Exploring Adults' and Healthcare Professionals' Experiences of Fibromyalgia

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It should also be noted that some material in this portfolio has been informed by the ClinPsyD Thesis Proposal and therefore there may be overlap where material could not be feasibly changed (e.g., methods sections).

Thesis Portfolio Abstract

Background: Research indicates the challenges people living with fibromyalgia face in healthcare due to lengthy diagnostic processes, unclear treatment guidance and unhelpful beliefs and attitudes from others. Pain management services have been identified as a positive resource, yet no research to date has explored pain clinicians' perceptions of fibromyalgia. Equally, peer support appears to offer value to those living with fibromyalgia, but the evidence has not yet been synthesised in a meaningful way. This thesis aims to explore pain clinicians' perceptions of fibromyalgia and adults' experiences of living with fibromyalgia in the context of peer support.

Methods: A qualitative thematic synthesis of the literature was carried out by searching eight electronic databases to understand how peer support is experienced by people living with fibromyalgia and the impact of this. Concurrently, a qualitative study using semi-structured interviews with 12 pain clinicians was conducted. Transcripts were analysed using reflexive thematic analysis.

Results: The systematic review synthesised evidence from 17 studies, producing three descriptive themes with five subthemes, and four analytical themes. The empirical research produced three themes, with two subthemes.

Conclusions: The systematic review highlighted a mostly positive regard for peer support in fibromyalgia, but identified how this may result in polarisation between healthcare professionals and those living with fibromyalgia. The empirical research identified perceptions of fibromyalgia which suggested awareness of challenges those living with the condition may have faced and a desire to provide alternative, more positive healthcare experiences. This portfolio highlighted the need for further understanding of fibromyalgia, allyship in services, and compassionate and equitable care.

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Chapter 1: General Introduction

What is Fibromyalgia?

Fibromyalgia is characterised by chronic widespread pain, increased sensitivity to pain, muscle stiffness, fatigue and difficulties with sleep, cognitive blunting, headaches, irritable bowels and feelings of frustration, anxiety, or low mood (National Health Service [NHS] 2022a). Despite this extensive list, these are just *some* of the many symptoms which people living with fibromyalgia (PLF) can experience, and the amount and extent of these difficulties vary from person to person (Faculty of Pain Medicine, 2020). In addition to this, NHS (2022b) indicates that the symptoms of fibromyalgia are fluid and may change suddenly, adding to the complexity of the condition. Fibromyalgia is a topic of controversy within the literature, not least because of the variety of symptoms it brings, as this makes it difficult for both PLF and healthcare professionals to manage.

Diagnosing Fibromyalgia

Fibromyalgia is a diagnosis of exclusion, meaning all other possible conditions accounting for an individual’s symptoms must be investigated and ruled out first (Wolfe et al., 2016). This means that people often wait years to receive an explanation for their experiences, resulting in them feeling desperate and exasperated (Undeland & Malterud, 2007; Mengshoel et al., 2017). There is also some controversy around the validity of the diagnosis, whereby PLF feel that the process of exclusion leaves them with a label which feels trivial and unclear (Boulton, 2018). From the perspective of the professionals, in earlier years there were debates about fibromyalgia being a socially constructed diagnosis: “no one has fibromyalgia until it is diagnosed” (Ehrlich, 2003, p.1666). Although understanding has progressed since 2003, and revisions have been made to diagnostic criteria following critiques and availability of new evidence (Wolfe et al., 2016), there are still no objective tests to determine a diagnosis of fibromyalgia, symptoms remain medically unexplained, and the aetiology is still unclear (NHS, 2022c). A recent critical review of the diagnostic criteria for fibromyalgia echoed the difficulties raised several years ago, in that diagnoses are based on clinical assessment and self-reports rather than objective markers or valid measures (Galvez-Sánchez & Reyes Del Paso, 2020). As such, Galvez- Sánchez and Reyes Del Paso considered that this lack of understanding undermines the healthcare and social acceptance of fibromyalgia.

Where the terms “medically unexplained” or “medically unexplained symptoms” are used throughout this portfolio, the authors refer to a medical condition which does not yet have clear biological or physical cause which can account for the individual’s experience. That is, there are no objective tests such as scans, or laboratory analysis of samples which can identify the condition. The terms are not used in this portfolio to discredit fibromyalgia diagnosis, rather to highlight the challenges it may bring for both the people living with it, and professionals working with those living with it.

How Fibromyalgia is Managed

Treatment for Fibromyalgia aims to reduce symptoms and improve quality of life, as there is no cure for the condition (Kwiatek, 2017). Conservative treatments are recommended for fibromyalgia, but these vary across the world depending on cultural beliefs and healthcare guidance; outside of the United Kingdom (UK), treatments such as acupuncture, meditation, Tai Chi, diet management, massage and medical cannabis are suggested (Prabhakar et al., 2019). Most countries tend to use psychological, occupational, and physical therapy, as well as patient education (Häuser et al., 2017). These modalities rely on individuals applying therapeutic skills to their everyday life, known as self-management. In the UK, the NHS long term plan encourages self-management for long-term health conditions particularly as this allows individuals to be more independent and responsible for their health (NHS, 2019). Further to self-management, the NHS recommends support groups for fibromyalgia, suggesting it can be helpful to share experiences with others who understand (NHS, 2022d). Charities such as Fibromyalgia Action United Kingdom (FMA UK) have a wide reach to PLF and their families, offering information, advice, and support groups (FMA, 2015).

Medication such as anti-depressants are commonly used as part of fibromyalgia treatment both in the UK and globally (e.g., NHS, 2022e) and some pharmacological treatments are used which are not available in the UK (Júnior & Almeida, 2018). However, a recent Cochrane review of chronic pain treatment (of which over a third of the included studies examined fibromyalgia) highlighted that the only efficacious anti-depressant was duloxetine (Birkinshaw et al., 2023). A meta-analysis by Pathak et al. (2023) reviewed the effectiveness of rehabilitation strategies for fibromyalgia; despite finding that mixed exercise therapies were the most effective in relieving pain symptoms and improving quality of life, a similar theme to the aforementioned Cochrane review became apparent in that there were limited options when rehabilitation strategies often failed to provide long-term impact. Therefore, it was indicated that several approaches would be needed to target the multiple symptoms of fibromyalgia. This is reflected by the National Institute of Health and Care Excellence (NICE) guidance for chronic primary pain (under which fibromyalgia is classified), whereby a biopsychosocial approach to treatment is recommended (NICE, 2021). As such, PLF are likely to be a patient under the care of several healthcare services and professionals, which may result in fragmented care. Indeed, Doebl et al. (2019) reviewed the evidence on models of patient care for PLF in the United Kingdom amongst four other countries and could not identify any evidence-based model that navigated the patient journey through the entire healthcare system. Instead, challenges were identified, including difficult interactions such as fibromyalgia being viewed as an illegitimate condition, and patients not feeling believed or listened to. Despite similarities and differences in treatment across the globe, there remains challenges to managing fibromyalgia.

The Cost to the NHS

Evidently, the ambiguity on how best to manage fibromyalgia can result in significant psychological expense to those living with the condition, but also significant financial expense to healthcare providers. In general, chronic pain conditions are estimated to cost £10 billion annually in healthcare globally, with significant additional costs to social care and the community (Vos et al., 2017). According to one study, inpatient admissions to English NHS hospitals for PLF between 2014-2018 cost around £20,000,000 despite there being little evidence to suggest that medical procedures are effective in fibromyalgia (Soni et al., 2020). The majority of PLF were admitted electively, for therapeutic transfusions and injections, some for diagnostic imaging and others for surgical procedures. In addition, inappropriate prescribing of medications for treating fibromyalgia has been indicated as an avoidable cost, however some general practitioners (GPs) have suggested that over-prescribing occurs due to limited access to other treatments (Wilson et al., 2022). Some evidence has also referred to the societal cost of medical expenses, lost wages and lost tax revenue as a result of the adverse effects of fibromyalgia on peoples' lives (Sturge-Jacobs, 2002). The impact on peoples' quality of life has been highlighted by research around mental health and fibromyalgia, and therefore not only are physical health services necessary for PLF, but mental health services too (Galvez-Sánchez et al., 2019; Glombiewski et al., 2010).

Stigma

Perhaps partly due to the complexity of this condition, the literature overwhelmingly suggests that PLF tend to have negative experiences when interacting with others. Even within their support network, consisting of close friends or family members, PLF have suggested they feel misunderstood (Briones-Vozmediano et al., 2017; Arnold et al., 2008). Considering their interactions with others, common themes PLF express are being disbelieved, questioned, and ignored by others (Juuso et al., 2014). Often, PLF tend to avoid social interactions, so they do not have to face the associated stigma and negative feelings this brings (Armentor, 2017). As a result, those living with fibromyalgia may struggle with physical and psychological loneliness (Rodham et al., 2010).

Within healthcare, unfortunately there are several accounts within the literature around clinicians' negative attitudes towards PLF. For example, PLF have found the need to justify their condition to healthcare professionals (Rodham et al., 2010), and felt blamed for being unwell (Mengshoel et al., 2017). This is likely linked to a commonly expressed belief that fibromyalgia is not a genuine medical condition (Mengshoel et al., 2017; Colmenares-Roa et al., 2016; Amber et al., 2014; Ghazan-Shahi et al., 2012), and the belief that PLF are "complainers" or "malingerers" (Briones-Vozmediano et al., 2018; Hayes et al., 2010). Unfortunately, this has led to some PLF receiving the message from their healthcare providers that their condition is "all in their head" (Diviney & Dowling, 2015), which may be a result of negative attitudes, as well as our understanding of fibromyalgia in terms of the bidirectional relationship between physical and psychological experiences (e.g., Butler & Moseley, 2015).

Peer Support

Given the difficulties that PLF appear to face due to isolation and a lack of understanding from others, it has been highlighted that peer support may be an extremely valuable resource (e.g., Sallinen et al., 2011). Generally, peer support in physical health conditions can offer encouragement, help people to feel more in control to improve their coping skills and health-related behaviour, as well as reduce stigma (Stenberg et al., 2022; Grant et al., 2021). This is particularly important in long-term, medically unexplained symptoms where individuals often feel that others do not understand, or are dismissed by others (Engebretson, 2013). PLF often express frustration at others and suggest that they are frequently disbelieved because others cannot see or relate to fibromyalgia, and therefore peers offer an alternative perspective because they have their own lived experiences (e.g., Homma et al., 2015; Juuso et al., 2014). Not only do peers provide understanding and legitimisation of the physical symptoms of fibromyalgia, they also provide validation and mutual understanding of difficult experiences they have faced with others. For example, a quantitative study reviewing support groups for people living with fibromyalgia and chronic fatigue found that the most frequently named benefits of peer support were legitimisation of the condition and feeling understood by others (Friedberg et al., 2005). Peer support for PLF is encouraged by the NHS (NHS, 2022d); this apparently valuable and cost-effective resource would be useful to understand further.

Chronic Pain Management Services

Despite several sources indicating negative experiences PLF have in healthcare, some research has identified positive aspects of support and treatment. Ashe et al. (2017) interviewed PLF in the UK about their experiences of living with and receiving treatment for fibromyalgia; acupuncture and hydrotherapy were seen as very effective for relieving symptoms, however these were offered on a time-limited basis and therefore were perceived as having little long-term impact. A third of the participants had been referred to a chronic pain clinic, which all reported to be extremely beneficial due to the clinic being seen as a hub of information, advice, and support. Participants in this study described their GPs as “obstructive” and reported having to battle to be prescribed medication and referred to specialist clinics. The NHS programme, “Getting It Right First Time” recommends that management of fibromyalgia should centre on primary care and indicates minimal evidence for better outcomes in secondary care (Kay et al., 2021). However, this is in contrast to a UK national survey study which highlighted GPs’ frustration at being unable to manage fibromyalgia without specialist multidisciplinary teams, and their exasperation at the sparsity of service provision for PLF (Wilson et al., 2022). Furthermore, the participants in the study by Ashe et al. (2017) suggested that the pain clinic was the closest they could get to a specialist fibromyalgia centre. It was not indicated in this study whether their satisfaction reflected objective changes in their symptomology, however some research suggests a bidirectional relationship between patient outcomes and compliance, and satisfaction (Chow et al., 2009). Ashe's qualitative interviews potentially provided *rich* accounts of peoples' experiences, which may be important considering the negative experiences expressed in the literature. In addition, the review of models of care for PLF by Doebl et al. (2019) indicated that positive care and satisfaction experiences included being listened to, collaborative decision making, and better support and information, which would likely be understood through qualitative methodology and satisfaction surveys.

