptualise stigma relating to cannabis-based products as something that was quite prominent in the data.

We reflected on my own bias and the roles of being a clinician and researcher (as discussed above). This helped to consider my position during interpretation of the data, particularly whilst being on a clinical placement at a site we recruited from.

Defining and naming themes

The process then went on to defining themes based on the emerging themes identified with PR. These themes were based on the discussions had and the interpretation and analysis of the data. I took quotes that represented the various emerging themes and identified these as initial themes, placing them in a table on MS Word. This helped me to sort and consider these as themes and move them dependent on their relation to each other and place them under broader themes. These were then sent via email to the wider research team (PR, KH, and NF) for consideration. Discussions about their position and relatedness took place and a meeting between the research team (KH and NF) took place on 11.5.23 (PR provided feedback via email). During this meeting, we developed discussed each of themes and prospective grouping in to broader themes. As a process, I developed a diagrammatic and visual way of representing the themes and sent this to the team who agreed it represented our discussion.

One theme was discussed at length; 'Taking control'. There was a discussion relating to an additional subtheme of 'Autonomy', which was distinctive from 'Advocating for self'. This was discussed as a being autonomous

from professionals and making their own decisions. However, it was felt that ‘Advocating for self’ was able to encapsulate this much better and did not necessitate a further subtheme.

By including the research team in the interpretation and identification of codes and themes, I was able to consider a broader perspective than my own and consider my positionality and reflect on this to reduce bias.