Theoretical Underpinnings

Throughout this thesis portfolio, theoretical underpinnings such as social identity theory (Tajfel, 1978; Tajfel & Turner 1979), confirmation bias (Mynatt et al., 1977), cognitive dissonance (Festinger, 1957), self-efficacy (Bandura, 1994), and social learning (Bandura, 1971) have been considered in order to make sense of the findings. Hypotheses around how these may help to understand the phenomena of peer support and clinicians' perceptions of fibromyalgia have been discussed using these theories in a post-hoc way. Since there are no existing theories which are generally considered exclusively applicable to fibromyalgia, the authors have drawn upon psychological concepts and research exploring similar phenomena to guide the discussion and clinical implications of this portfolio.

The Thesis Portfolio

The primary focus of this thesis portfolio is the experience of fibromyalgia in healthcare. Specific questions are addressed in chapter two (the systematic review), and chapter four (the empirical research project). The systematic review provides an original synthesis of the literature around how people living with fibromyalgia experience peer support, and what the impact of this is. The empirical research project explores specialist pain clinicians' perceptions of fibromyalgia and considers the influence of these on the interaction between patient and professional. Chapter three serves to bridge these chapters, giving an overview of the systematic review findings and a brief discussion to provide rationale for the links between them. Chapter five gives extended detail into the chosen methodology for the empirical research project. This is to clearly describe and justify the research process and decision making for the qualitative portfolio. Chapter six joins the findings from both the systematic review and empirical research project, critically evaluating and discussing the findings, with consideration for clinical and theoretical implications.

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Chapter 2. Systematic Review

How is Peer support Experienced by People Living with Fibromyalgia and what is the Impact of this? A Systematic Review

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Abstract

Purpose: This systematic review aimed to synthesise qualitative findings on how peer support for fibromyalgia is experienced, and the impact of this. Peer support has been recognised as having both benefits and drawbacks for those living with fibromyalgia.

Methods: Eight databases were searched using keywords; manual searches of screened studies' reference lists were conducted. Selected studies underwent quality appraisal with the Critical Appraisal Skills Programme tool. Data from original studies' findings sections were extracted using thematic synthesis, with inductive coding.

Results: 17 studies were included in the systematic review, representing experiences of over 225 people living with fibromyalgia. Three main descriptive themes were developed, "the contrast of peer support versus others", "motivation to keep going" and "peer groups can be negative". Four analytical themes were developed, "the benefits of peer support are emphasised by the drawbacks of the outside world", "others don't understand: a maintenance loop", "peer social learning" and "peer support must be just right". Review findings were rated by the GRADE-CERQual between moderate and low confidence.

Conclusions: Peer support is generally experienced by people living with fibromyalgia as a beneficial resource. There is potential for various consequences, some of which might be construed as negative. The contrast between the value of peer support and the perceived negative attitudes of others may contribute to a maintenance loop of difficult experiences within healthcare appointments. It is important that future research explores these concepts further to understand how healthcare improvements can be made for people living with fibromyalgia.

Key Words: Fibromyalgia, Peer support, Peers, Qualitative, Negative attitudes, Empathy, Compassion, Self-management.

Introduction

In healthcare, there is a growing appreciation for the benefit of peer support; several studies have identified how peers can offer encouragement, help people to feel more in control, reduce stigma, enhance coping skills, and improve overall health-related behaviours (Grant et al., 2021; Elafros et al., 2013; Peterson et al., 2012; Brownson & Heisler, 2012). Peer support takes various names, but refers to individuals with lived experience providing knowledge, advice, emotional and practical support to those who share their experiences (Beales & Wilson, 2015). It is versatile in how it can be delivered, for example in person, online, on a group or one to one level, and engagement can be active or passive. Often, the benefits are mutual for those providing and receiving support; themes across the research include an improvement in confidence, self-esteem and having a sense of helping others (Tse et al., 2019; Matthias et al., 2016; Brunier et al., 2002). Peer support can be particularly useful for long-term health conditions which must be self-managed, for example in chronic pain populations peer support has been identified to provide competence and autonomy to better manage the condition (Stenberg et al., 2022).

Peer support for people living with fibromyalgia (PLF) may be especially important because it is considered medically unexplained and therefore often associated with scepticism (e.g., Doebl et al., 2020; Mik-Meyer & Obling, 2012). Where the terms “medically unexplained” or “medically unexplained symptoms” are used by the authors of this review, they refer to a condition which does not yet have objective tests such as scans, or sample analysis to identify the condition. The terms are not intended to undermine fibromyalgia diagnosis, rather to highlight the challenge it may bring for those living with the condition. Individuals are often disbelieved and dismissed by others, perhaps due to the lack of understanding and medical validation of fibromyalgia (Undeland & Malterud, 2007; Söderberg et al., 2001). Fibromyalgia is a diagnosis of exclusion, meaning people will have undergone multiple investigations, and may have had to fight to be heard by medical professionals (Mengshoel et al., 2017). This process unfortunately causes several PLF to feel frustration or self-doubt, particularly when this is reinforced by being seen as a malingerer (e.g., Hayes et al., 2010) and messages such as “it’s all in your head” (e.g., Diviney and Dowling 2015, Rodham et al., 2010). As such, meeting peers can provide validation of experiences, legitimisation of the condition, and feelings of being understood (Friedberg et al., 2005).

Fibromyalgia can not only be psychologically isolating because of others' limited understanding but can also be physically isolating due to the unpredictability and severity of symptoms causing disruptions in social relationships (Hamama and Itzhaki, 2023; Arnold et al., 2008). Peer support may therefore also provide socialising opportunities, to form connections with others who understand the physical limitations of the condition. Hamama and Itzhaki (2023) conducted a focus group with women living with fibromyalgia, and one participant emphasised the difference between her feelings towards meeting with peers versus family: "I feel best with friends who have fibro; they are like sisters. But many times when I plan weekends with the family, I am afraid to book a place because I don't know how I will feel" (p.6). This indicates a sense of guilt experienced for PLF when with others who do not understand their condition. Indeed, Hamama and Itzhaki discuss several negative emotions, and complex feelings associated with relationships with others.

Unfortunately, research suggests that some PLF feel ostracised by the general population including healthcare professionals, through a lack of understanding and negative stereotyping (Armentor, 2017; Undeland and Malterud, 2007). People living with fibromyalgia have expressed feeling they must prove the legitimacy of the condition to health professionals (Rodham et al., 2010) and others felt blamed by clinicians for being unwell (Mengshoel et al., 2017). This is in stark contrast to what peers may provide, for example the "unconditional acceptance" described by cancer peer support group members (Ussher et al., 2006). Additionally, medical settings may set out a power hierarchy whereby knowledge is less accessible than when shared by peers, who tend to empower one another through the sharing of information (Solomon, 2004). This could contribute to the benefit of peer support for those living with fibromyalgia, particularly if their perception of healthcare is primed through negative past experiences. Supporting this idea, Bratter and Freeman (1990) identified that peers may seem more approachable for some people than healthcare professionals, and Dennis (2003) proposes that peers can be a preferable choice of support over healthcare professionals due to a non-hierarchical, reciprocal relationship. Alternatively, although peers may be a potentially credible source of information due to experiential knowledge (Cohen et al., 2000), van Unden-Kraan et al. (2008) identified individuals' uncertainty around the legitimacy and quality of the information peers shared in online groups.

In addition to the potential success of peer support, it is important to also consider the drawbacks. In progressive health conditions such as motor neurone disease, individuals have expressed distress at meeting with peers, due to feeling dread of what may lie ahead (Mazanderani et al., 2012). This is mirrored by a study exploring peer support for those living with fibromyalgia, breast cancer, or arthritis, where individuals felt concerned or disempowered when faced with the negative sides of the conditions (van Uden-Kraan et al., 2008). In addition, some research suggests that there are subtleties to peer support, which may influence the extent of its positive impact. For example, Cabrera-Perona et al. (2017) found that PLF may catastrophise more if they compared themselves to peers in a negative way, rather than positive (i.e., through upward and downward social comparison). Friedberg et al. (2005) echoed the advantages of peer support suggested by other research in a study with PLF and chronic fatigue syndrome, however identified that active members reported greater symptom severity and less illness improvements than inactive members. Reasons for this are speculated, for example those with greater severity may be more likely to access support groups, but groups may not provide the desired companionship and may expose individuals to the negatives of the condition, as other research has indicated.

There appear to be both benefits and drawbacks of peer support, however it is not always clear why these phenomena occur, suggesting possible psychological processes that impact peer support are complex. The guidance is also unclear, peer support is not mentioned within the National Institute for Health and Care Excellence (NICE) guidelines for management of chronic primary pain (NICE, 2021), despite evidence that peer support is a key element of self-management for chronic pain conditions (Stenberg et al., 2022). While there are indications within the literature around the benefits and drawbacks of peer support for PLF, the impact of these have not yet been synthesised in a way that may improve experiences for those accessing peer support. Synthesis may also further understanding of the processes which may underlie peer support, and inform guidelines and service provision of formal peer support. The aims of this systematic review are to aggregate qualitative data from research studies which explore peer support to address the following questions:

i) How is peer support experienced by PLF?
ii) What is the impact of this?

Methods

The protocol for this systematic review was registered on PROSPERO on 25th August 2023 (registration number CRD42023457125) and adheres to the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) guidelines.

Inclusion and Exclusion Criteria

A systematic search of eight databases was carried out, using the SPIDER framework (Cooke et al., 2012) to define inclusion and exclusion criteria (Sample, Phenomenon of Interest, Design, Evaluation Research type). Studies were included if:

- Participants were PLF (any gender, race, and age*, worldwide).
- There was relevance to peer support in any format (i.e., support groups, online forums, social media groups etc.).
- They used mixed methods or qualitative methodology.
- They were published in a peer-reviewed journal or book.
- They were available in English.
- They were published within the last 20 years (2003-2023).
- They were available in full text format (i.e., not a poster or abstract).

*There was no age limit due to the inclusion of studies using online forums resulting in difficulty controlling this variable, however fibromyalgia is generally diagnosed after 16 years of age (Royal College of Physicians, 2022).

Studies were excluded if they:

- Were grey literature, not peer reviewed or published in an academic book or journal.
- Used purely quantitative methodology.
- Were not available in English language.
- Were published prior to 2003.
- Included participants with various health conditions (because findings would not be exclusively applicable to fibromyalgia).

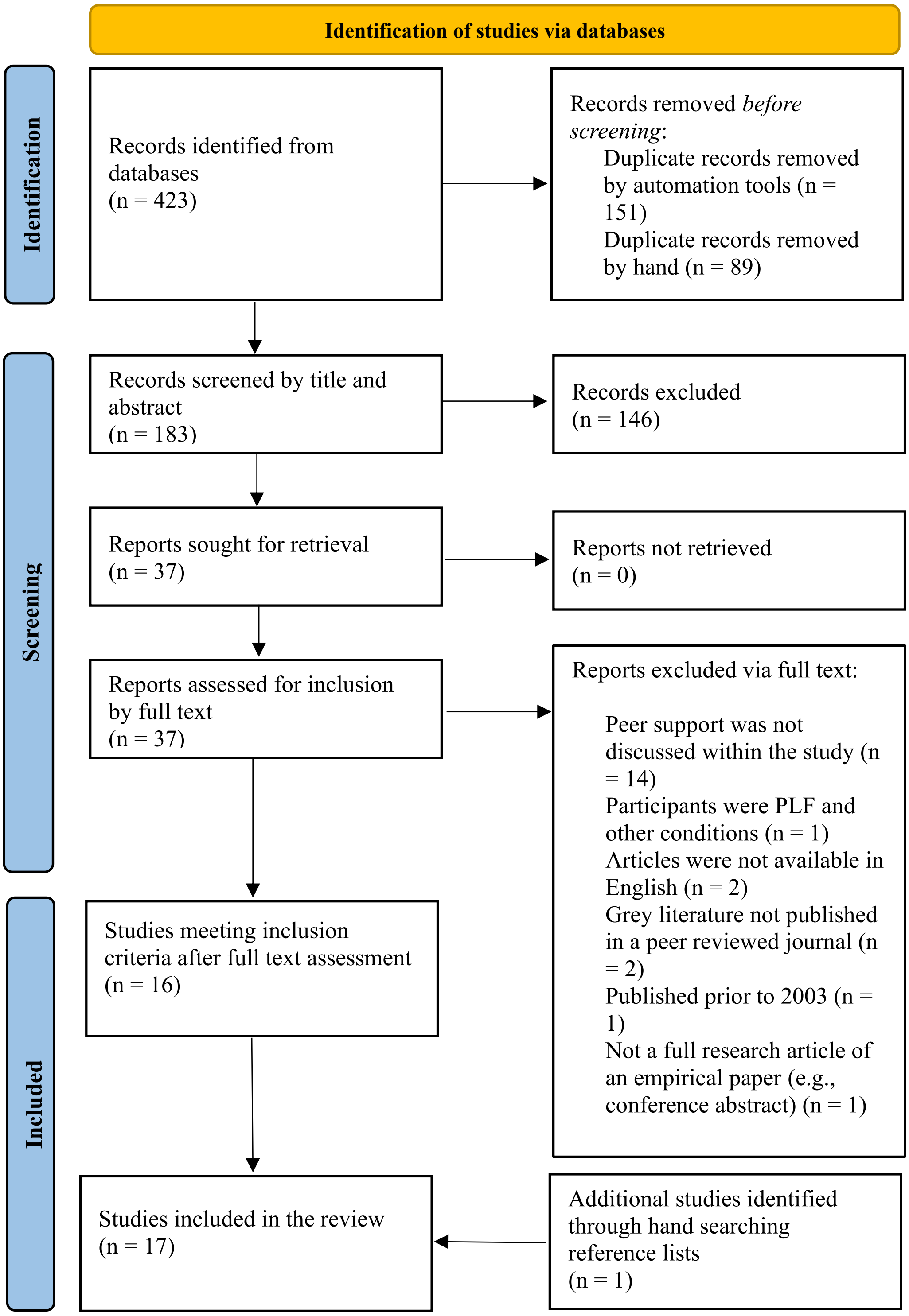
Search Strategy

The following databases were searched in September 2023 and repeated in January 2024: MEDLINE, Cumulative Index to Nursing and Allied Health Literature (CINAHL), APA PsycInfo, Social Sciences Citation Index (SSCI), Academic Search Ultimate, Directory of Open Access Journals (DOAJ), ScienceDirect, and Scopus. The search terms used were: (Fibromyalgia [title]) AND (peer* OR "peer support" OR "support group" OR "peer group" OR group OR "self help" OR "self help group" OR "peer mentor" OR mentor OR coach OR "peer-led" OR "social support" OR forum OR "peer intervention" OR "lay advisor" OR "lay support" OR "patient led") AND (qualitative).

Once duplicates had been removed, the first author (OF) screened the remaining papers' titles and abstracts. Full texts were sourced, and reference lists were hand searched to identify additional relevant studies. The remaining papers were read in full by OF, and additionally, were split between the second and third author to screen full texts. A screening tool (appendix B) was used to aid decision making about whether to include or exclude a study. The authors met and compared outcomes on included papers, which were deliberated, and consensus was reached with 17 papers to be included in the review. Figure 1. Demonstrates the search process.

Figure 1.

Consort Diagram of Search Process



Study Characteristics

All 17 studies explored elements of peer support for PLF. Descriptive information was extracted from each study's methods section, see table 1 for a summary of the included studies.

Table 1

Summary of Included Studies

First author, year, country	Sample characteristics	Focus of study	Data collection methods	Data analysis methods
Al-Qadi et al., 2021. Germany	10 participants	Coping methods and healthcare needs	Qualitative interviews	Content analysis
Arfuch et al., 2022. Spain	10 female primary care patients	Experiences of a multicomponent intervention programme	Qualitative interviews	Thematic analysis
Arfuch et al., 2021. Spain	19 primary care patients	Experiences of a multicomponent intervention programme	Two separate focus groups	Thematic analysis
Beltrán-Carillo et al., 2013. Spain	25 women participating in a 9-month group-based exercise programme	Experiences of a group-based exercise programme	Observations, interviews and focus groups	Content analysis
Berard et al., 2018. North America	15 anonymous Instagram users	Community via social media for PLF	Using the hashtag #fibromyalgia to search Instagram, plus open -ended questionnaires	Content analysis and thematic analysis

Bravo et al., 2018. Spain	19 therapy programme patients	Experiences of a basic body awareness therapy group programme	Interviews and focus groups	Giorgi's analysis
Cipolletta et al., 2020. Italy	76 members of a fibromyalgia Facebook group, and 14 individuals for interviews	Online communities and PLF's medication attitudes and beliefs medication	Searching 19 online forum conversations and 14 qualitative interviews	Grounded theory
Crump et al., 2022. Canada	Approximately 15,000 members of three Facebook peer support groups	Online support	Searching three Facebook groups for PLF	Thematic analysis
Cunningham et al., 2006. Location not stated	Eight participants	Lived experiences of fibromyalgia	Semi-structured interviews	Constant comparative analytic method
Granero-Molina et al., 2018. Location not stated	13 female participants	Sexual dysfunction and social support	Focus groups and interviews	Fleming's method
Homma et al., 2015. Japan	13 participants	Experiences of meeting peers	Qualitative interviews	Hermeneutic-phenomenological analysis
Juuso et al., 2014. Sweden	Nine female participants	Perceptions of being received by others	Qualitative interviews	Hermeneutic-phenomenological analysis
Juuso et al., 2013. Sweden	17 female participants	Fibromyalgia associations	Focus groups	Thematic content analysis

Mannerkorpi et al., 2003. Sweden	19 patients of a physiotherapy programme for PLF	Experiences of a group-based physiotherapy programme	Qualitative interviews	Phenomenological life-world approach
Reig-Garcia et al., 2021. Spain	Six participants	The impact of a peer social support network	Semi-structured interviews	Thematic analysis
Sallinen et al., 2011. Finland	20 female participants	Experiences of peer support several years after a group rehabilitation intervention	Narrative interviews	Stepwise hermeneutic-phenomenological analysis
Traska et al., 2012. North America	Eight female participants	How PLF manage their condition	Qualitative interviews	Content analysis

Assessment of Quality and Risk Bias of Included Studies

Included studies were appraised using the Critical Appraisal Skills Programme tool ([CASP], 2018) (appendix C). The tool provides a checklist of questions as a guide to appraise qualitative studies but does not advise a scoring system or overall quality rating. Noyes et al. (2018) propose that scores are arbitrary and may give a false sense of precision, so instead advocate for discussion of the appraisal and transparency of methodological limitations. As such, no studies were excluded based on their quality appraisal; CASP checklist responses are reported in Table 2, quality issues are discussed below, and methodological limitations inform the confidence in the review findings.

Included studies clearly stated the aims of the research, and qualitative methodology was deemed appropriate to address these. Recruitment strategies were largely appropriate however, some studies may have limited the scope of their findings as a result of their recruitment; Traska et al. (2012) recruited from a previous experimental study, assigning participants to either take part in one of two qualitative studies. Berard and Smith (2018) recruited 15 participants from *Instagram* based on the popularity of their posts, which may have overlooked uncommon perspectives in their population.

Fourteen studies used qualitative interviews or focus groups; three analysed existing online content. Al-Qadi et al. (2021) had a large range of interview durations (between 13 – 79 minutes), which suggests findings may have been skewed in favour of data from participants with longer interviews. In addition, Arfuch et al. (2022) conducted interviews with an average duration of 30 minutes, which may have limited the richness of findings.

Only four of the 17 included studies discussed the relationship between the researcher and participant, while this was not applicable for an additional two studies due to no direct contact with participants. For six of the 17 studies, rigour of the analysis was unclear due to limited information provided in the article (Berard and Smith, 2018; Cipolletta et al., 2020; Juuso et al., 2013; Traska et al., 2012; Mannerkorpi et al., 2003; Sallinen et al., 2011). Triangulation and member checking were used, reflexivity was discussed, and multiple researchers were involved with the analysis process according to the majority of studies. One study (Al-Qadi et al., 2021) gained consent but no ethical approvals were obtained. Justifications were that it was not an intervention study, and no risks were anticipated. However, not encountering risks in any research is unlikely, and participants should be given due consideration. Cunningham and Jillings (2006) also obtained consent from participants but did not discuss ethical approvals. As such it is important to hold in mind how these studies may impact the confidence of the review findings, as different countries may have varying standards of ethical research practice.

Table 2

CASP Appraisal

First author, year, country	Aims clearly stated?	Appropriate methodology?	Appropriate design?	Appropriate recruitment strategy?	Data collection addresses research issue?	Consideration of relationship between participant and researcher?	Consideration of ethical issues?	Rigorous data analysis?	Clear statement of findings?	How valuable is the research?
Al-Qadi et al., 2021. Germany	Yes	Yes	Yes	Yes	Yes. Although interview duration differences	No	No ethical approvals	Yes	Yes	Recommendations for improved healthcare experiences.
Arfuch et al., 2022. Spain	Yes	Yes	Yes	Yes	Yes. Although short interview duration	Yes	Yes (some)	Yes	Yes	Implications for healthcare improvements and for service level changes.
Arfuch et al., 2021. Spain	Yes	Yes	Yes	Yes. Although inclusion criteria not always met	Yes	Yes	Yes (some)	Yes	Yes	Some service level adjustments suggested
Beltrán-Carillo et al., 2013. Spain	Yes	Yes	Yes	Yes	Yes +	No	Yes (some)	Yes	Yes	Service level improvements discussed. Recommendations for healthcare.

Berard et al., 2018. North America	Yes	Yes	Yes	Yes (although popular posts selected)	Yes (although popular posts selected).	N/A (no direct contact)	Limited	Limited information	Yes	Promotes social media communities for people with newly diagnosed fibromyalgia
Bravo et al., 2018. Spain	Yes	Yes	Yes	Yes	Yes +	No	Yes (some)	Yes	Yes	Therapeutic value of body awareness sessions for fibromyalgia
Cipolletta et al., 2020. Italy	Yes	Yes	Yes	Yes	Yes	No	Yes	No (limited information about analysis process)	Yes	Online communities as a positive resource, but little clinical applicability
Crump et al., 2022. Canada	Yes	Yes	Yes	N/A (non-participatory)	Yes	N/A (no direct contact)	Yes +	Yes +	Yes	Several implications for PLF and healthcare professionals
Cunningham et al., 2006. Location not stated	Yes	Yes	Yes	Yes	Yes	No	No	Yes +	Yes	Implications for improved healthcare interactions
Granero-Molina et al., 2018. Location not stated	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Implications for sexual dysfunction in fibromyalgia

Homma et al., 2015. Japan	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Deeper understanding of Japanese peoples' experiences of fibromyalgia
Juuso et al., 2014. Sweden	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Transferability and recommendations for healthcare contexts
Juuso et al., 2013. Sweden	Yes	Yes	Yes	Yes	Yes	No	Yes	Limited information	Yes	Encouraged healthcare provider cooperation with fibromyalgia associations
Mannerkorpi et al., 2003. Sweden	Yes	Yes	Yes	Yes	Yes	No	Limited	Some discussion of "preunderstandings"	Yes	Benefits of group physiotherapy for PLF
Reig-Garcia et al., 2021. Spain	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Recommendations for integration of peer support into healthcare
Sallinen et al., 2011. Finland	Yes	Yes	Yes	Yes	Yes	No	Yes	Limited information	Yes	Implications for improved care

Traska et al., 2012. North America	Yes	Yes	Yes	Strategy may have limited scope of findings	Yes	No	Yes (some)	Limited information	Yes	Implications for biopsychosocial fibromyalgia interventions

Method of Synthesis

Thematic synthesis as described by Thomas and Harden (2008) was used for this review, whereby extracted data was coded, descriptive themes were developed, and analytical themes were generated.

There are some debates within the qualitative literature around only extracting primary data, (i.e., participant quotes) from original studies to inform thematic synthesis, as these are distinct from authors' interpretations and conclusions (e.g., Sandelowski & Barroso, 2002). However, Thomas and Harden (2008) discuss the challenges of this, particularly when there are no clear criteria for the methods and quantity of data reported in qualitative studies. This review included studies with diverse quantity (e.g., detail of participant quotes) and questionable quality. Using primary data exclusively for thematic synthesis would have limited the depth and resulted in some studies contributing less to the review findings. Furthermore, the authors take a social constructionist epistemological stance, which takes into account how findings of qualitative research are interpretations of the data by the researchers, rather than raw truths. As such, the data extracted from studies included all text under "results" or "findings" headings, including primary data as well as authors' summaries and interpretations.

Extracted data was entered verbatim into NVivo 12 (software for qualitative data analysis). Data was coded inductively line by line by OF, with the review question in mind. This was to ensure that codes were data driven, rather than being formed through an a priori framework or specific theoretical lens. Once coding was complete, each extract belonging to a specific code was reviewed to ensure consistency of interpretations and, where appropriate, recoding was carried out. There were a total of 80 codes developed from the extracted data, which were discussed, organised, and reorganised by the authors to develop initial descriptive themes. The descriptive themes set out to closely reflect the extracted data, to address how peer support is experienced by PLF. Table 3 demonstrates the process of coding and developing descriptive themes.

Table 3

An Example of Coding and Development of Descriptive Themes

Extract	Codes	Descriptive Theme	Subtheme

"To be wished well and welcomed was described as providing them with strength and giving them the spirit to continue struggling against their illness"	Peers inspire strength and motivation; providing hope	Motivation to keep going	Empowerment and encouragement

Analytical themes were developed by the authors through discussing interpretations of the descriptive themes, in order to address the impact of peer support for PLF. The analytical themes set out to explore underpinnings of the descriptive themes, so that hypotheses may be made. The generation of themes were influenced in the context of the authors' worldviews and positionality. Therefore, it is important to note how other reviews may draw alternative themes from the extracted data. All three authors have an interest in fibromyalgia, previously worked at a National Health Service (NHS) chronic pain management service, under the discipline of clinical psychology. All three are female, able-bodied, white British and less than 45 years of age. Analytical perspectives are influenced by psychological theories and clinical and personal experience. From a social constructionist perspective, the phenomenon of peer support for PLF has been made sense of through the context of the authors' experiences.

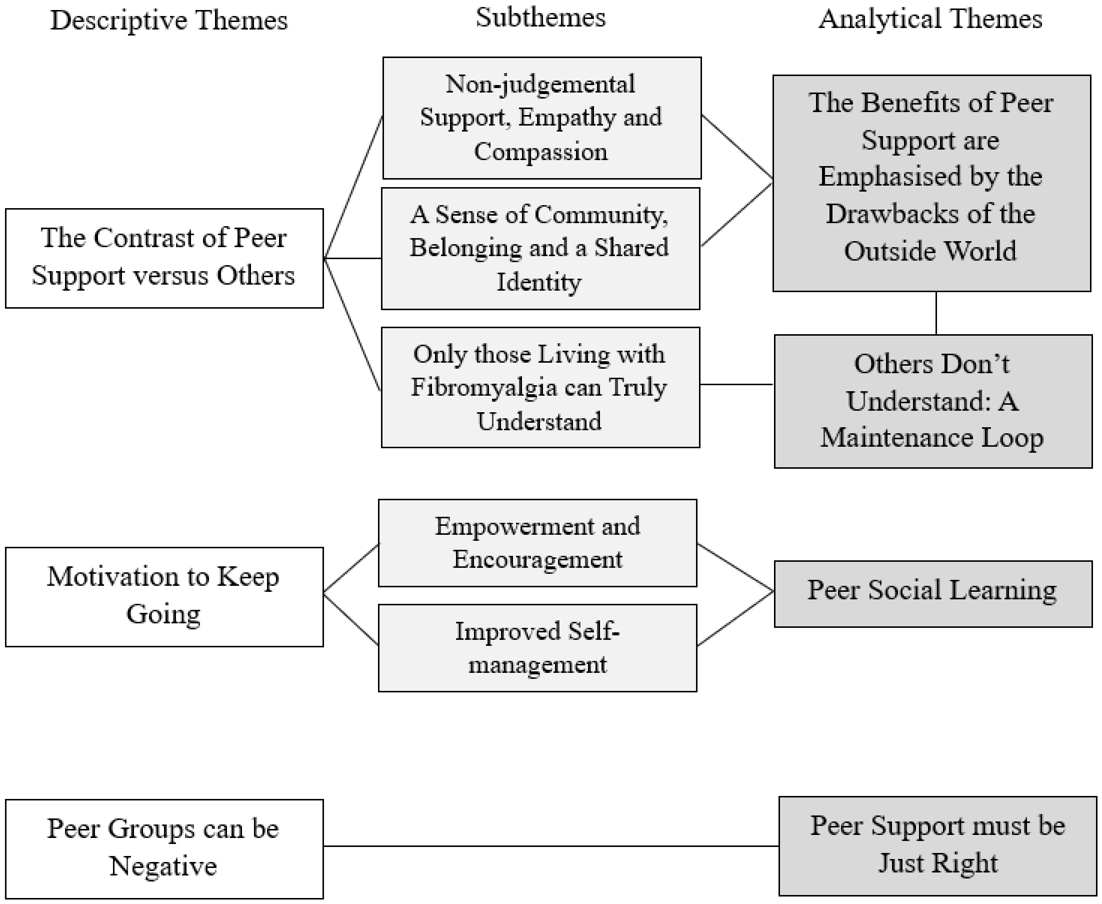
To ensure themes were sensitively conveyed, three PLF were recruited via social media to read the results independently and provide written feedback. They were not asked to validate the findings, as the purpose of the review was not to identify "truth values", however they were encouraged to share any disputes with the findings. No incentive was given, but each received a £10 *Amazon* voucher retrospectively as a token of gratitude for their time and effort. Each person living with fibromyalgia concluded that the findings were sensitively conveyed and noted how these resonated with their own experiences. As such no changes were made, however it is important to consider issues of power and ethics, similar to those raised by Boser (2007) who suggests how participants involved in developing research must be given equal power to contribute.

Results

Three descriptive themes were developed from the synthesis, with additional subthemes. Four analytical themes were also formed, as seen in figure 2.

Figure 2.

Thematic Synthesis Map



Extracts are italicised, underlined words were previously abbreviations made by original study authors. Bold text indicates emphasised words. Where small amounts of text were omitted by original authors […] is used, while "…" represents a pause in speech. Original authors provide some information in brackets to provide context.

Descriptive Theme 1. The contrast of peer support versus others

Throughout the studies the benefits of peer support were discussed, and these demonstrated the contrast between what peers provide and what cannot be provided by others.

Subtheme: Non-judgemental support, empathy and compassion

The studies demonstrated how peers showed unconditional empathy, and non-judgemental attitudes toward one another:

"Don't stress yourself out. Know you are safe to say what you want here and know we will support and understand you!!" – Crump and LaChapelle, 2022

The local fibromyalgia association plays a vital part in providing social support for these women. They feel understood, not judged, and able to share experiences without hiding anything, helping each other to face the illness. – Granero-Molina et al., 2018

They provided comfort and understanding, as well as a sense of safety within the peer group:

Participants believe that the community is a place not just to share personal experiences and complaints, but also to support and provide emotional containment - Cipolletta et al., 2020

Responses also occasionally conveyed gratitude for the existence of "our site," which was described as a "safe place to go" to vent about experiences of judgment and to seek support from similarly affected others. – Crump and LaChapelle, 2022

PLF were empathetic toward their peers, as they understood each other's experiences. Sharing this together allowed for legitimisation of their symptoms, as well as validation of their experiences:

While there is no medical evidence for supporting fibromyalgia syndrome, it has been detected that peers' illness experiences provide living testimony to support this health condition. -Arfuch et al 2022

they were believed, and nobody in the program thought they were making up the pain or the fatigue. – Beltrán-Carillo et al., 2013

Subtheme: A sense of community, belonging and a shared identity

Across the studies, peers were seen as a community; PLF discussed how they previously felt like an outsider, but the group provided a sense of belonging:

The earlier experience of being odd, strange or an outsider was displaced by an experience of belonging to a group and not being alone with one's problems. -Sallinen et al., 2011

The women explained that, in general, sharing needs, desires, perceptions, and goals with other people in the social support network increased their sense of identity with and belonging. "I feel like I belong to a likeminded group of people." -Reig-Garcia et al., 2021

Additionally, strong connections were formed between peers and lasting relationships were built for some:

Not surprisingly, the participants formed a strong connection with each other. Signs of love and affection, such as kisses or hugs, were often observed in the program. - Beltrán-Carillo et al., 2013

"A very warm bond was born between the participants of the program. Having the opportunity to talk, exchange experiences, and obtain new information blessed me with relief." –Arfuch et al., 2022

These strong connections helped to diminish feelings of physical and psychological loneliness which they had felt prior to meeting those who shared their diagnosis:

They described the sense of belonging and togetherness they felt in the fibromyalgia association as a joyful experience and a way to break their isolation. -Juuso et al., 2013

…namely, fellow members who have the same diagnosis understood their pain, which other people failed to understand. Although they had previously been isolated, attendees received emotional support by realising there was a place for them and that they were not alone. -Homma et al., 2015

"Connecting with fibro warriors is a reminder that other people out there live this same life every day and struggle the same way I do. We really are in a battle and it's nice to

know you aren't alone and that other warriors are fighting for recognition as well." – Berard and Smith, 2018

Subtheme: Only those living with fibromyalgia can truly understand

There were accounts throughout that others (who do not live with fibromyalgia) were unable to understand what it is like to live with fibromyalgia. Frustration was frequently shared amongst peers:

"I have had a horrible time with this disease because nobody understood me, nobody knew what it was. My husband, for instance, is a person who has never understood it and does not want to; he does not want to believe that I am sick." -Arfuch et al 2022

"Unless the fibro monster lives within you, there is no way to understand, period. Instagram has linked me with other people with chronic pain, people who know the life and the exhausting reality." -Berard and Smith, 2018

Some expressed strong negative emotions toward others when sharing their lack of understanding:

"These archaic uninformed "Drs" need to get with the program. Don't put up with their smug BS. We know more about our condition than anyone else. We live it. We need to have our voice heard." -Crump and LaChapelle, 2022

Alternatively, peers offered true understanding due to mutual experiences, which was received with great value:

I think they understand me better here (at the association). Normally women with fibromyalgia understand each other better. -Granero-Molina et al., 2018

All believed that having persons with fibromyalgia whom they could share experiences with was important because these were the only people who ***really*** *understood and 'finding people that understand and have the same experiences that you do are really what help get you through it.'* – Traska et al., 2012

Women with fibromyalgia described that they were met and received with understanding by others with experiences similar to theirs. These were the only people who could really understand them and did not demand explanations. – Juuso et al., 2014

Eight of the studies described how PLF felt unable to talk to others, having learnt from invalidating or unhelpful past experiences:

The women explained that they were not able to tell about their pain and other symptoms at home or at work, because it was seen as 'whining for nothing'. -Sallinen et al., 2011

Women with fibromyalgia need support from health care professionals, but our participants feel stigmatized by the system and health care workers. They feel they are labelled as mentally ill patients. Met with this lack of credibility in medical consolations, they are afraid to speak about fibromyalgia and even more so about the associated sexual problems. -Granero-Molina et al., 2018

In contrast, some papers reported that peers gave PLF permission to talk openly about their experiences, without fear of being judged or dismissed:

"Nobody needed to hide behind 'a curtain'. It was not like that, it was very easy going. [...] That alleviates pain a little. It really does. You feel that you are not that bad." -Mannerkorpi and Gard, 2003

"When I meet one of you ... I get so happy because it's someone who has it the same way as I do" (P3). "Then you are allowed to talk about it [fibromyalgia], which you aren't anywhere else" (P1). "Yes, you experience that people don't take you seriously" (P4). "But here it's just that you don't need to explain all the time" (P1). -Juuso et al, 2013

Analytical Theme 1. The benefits of peer support are emphasised by the drawbacks of the outside world

This analytical theme encompasses the first two subthemes, "non-judgemental support, empathy and compassion" and "a sense of community, belonging and a shared identity". While the included studies demonstrated benefits of peer support, these were difficult to separate from comparisons to other peoples' attitudes, or negative past experiences. Often, the studies indicated that the benefits were not only valued on their own but accentuated due to the stark contrast between this and what others provided:

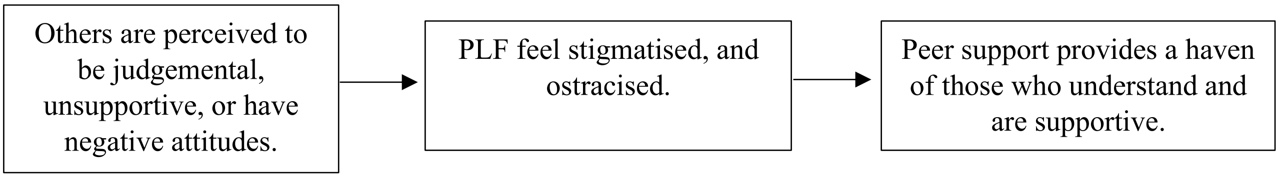
In the narratives, the encounters with peers appeared to be a significant turning point after struggling with uncertainty and negative attitudes for years. -Sallinen et al., 2011

The significance of this experience, not being alone with unclear symptoms and frequent difficulty when trying to manage situations in everyday life, was understood against the background of insecurity that many respondents had experienced when trying to interpret and describe their perceptions and apprehensions to their significant others or to health care professionals. -Mannerkorpi and Gard, 2003

Figure 3. provides a visual example of a hypothesis underlying this analytical theme.

Figure 3.

Flowchart Demonstrating a Hypothesis around the Benefits of Peer Support being Emphasised by the Drawbacks of the Outside World.



Analytical Theme 2. Others don't understand: A maintenance loop

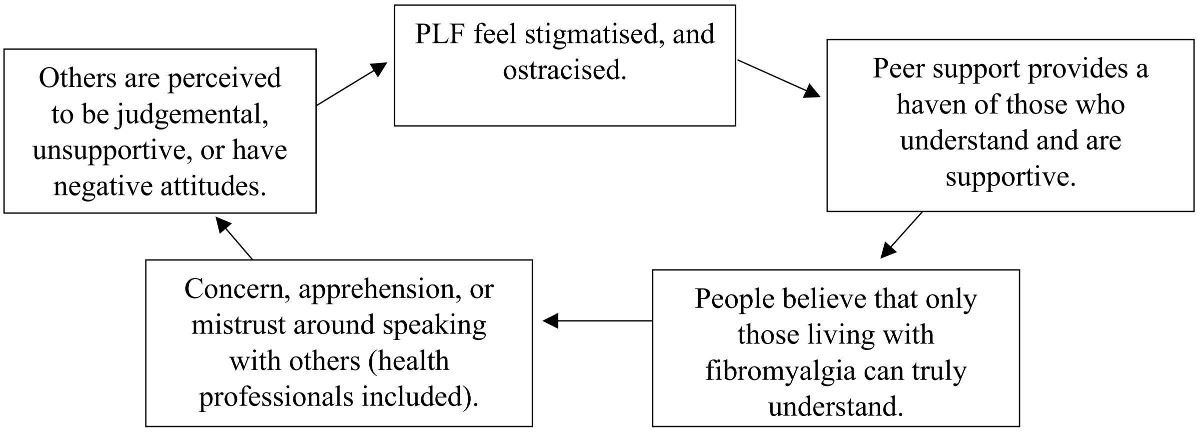
This analytical theme is an extension of the first analytical theme, including the subtheme "only those living with fibromyalgia can truly understand" and considers the contrast between supportive peers versus unsupportive others. It suggests that this may form a maintenance loop of negative experiences which confirm beliefs that only peers can truly understand and provide positive, validating experiences:

Stigmatizing encounters with medical professionals appeared to be particularly damaging to members' willingness to strive for and place trust in patient–provider relationships, leading some members to describe the world outside their fibromyalgia online peer support groups as hostile. – Crump and LaChapelle, 2022

Figure 4. provides a visual example of a hypothesis underlying this analytical theme, which is an extension of the flow diagram presented in figure 3.

Figure 4.

Maintenance Loop Demonstrating a Hypothesis around Peer Support Experienced as Positive, while Others Reinforce Negative Beliefs and Expectations.



Descriptive Theme 2. Motivation to keep going

A common element of peer support which arose was the motivation peers provided to manage their condition. Motivation was offered in various ways, including encouragement, empowerment and offering advice on self-management strategies.

Subtheme: Empowerment and encouragement

Peers gave positive statements and words of encouragement to one another, which empowered PLF to feel able to continue managing a difficult condition:

"Fibro is painful but as fighters we shall never give up or give in. Gentle hugs my fellow warriors" -Crump and LaChapelle, 2022

"*We talk a lot about the pain ... and then we send each other motivational words ... this encourages you and makes the pain less."* -Reig-Garcia et al., 2021

In some of the studies, peers were seen as role models, which inspired motivation:

in these self-help groups, informants identified a positive individual as a role model who lifted their spirits. – Homma et al., 2015

Participants recalled how their interactions as new users with mentors brought them to a stronger place both mentally and emotionally. -Berard and Smith., 2018

Hearing peers' experiences provided encouragement, inspiration and ideas to manage the condition:

"Yes, it has been very good to discuss things. It has been very useful, as there may be things that you haven't thought about and that you suddenly realize. You get a kick, you start to think that I might be able to do things the same way, although I had not thought about it before. You give each other a carrot all the time, although you sometimes feel very bad." – Mannerkorpi and Gard, 2003

Peers provided positive reinforcement, as well as hope for the future, which they had previously lacked from others:

In some cases, doctors told them that they could do nothing but just accept it, so the fact that they were experiencing physical and psychosocial benefits with this activity acted as a powerful stimulus to be more optimistic about their condition. - Beltrán-Carillo et al., 2013

"Sometimes you know, you can't cope, you're sinking, but then you talk to them [the group] and you know it will pass, that this is how the disease is, and that better times are coming, and that helps you." -Reig-Garcia et al., 2021

Additionally, several of the studies described contagious positivity, which allowed people to get distance from the difficulties of fibromyalgia for a period of time:

The atmosphere created in the program had much to do with the positive attitude of some women, which was contagious. When they were having a good time, it was easier for them to forget about the pain (at least for a while), become more optimistic, and keep the disease in perspective. - Beltrán-Carillo et al., 2013

Subtheme: Improved self-management

Peers helped contribute to their self-management strategies of fibromyalgia:

They explained that, since becoming part of the social support network, they generally felt better about themselves and felt more encouraged to achieve goals in relation to their disease. -Reig-Garcia et al., 2021

This was found to be a result of various factors, including explicit advice, or through sharing lived experience of how they managed:

Some participants had longer experience with fibromyalgia and were able to share their own knowledge of different medications or other treatment modalities in the peer group. The peers also gave practical advice for managing the difficulties in everyday life, such as how to deal with sleeping problems or how to cope with the constant pain. -Sallinen et al., 2011

everyone emphasized the great value of self-help groups, where they would experience both understanding and benefit from the exchange of information and experiences. - Al-Qadi et al., 2021

Lived experience appeared to be a vital element of improving individuals' self-management; often peers' experiential knowledge was valued more than professionals' theoretical and clinical knowledge:

"*I decided to ask you because I admit to having minimal trust in doctors and would like a comparison with direct experiences*" -Cipolletta et al., 2020

Although information given by professionals was highly appreciated, the experiential knowledge of peers was perceived as essential to make the information easier to understand and digest. -Sallinen et al., 2011

Often, confidence was increased through comparison to peers; when PLF compared themselves to peers whom they perceived were in a worse position than them, they felt empowered and reassured at how they were managing:

"this experience was helpful to find out that there are many people in worse conditions than me. In this sense, I realized that I am not handling it as bad as I thought." - Arfuch et al., 2022

"Knowing others helps me realize that my case is not so serious. ...But, when I am alone, I tend to think that I can never bear this. Seeing others helps me view myself relatively and gives me some comparisons to see where I am." - Homma et al., 2015

Analytical Theme 3. Peer social learning

This analytical theme extends the theme "motivation to keep going" and considers how peers seem to motivate one another through social learning. PLF seem to become more determined by observing, role modelling and imitating their peers' successes:

Some of the women had participated in a local fibromyalgia group as a peer supporter after the rehabilitation course because they thought it was important for the 'beginners' to see others who have managed to cope with the illness and to give hope. - Sallinen et al., 2011

Descriptive Theme 3. Peer groups can be negative

Despite the benefits of peer support, some studies highlighted the drawbacks, suggesting it is not a wholly positive experience for all PLF. Some studies identified individuals who found peer groups spread negativity, rather than hope or support. Others found it distressing to hear about the difficulties of the condition:

"Being in a group was rather depressing because you found that there would be whiners who couldn't put up with any pain and didn't put themselves forth to do anything, and just complained and complained...and so...it wasn't a good idea for me anyway to be in a group. It pulled me down." -Cunningham and Jillings, 2006

she became more distressed when listening to the others' suffering [...] "No, it wasn't fun. You find that other people also have a hard time [...] I wanted to hear that they were well, that they had found something"- Mannerkorpi and Gard, 2003

In addition, it was identified that not everyone felt comfortable to share, and some found it difficult to speak openly with peers:

The third subject, a native Swedish woman, was also feeling down and she chose not to open up to permit closer contact with the other participants. [...] "I was doing quite badly at that time, so I did not want to make that much contact with anybody, but I think I was mostly in my own world. They were nice, the girls, but we never really talked, no, not like that." -Mannerkorpi and Gard, 2003

"In the groups, for example, I always take the role of the funny guy. It is my shield. I am not that expressive." -Arfuch et al 2022

There were concerns around misinformation or endorsing strategies which would not be in line with professional advice, particularly the studies exploring online sources of peer support:

Occasionally, group members posted information with a less credible scientific basis (e.g., article claiming fibromyalgia pain stems from excess blood vessels in the hands) - Crump and LaChapelle, 2022

Practical issues were raised by some; PLF felt the groups were too large, or time was limited, which meant they did not always feel they were heard:

"The problem was the lack of time to delve a little deeper into the different topics. Moreover, because each person had things to say and issues to share, and there was not enough time for everybody." - Arfuch et al., 2021

Analytical Theme 4. Peer support must be just right

There were several reasons why peer support was experienced in an unhelpful way in the theme “peer support can be negative”. Therefore, it seems that there are subtleties to the various factors which contribute to an optimal experience of peer support for PLF:

“I needed to get out of a group of sick people. Here [in gym] all people have fibromyalgia like me, but this is a group that tries to get out of it. There are persons in the group that have a very good mood and they spread this joy. Before, in the groups with psychologists, I was fed up of being with people completely down, who only went to complain ... then I went down more and more.” -Beltran-Carillo et al., 2013

Confidence in Review Findings

The GRADE-CERQual (Grading of Recommendations Assessment, Development, and Evaluation - Confidence in the Evidence from Reviews of Qualitative Research) (Lewin et al., 2018) approach was used to assess confidence in each of the review findings. The GRADE-CERQual uses four steps to assess the review findings, including:

- Methodological limitations: the extent to which concerns were raised about the design or conduct of primary studies which contributed evidence to a review finding.
- Coherence: how clear, well supported and compelling the data from primary studies fits with a review finding.
- Adequacy of data: the richness and quantity of data from primary studies which supports a review finding.
- Relevance: the evidence from primary studies which support a review finding is applicable to the context of the review question.

Each review finding was assessed using these four steps, and an overall confidence description has been indicated in table 4. Lewin et al. (2018) suggest the following confidence descriptions:

- High confidence: It is highly likely that the review finding is a reasonable representation of the phenomenon of interest.
- Moderate confidence: It is likely that the review finding is a reasonable representation of the phenomenon of interest.

- Low confidence: It is possible that the review finding is a reasonable representation of the phenomenon of interest.
- Very low confidence: It is not clear whether the review finding is a reasonable representation of the phenomenon of interest.

Table 4

GRADE-CERQual Evidence Profile

Summarised Review Finding	Studies Contributing to Review Finding	Methodological Limitations	Coherence	Adequacy	Relevance	GRADE-CERQual Assessment of Confidence
Descriptive Theme 1. PLF found peer support provided a positive community where they received non-judgemental support and care, allowing them to feel they belonged and were understood. This contrasted with experiences with others who do not live with fibromyalgia.	16/17 studies. One did not contribute: Al-Qadi et al., 2021	**Minor concerns** Eight studies with minor methodological limitations. However data was equally weighted between studies.	**No / very minor concerns** The majority of studies contributed to this finding, with consistency in the data around belonging, feeling understood and supported with peers, while other people did not provide this	**No / very minor concerns** Data were rich and provided sufficient quantity from which to draw findings.	**Minor concerns** All studies took place outside of the United Kingdom and therefore caution should be made around cultural sensitivity when applying the finding.	**Moderate Confidence**

Analytical Theme 1. Peer support was beneficial to PLF and this was emphasised by the opposing negative experiences with others.	15/17. Two did not contribute: Al-Qadi et al., 2021; Traska et al., 2012	**Minor concerns** Seven studies with minor methodological limitations. However, data was equally weighted through studies.	**No / very minor concerns** Data frequently referred to the benefits of peer support in contrast to experiences with others.	**No / very minor concerns** As above.	**Minor concerns** As above.	**Moderate Confidence**
Analytical theme 2. Negative experiences with others and positive experiences with peers created a maintenance loop whereby expectations of both were fulfilled.	15/17. Two did not contribute: Al-Qadi et al., 2021; Traska et al., 2012	**Minor concerns** As above.	**Moderate concerns** The interpretation in this finding is somewhat supported by the data from several studies, however, is a hypothesis which requires further research to support.	**No / very minor concerns** As above.	**Minor concerns** As above.	**Low Confidence**
Descriptive theme 2. Peers provided motivation to continue to manage fibromyalgia through encouragement, advice, sharing of strategies and increased confidence.	14/17. Three did not contribute: Cunningham & Jillings, 2006; Granero-Molina et al., 2018; Traska et al., 2012	**Minor concerns** As above.	**No / very minor concerns** Several studies contributed to this finding, with consistency in the data. It reflects the	**No / very minor concerns** As above.	**Minor concerns** As above.	**Moderate Confidence**

			various factors influencing motivation via peer interaction.			
Analytical theme 3. PLF learnt from their peers how to manage life with a complex condition, through observing and imitating them.	14/17. Three did not contribute: Cunningham & Jillings, 2006; Granero-Molina et al., 2018; Traska et al., 2012	**Minor concerns** As above.	**Minor concerns** Data were consistent in that peers provide learning opportunities, however there were additional reasons which could account for increased motivation to manage fibromyalgia.	**No / very minor concerns** As above.	**Minor concerns** As above.	**Moderate Confidence**
Descriptive theme 3. Drawbacks of peer support included negativity, hopelessness, feeling unable to share, sharing of misinformation and practical issues.	11/17. Six did not contribute: Al-Qadi et al., 2021; Bravo et al., 2018; Cipoletta et al., 2020; Granero-Molina et al., 2018; Juuso et al., 2014; Traska et al., 2012	**No or very minor concerns** Five studies with minor methodological limitations. However data was equally weighted through studies.	**Moderate concerns** Six of the 17 studies did not contribute to this finding; data indicated varied drawbacks which were not reported in every study which did contribute.	**Moderate concerns** Although quantity was not an issue, variation in the studies resulted in limited depth of data.	**Minor concerns** As above.	**Low Confidence**

Analytical theme 4. There are subtleties to peer support which contribute to making it either a positive or negative experience for individuals.	11/17. Six did not contribute: Al-Qadi et al., 2021; Bravo et al., 2018; Cipoletta et al., 2020; Granero-Molina et al., 2018; Juuso et al., 2014; Traska et al., 2012	**Minor concerns** Five studies with minor methodological limitations. However data was equally weighted through studies.	**No / very minor concerns** This interpretation reflects the variation in the data around the benefits and drawbacks of peer support for PLF.	**Moderate concerns** This finding may be oversimplified due to the limited depth of data.	**Minor concerns** As above.	**Low Confidence**

Discussion

This thematic synthesis of qualitative research identified three descriptive themes with five subthemes which described how PLF experience peer support, and four analytical themes which considered the impact of this. This review indicates that mostly, peer support is a positive resource for PLF, providing understanding, empathy, encouragement and belonging, corroborating similar findings from reviews exploring peer support for other long-term health conditions (e.g., Grant et al., 2021). Some drawbacks of peer support were identified, including feelings of hopelessness, difficulty sharing, misinformation, and practical issues.

The first descriptive theme “the contrast of peer support versus others” highlights the benefits of peer support for PLF. The subthemes describe experiences of validation and non-judgement, which contrasts with existing literature around PLF finding others (both lay and professional) disbelieving and perceiving them to be complaining (Diviney and Dowling 2015, Rodham et al., 2010; Hayes et al., 2010). As such, the analytical theme “the benefits of peer support are emphasised by the drawbacks of the outside world” demonstrates how peer support might be experienced as extremely positive due to what it provides compared to frequently described negative experiences with others. This analytical theme could be understood through social identity theory, which proposes how individuals establish those they share a collective identity with as the “in-group”, and those who oppose this as the “out-group” (Tajfel, 1978; Tajfel & Turner 1979). Given the subtheme “a sense of community, belonging and a shared identity”, it seems that peers are strongly identified with, versus opposing experiences with others.

Social identity theory may also link with the second analytical theme “others don’t understand: a maintenance loop”; once the “in-group” is established, this tends to be viewed with a positive cognitive bias, versus a negative cognitive bias for those in the “out-group”. There are ample evidence around negative healthcare experiences for PLF (e.g., Mengshoel et al., 2017). Therefore, the maintenance loop considers how past experiences may prime future experiences, and expectations may be fulfilled perhaps with some level of confirmation bias (Mynatt et al., 1977) which maintains healthcare challenges. This may not be unique to fibromyalgia; similar findings by Gigler et al. (2022) show how adolescents’ expectations of healthcare can be influenced by previous negative experiences. The analytical theme hypothesises that peer support provides a haven for PLF, which whilst a positive resource, continued negative experiences with others may reinforce possible polarisation of healthcare professionals from PLF.

The finding “others don’t understand: a maintenance loop” supports the recent work of Byrne et al. (2023) who describe a similar cycle in their synthesis, whereby factors such as lack of knowledge and understanding, and differing expectations in primary care led to an exacerbation of the difficulties between PLF and general practitioners. In the review, resistance, and resentment toward one another is described, possibly signalling preconceptions and confirmation bias within appointments (i.e., doubts about fibromyalgia or beliefs that PLF are “soft”). Furthermore, Rowe et al. (2019) indicated a relationship which seem to perpetuate negative experiences for PLF and may support this analytical finding; in their research, mistrusting attitudes toward healthcare professionals were negatively related to treatment adherence, physical and mental health. Mistrust and apprehension are demonstrated by the present review, particularly in the theme “motivation to keep going” whereby some PLF valued advice from peers more so than from professionals. Possible apprehension may therefore also be an important factor to consider in understanding the maintenance loop of negative healthcare experiences versus positive experiences within peer support.

Some evidence may refute the hypothesis of a maintenance loop, and so this finding must be interpreted and applied with caution. While the review adds to the literature in an under researched area, the scope did not allow depth to sufficiently support this interpretation. Indeed, the theme “peer groups can be negative” offers evidence to the contrary, in that peer support for PLF is not a wholly positive resource. As such, future research is necessary to explore the maintenance loop concept with both PLF and professionals as participants to understand their perceptions of one another. This would be helpful to learn more about the patient-professional relationship which has been shown to play an important role in long-term health conditions (Kornelsen et al., 2016; Ranque & Nardon, 2017). Furthermore, relationships are dynamic and a maintenance loop, while potentially useful as a conceptualisation tool, may oversimplify a complex phenomenon.

The descriptive theme “motivation to keep going” encompasses two subthemes indicating how peers provide encouragement, empowerment and improve self-management of fibromyalgia. The analytical theme “peer social learning” suggests that the impact of peer support is positive, when others are received as role models, or in it together (perhaps part of the “in-group”). Bandura’s social learning and modelling theories suggest that people observe, model and imitate the behaviours of others, and this is more likely to be effective when others are perceived to be similar (Bandura, 1971; 1972). The findings show how peers are easily identified with and strong connections are built, which would encourage positive change when considering how self-efficacy and self-determination can be increased through vicarious experiences provided by social role models (Bandura, 1994; Stenberg, 2022). These processes encourage individuals to feel more in control and able to manage challenges, for example self-management strategies or medication adherence, which is in line with evidence exploring the benefits of peer support in other long-term health conditions (e.g., Elafros et al., 2013; Peterson et al., 2012; Brownson & Heisler, 2012). However, the descriptive theme indicates that there may be various methods through which peers motivate one another, rather than solely through social learning and therefore this analytical theme highlights only one aspect. It is also important to consider that comparing oneself to peers can be done through upward, or downward social comparison (Festinger, 1954), which may impact on how beneficial peer support may be (e.g., Cabrera-Perona et al., 2017). In addition, although this theme identified how peers provide positive social learning, the theme "peer groups can be negative" demonstrates how peers may share unhelpful experiences or information, which may lead to negative social learning (Bandura, 1971). This again, may cause distance between PLF and healthcare professionals, for instance as demonstrated by Crump and LaChapelle (2022): "These archaic uninformed "Drs" need to get with the program. Don't put up with their smug BS" (p.104).

The final descriptive theme "peer groups can be negative" identifies several factors which may influence how beneficial peer support might be. Despite other themes demonstrating how sharing experiences can be validating, this could also induce distress or hopelessness, which has been mirrored by other research exploring peer support in long-term health conditions (Mazanderani et al., 2012; van Uden-Kraan et al., 2008). Scott (2011) suggests peer relationships need emotional engagement to create safety and this forms beneficial experiences; alternatively, some PLF were unable to share, describing vulnerability at being honest with peers. Watson (2017) reviewed relevant literature and indicated that peer relationships are dependent on context, and each element which provides benefit can equally have negative consequences. This links with the analytical theme "peer support must be just right", whereby individual and contextual factors mean it is not an unconditionally positive resource for PLF. Some practical issues such as availability and time may be easily rectified, however more subtle factors are not as easily managed. This review did not identify evidence to understand whether there are particular PLF for whom peer support is not beneficial, rather, that peer support may be experienced as both positive and negative and there are several factors which may influence this. Some included studies suggest initial ideas for improving peer support, although these factors may be unique to individuals and relate to specific group dynamics. Therefore, future research with PLF may help to understand the subtleties of peer support within specific contexts. Participatory action research may be necessary to provide space for the voices of PLF to be heard, while contributing to tangible change within services (e.g., NHS, 2023). At a more systemic level, peer support may become embedded into healthcare for PLF through combining existing evidence with quantitative randomised controlled trials examining outcomes of peer support interventions. This will contribute to policy and guidance such as NICE guidelines, which currently recommend group intervention for chronic primary pain but make no reference to peer support and the value it can offer (NICE, 2021).

While not identified within this review, research has suggested a link between fibromyalgia and experiences of psychological trauma (e.g. Yavne et al., 2018). The subthemes “a sense of community, belonging and a shared identity” and “non-judgemental support, empathy and compassion” may also relate to safety provided within peer groups, for example research has indicated respect, hope and empowerment within peer groups for trauma survivors (McCormack & Katalinic, 2016). Future research may seek to explore the possibility of this factor in peer support for PLF. This may offer further insights into the patient-professional relationship, in providing rationale for trauma informed care within healthcare for PLF.

Limitations

While the findings of this systematic review further understanding of peer support for fibromyalgia, there are some limitations. Firstly, medical subject headings (MeSH) were not used within the search, and therefore important publications may have been overlooked. Despite this, the search was extensive, using key words and searching reference lists. Only qualitative evidence was included in this review, meaning that additional information may be gathered from quantitative research. Although key databases were searched, only 17 papers were included, and it is possible that other search strategies may have identified additional papers. A strength of this review was that findings were based equally throughout each of the

17 papers. Despite this, none of the included studies were based in the United Kingdom (UK), meaning that social and cultural differences, as well as medical practice are likely to differ in other countries and regions. Caution must be taken when generalising these findings to the NHS in the UK. In addition, only studies published in English in peer-reviewed journals were included, and therefore additional evidence in other forms and languages may contribute to new or alternative findings. As indicated by the CASP, the synthesised studies had various methodological limitations which should be held in mind when applying the review findings. The GRADE-CERQual evidence profile indicates findings in this review to range from moderate to low confidence, mainly due to variation or depth of the data, and methodological limitations of studies.

Conclusions

Peer support is generally experienced by PLF as a positive resource, providing support, compassion, understanding, a community, and motivation to manage the condition. There are several elements of peer support which contribute to an optimum experience and whilst beneficial for some, may also have negative consequences depending on individuals and context. Some PLF do not find peer support beneficial due to finding that others induce hopelessness, feeling unable to share, facing practical issues such as time limitations, and some identified the sharing of misinformation or unhelpful strategies. Some of the benefits of peer support may be related to peer social learning but are also emphasised due to difficult past experiences and perceived negative attitudes of others. The contrast between these may contribute to a maintenance loop of difficult experiences outside of peer support. Collaboration between PLF and healthcare professionals may help to break the hypothesised maintenance loop, and further research understanding clinicians' perceptions of fibromyalgia may help to improve healthcare experiences for PLF given the importance of the interaction.

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Chapter 3. Bridging Chapter

The systematic review identified three descriptive themes, including five subthemes, and four analytical themes. The empirical research is centred around the descriptive theme: “the contrast of peer support versus others” and its’ subthemes, as well as the two analytical themes linked to these: “the benefits of peer support for fibromyalgia are emphasised by the drawbacks of the outside world” and “others don’t understand: a maintenance loop”.

The descriptive theme “the contrast of peer support versus others” indicates how peer support for people living with fibromyalgia (PLF) can provide non-judgemental support, empathy and compassion, as a sense of community, belonging and a shared identity, as well as a sense of being understood. These positive aspects of peer support were difficult to separate from (and in fact highlighted by) the negative experiences PLF have had with others (including family members, friends and healthcare professionals). The first analytical theme encapsulates this idea and suggests that “the benefits of peer support for fibromyalgia are emphasised by the drawbacks of the outside world”. When considering the subtheme “only those living with fibromyalgia can truly understand”, this again highlights the stark contrast between peer support and PLF’s perception of others based on their past experiences. As discussed in other chapters, there is ample evidence demonstrating not only negative experiences from the perspectives of PLF (e.g., Mengshoel et al., 2017; Diviney & Dowling, 2015; Rodham et al., 2010), but also the negative attitudes from the perspectives of others (e.g., Roitenberg & Shoshana, 2021; Aloush et al., 2020; Briones-Vozmediano et al., 2018; Colmenares-Roa et al., 2016; Amber et al., 2014; Ghazan-Shahi et al., 2012; Hayes et al., 2010). Together, these subthemes contributed to the analytical theme “others don’t understand: a maintenance loop”, which considers how positive experiences with peers, and negative past experiences with others may prime future experiences. It is discussed that this is perhaps due to confirmation bias (Mynatt et al., 1977), or favourable opinions given to the “in-group”, versus a negative cognitive bias for the “out-group” (Tajfel, 1978; Tajfel & Turner 1979). As such, there may be concern, apprehension, or mistrust around interactions with others. So, unfortunately when others are either unhelpful and judgemental (as suggested by the literature), or are *perceived* to be unhelpful and judgemental, this reinforces the belief that only those living with fibromyalgia can truly understand, and further contributes to the distance between healthcare professionals and PLF.

It is evident that individuals' attitudes can influence the course of an interaction (e.g., Ajzen et al., 2018; Fitzgerald & Hurst, 2017). Given the idea of the maintenance loop within the analytical theme of the systematic review, it may be useful to focus on the perceptions of clinicians, in order to understand one of the key possible maintaining factors around the difficult experiences PLF tend to report around healthcare. Gaining further insight into this area may offer to support or refute the maintenance loop hypothesis and may help to guide clinical implications.

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Chapter 4. Empirical Research Project

What are Pain Clinicians' Perceptions of Patients Living with Fibromyalgia, and does this Influence the Patient-Professional Encounter? A Qualitative Study

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Abstract

People living with fibromyalgia often report difficult and distressing experiences in healthcare, including not feeling believed or listened to, and being faced with limited treatment options. Clinicians' attitudes and beliefs have been shown to influence healthcare experiences for people living with fibromyalgia, however no research to date has explored specialist chronic pain management clinicians' perceptions of fibromyalgia, using in-depth qualitative interviews. The aims of this research were to understand why there may be challenges and how to overcome these, through exploring clinicians' perceptions of fibromyalgia and the influence of these on the patient-patient professional encounter. 12 clinicians from three National Health Service chronic pain management centres in the United Kingdom were interviewed. Reflexive thematic analysis was used to develop three themes: "fibromyalgia as a personal challenge", "wanting to get it *right*", and "overt and covert narratives" with two subthemes "looking beyond the label" and "beneath the surface of the interaction". The findings suggest that participants perceived fibromyalgia as a challenge, striving to provide positive and equitable healthcare experiences despite limited intervention guidance and unhelpful ideas surrounding the condition. This research considers how equity and allyship may be appropriate and useful for the care provider and service-user relationship. Recognising and confronting unhelpful beliefs, as well as ensuring a compassionate stance based on knowledge and understanding of the condition is likely to be beneficial to both clinicians and patients.

Key words: Fibromyalgia, chronic pain, clinicians, perceptions, interaction, healthcare

Introduction

Our understanding of fibromyalgia is ever evolving, due to the complexity of the condition. Despite progress over recent years, diagnosing and treating fibromyalgia remains an area of uncertainty (e.g., Wolfe et al., 2019; Fernández-Ávila et al., 2020). For diagnosis, other conditions must be ruled out before concluding that symptoms cannot be accounted for by any visible medical cause. Unfortunately, this can be a lengthy process, and often leaves people living with fibromyalgia (PLF) feeling their diagnosis is vague and meaningless, failing to provide credibility for their experiences (Boulton, 2018). For clinicians, diagnosing fibromyalgia can feel equally challenging as a diagnosis of exclusion can lack the certainty and rigour which medical professionals appear to strive for (e.g., Fernández-Ávila, 2020; Perrot et al., 2012).

Even when the confirmation of a diagnosis brings relief, this quickly turns into hopelessness when faced with limited treatment options and a lack of understanding from others (Mengshoel et al., 2017). There is no known cure for fibromyalgia, therefore treatment is based around managing the condition, initially through primary care, with possible secondary care referrals to rheumatology, neurology, and specialist pain management clinics. The International Classification of Diseases (ICD-11) classifies fibromyalgia under chronic primary pain (World Health Organisation, 2019), guidance for which emphasises a biopsychosocial approach, using conservative strategies as well as medication (National Institute for Health and Care Excellence [NICE] 2021). The NICE guidelines are generalised, applying to all chronic primary pain conditions, and are not specific to fibromyalgia. They indicate tentative recommendations of specific exercises and medications and highlight the importance of clinical and collaborative decision making. Concerns have been raised by the Faculty of Pain Medicine (2020) with respect to PLF being an extremely heterogenous group, resulting in tenuous treatment options for individuals. As such, both patients and professionals tend to agree that treatment is complicated and unclear (Busse et al., 2008; Briones-Vozmediano et al., 2013). This may be partly accountable for the overwhelming evidence base indicating that PLF tend to have negative healthcare experiences. Diviney and Dowling (2015) gave voice to PLF, who expressed that their doctors appeared to lack knowledge on their condition and did not seem interested or to understand them as individuals. Some clinicians indicated limited confidence with fibromyalgia (Perrot et al., 2012; Hayes et al., 2010); although these studies were some time ago and revisions have since been made to diagnostic criteria (Wolfe et al., 2016), a recent study suggested disparity remains between criteria and clinician-based diagnosis of fibromyalgia (Wolfe et al., 2019). Furthermore, PLF in several countries have expressed feelings of being scrutinised for being unwell and felt blamed for their lack of recovery (Mengshoel et al., 2017).

However, negative healthcare experiences for PLF are not solely due to ambiguous treatment options; *because* of the ambiguity, clinical judgement is essential and therefore the therapeutic exchange and psychological processes which underlie this may become a key part of fibromyalgia treatment. One study suggested the increased importance of the therapeutic relationship when facing medical uncertainty (Kornelsen et al., 2016), and Ranque and Nardon (2017) go as far to say that the clinician-patient relationship is key to recovery in medically unexplained symptoms. With regard to fibromyalgia, the therapeutic alliance has consistently been associated with positive outcomes (Varinen et al., 2022; Grahl et al., 2022), suggesting the importance of the interaction. Matthias et al. (2010) also emphasised a good patient-provider relationship in chronic pain services, whilst highlighting some of the practical and emotional challenges for clinicians which may impede this. The therapeutic alliance is built through several elements, including trust, collaboration, and mutual respect (e.g., Pinto, 2012). However, these may be dependent on clinicians' perceptions of the person and the condition they live with; for fibromyalgia, this may be a particular challenge given its uncertain aetiology. Perhaps because of this uncertainty, research has indicated that healthcare professionals across several parts of the world (including the United Kingdom [UK]) question the validity of fibromyalgia as a legitimate physical condition, with preconceptions around psychological issues (Mengshoel et al., 2017; Colmenares-Roa et al., 2016; Amber et al., 2014; Ghazan-Shahi et al., 2012). As such, PLF have described feeling they must prove the legitimacy of their pain to clinicians (Rodham et al., 2010) which could impact on healthcare experiences.

A systematic review has highlighted how implicit bias in healthcare can reduce quality of care (Fitzgerald and Hurst, 2017). This is evident in fibromyalgia treatment; some clinicians believe PLF to be malingerers, for example the participants from a wide range of professional disciplines in studies by Briones-Vozmediano et al. (2018) and Hayes et al. (2010). It is important to note that these studies were based in Spain and Canada respectively, and therefore although they may reflect a Western perspective, expectations of how participants convey their experiences are formed through cultural norms. Considering further literature outside of the UK, some evidence has shown how patients feel more concerned, but less able to be honest about their health when they perceive their clinician to lack empathy

(Aloush et al., 2020; Eide et al., 2011). Furthermore, mistrust of clinicians has been negatively related with treatment adherence and quality of life in PLF (Rowe et al., 2019). This means a difficult patient-clinician relationship could result in PLF being limited in their opportunity to improve symptoms, and this is corroborated by research exploring other chronic health conditions including obesity and HIV; negative biases from healthcare providers in America are associated with interpersonal behaviour, quality of care, and decision making for treatment (Kay et al., 2018; Phelan et al., 2015). Preconceptions may also impact on access to services for PLF, clinicians from various geographical areas (including the UK) were described as "gatekeeping" services according to their behaviours and beliefs (Doebl et al., 2020) and a study based in Israel found that 47% of rheumatologists refused to accept referrals for consultations for PLF due to the difficult doctor-patient relationship (Aloush et al., 2020).

Similar findings around refusing fibromyalgia referrals have been shown by Agarwal et al. (2018) and Homma et al. (2016), concluding the rationale for doing so was clinicians' *frustration* at being unable to control the symptoms. Although clinicians' emotions may not be explicit within consultations, the personal impact of working with PLF can be inferred. Interestingly, clinicians' emotions in the context of interpersonal interactions have been suggested to be important in diagnosing fibromyalgia; UK guidelines encourage clinicians to reflect on the interaction and how it makes them feel, as "it is not unusual for consultations to invoke feelings of being overwhelmed… this can be useful information in itself and point towards FMS" (Royal College of Physicians, 2022, p.16). In the research, clinicians are often reported to feel frustrated, showing empathy for PLF when treatments are ineffective (Briones-Vozmediano et al., 2013). However, frustrations sometimes appear directed toward the individual, for example accounts from physiotherapists in Israel expressed wanting to "shake them and say: 'snap out of it already'" (Roitenberg & Shoshana, 2021, p.548). Although this study's sample size was reasonable (n=20), it only focused on one professional discipline in an Israeli population, and therefore there may be discipline and cultural aspects to consider when interpreting these findings. Negative attitudes are evident in the literature across disciplines (e.g., Briones-Vozmediano et al., 2018), however overwhelmingly the research is from outside of the UK and National Health Service (NHS). As such, findings must be considered with varying guidance and professional bodies in the context of social and cultural influences.

In the UK, specialist pain management clinics have been described by PLF as an extremely valuable resource due to the biopsychosocial expertise available within one service (Ashe et al., 2017). However, this study described PLF "fighting" for a pain clinic referral, and this is echoed by a national survey study, showing that specialist services for PLF are sparce and fibromyalgia care seems to be low priority within the NHS (Wilson et al., 2022). A recent review of healthcare for fibromyalgia highlighted the lack of an evidence-based model of care and indicated a strong rationale to develop a new model for fibromyalgia by exploring the different parts of the healthcare system (Doebl et al., 2020). Much of the clinicians' perspectives in the literature belong to rheumatologists and general practitioners (GP) (e.g., Zih et al, 2004; Agarwal et al., 2018), and Briones-Vozmediano et al. (2013) advise that future research should include other healthcare professionals. One UK study explored various clinicians' (physiotherapists, clinical psychologists, nurses, a pharmacist, an occupational therapist, an optometrist and a GP) attitudes of fibromyalgia using a Q-methodological approach and found supportive attitudes toward fibromyalgia (Scott et al., 2023). The first author (OF) consulted with Scott, concluding that in depth interviews may provide rich accounts to offer background to clinicians' attitudes. To this end, to the authors' knowledge, no existing research uses qualitative interviews to understand specialist pain management clinicians' perceptions of fibromyalgia. There are evidently nuances to managing fibromyalgia, and we may begin to understand these through research around perceptions of the condition and of the people living with it. Given that pain management clinics are potentially useful services for PLF, it is considered necessary to seek to understand specialist pain clinicians' perceptions of fibromyalgia in the UK. These may play an important role in offering understanding to NHS services around treatment and healthcare experiences.

Aims

The aim of this study is to gain insight into specialist pain clinicians' perceptions of fibromyalgia and those living with it, to understand if these influence the patient-professional encounter. An in depth understanding of how perceptions may underlie the challenges and successes may offer possibilities for wider healthcare with regard to clarifying misconceptions and biases to move toward open and positive interactions which benefit both patients and professionals.

Methods

Design

This qualitative study was conducted via in depth semi-structured interviews. The use of this method enabled a nuanced topic to be explored in greater depth.

Participants and Recruitment

Five members of the target participant group from an NHS chronic pain service volunteered to form preliminary focus groups to inform the inclusion and exclusion criteria, as well as to develop the topic guide. These five people did not work at the recruitment sites for this research. Focus groups took place via *Microsoft Teams* in June 2022. The systematic nature of multidisciplinary pain management clinics was highlighted and indicated the importance of gathering perceptions from staff of all disciplines. It was also felt that sufficient experience would need to be drawn upon by participants, and participants would need to be a fluent English speaker so their experiences could be conveyed and understood as intended. As such, the inclusion criteria were as follows:

- Clinicians in any professional discipline working at a pain management service

The exclusion criteria were:

- Clinicians who had not worked with PLF
- Clinicians working in the role for less than six months
- Clinicians who were not a fluent English speaker

Participants were recruited through purposive sampling from four NHS chronic pain management services across the East and Midlands of England. Gatekeepers were identified at each site, and consent was gained to enable the recruitment process. OF joined online team meetings for each service to introduce the proposed research and to share their background relating to the research. An email (appendix E) including an information sheet (appendix F) and poster (appendix G) was sent by gatekeepers to their team. Participants expressed interest by emailing OF who gave further study details, attached a consent form (appendix H), and arranged a time to conduct the interview.

The recruitment period lasted six months and 12 staff members who met inclusion criteria from three of the four recruitment sites consented to take part in the study. One site did not yield any participants, despite several attempts to recruit. The reasons for this were unknown, however the gatekeeper suggested several possible contributing factors, including time limitations.

Demographic information was gathered via the consent form. The length of time participants had worked in a pain management service ranged from 10 months to 37 years. Participants included four consultant anaesthetists, three occupational therapists, two clinical psychologists, two physiotherapists and one nurse. Seven were white British, one was white Irish, one was white British/other, one was British Indian, and two preferred not to disclose their ethnicity. Two were male, nine were female, and one participant preferred not to disclose their gender; their ages ranged from 38 to 72 years old. OF had no prior relationship with participants.

Data Collection

Having been developed collaboratively and piloted in the focus groups for relevance and sensitivity of questions, the semi-structured interview topic guide (appendix I) covered five main areas: immediate thoughts about fibromyalgia; the challenges; the pleasures; how interactions are approached; and feelings about fibromyalgia consultations. Information given by participants was responded to as and when important issues arose and questioned further when deemed necessary so that rich data could be gathered.

Data collection took place between February and July 2023. All semi-structured interviews lasted around one hour in duration and were conducted by OF via *Microsoft Teams* in private spaces, with no one else present for both the interviewer and participant. Interviews were audio recorded and transcribed concurrently via *Microsoft Teams'* automated transcription software. OF wrote in the reflective journal after each interview to record initial impressions and reflections.

Transcripts were anonymised immediately after the interview, then reviewed and amended for accuracy. These were returned to participants for comment and correction within a 10-day window and once finalised, audio recordings were deleted.

Data Analysis

Once all interviews were complete and transcripts finalised, data were imported into NVivo (a qualitative analysis software) and analysed using reflexive thematic analysis (RTA) (Braun & Clarke, 2019). No participants withdrew and therefore all 12 interviews were analysed.

A social constructionist epistemological stance was taken by the authors, meaning that multiple realities exist and are perceived based on individuals' unique experiences and context. Therefore, it was not the aims of the analysis to set out to find absolute truths, rather to provide interpretations of the data.

Braun and Clarke's (2006) six stage guidance for thematic analysis, and the RTA approach was followed (Braun & Clarke, 2019). OF read and reread transcripts to build familiarisation with the data. The transcripts were then coded line by line by OF for relevance to the research question using an inductive method, allowing meaning to be driven by the data. Semantic codes were used to keep as closely to the original data as possible; as per RTA, OF continually considered their assumptions and interpretations when forming the codes, recognising their active role in analysis. 125 codes were formed from the data. Themes and subthemes were developed through an iterative approach of collating similar codes. The research team deliberated the viewpoint of the codes, and the original data was returned to, to reach a consensus on how to represent this meaningfully in line with the research questions. Codes were rearranged and subsequent interpretations of possible themes were discussed and recorded over a period of weeks. Once consensus was reached, themes were formed, and names were agreed.

Throughout analysis, several steps were followed to ensure rigour, following Lincoln and Guba's (1985) framework for validity and reliability. The authors' frame of reference and experiences were acknowledged through prior discussions. This was recorded in a reflective journal which was cross-referenced during each stage of analysis, in line with RTA (Braun & Clarke, 2019). Further assumptions and ideas were recorded to provide transparency and auditability of decision making and subsequent interpretations. Rich and detailed extracts are used to provide readers the opportunity to judge credibility and applicability of the findings. All participants were invited to offer member reflections (Tracy, 2010), with one participant being able to offer their time and effort. They were asked to read the analysis at two stages, so they could give feedback on whether they felt the research questions had been addressed and whether the findings were conveyed in a sensitive, respectful way. Their feedback was considered, and amendments were made accordingly. Braun and Clarke (2023) suggest member reflections are an appropriate method of reflexive elaboration where verification of findings is not the purpose of collaboration with participants.

Ethical Considerations

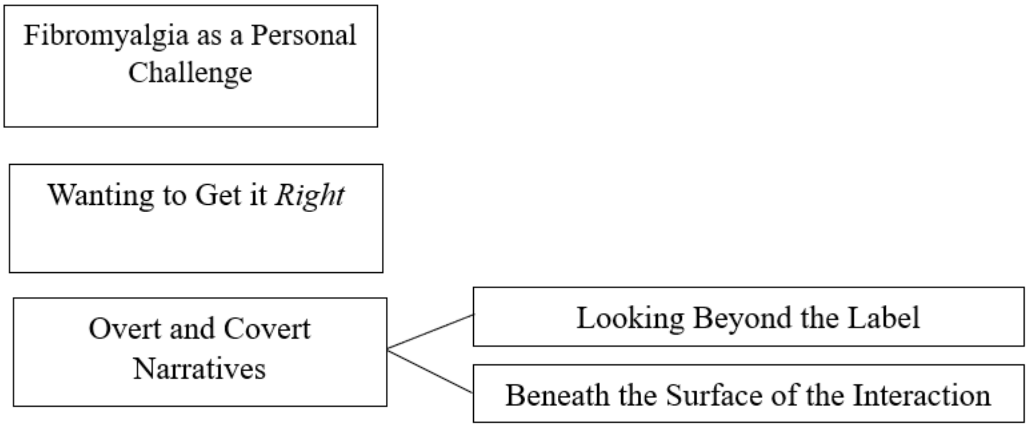
Ethical approval was granted by the University of East Anglia's Faculty of Medicine & Health Sciences Research & Ethics Committee (appendix J) and Health Research Authority (HRA) and Health and Care Research Wales (HCRW), REC reference 23/HRA/0086 (appendix K).

All participants provided written consent by signing the electronic consent form (HRA and Medicines and Healthcare Products Regulatory Agency, 2018) after having read the participant information sheet. Participants were aware that they could withdraw at any time prior to data analysis (August 2023). Interviews took place during working hours and therefore this was discussed at team meetings and participants were offered a £10 *Amazon* e-voucher as a token of appreciation for their time. All identifiable information was anonymised in the transcripts, and these were returned to participants to ensure they were confident that they would not be identifiable.

Findings

Three themes were developed from the 12 interviews, with one theme being made up by two subthemes, as outlined in figure 5.

Figure 5.
Thematic Map



Extracts are italicised, bold text indicates emphasised words, […] represents a small amount of omitted text, while … indicates a pause in speech. Text inside asterisks indicate non-verbal communication. Some information may be provided in brackets to provide context.

Theme 1. Fibromyalgia as a Personal Challenge

The participants discussed fibromyalgia as challenging to manage due to the broad impact of the condition, the guidance limitations and the need for clinical decision making. There was hope for guidance and treatment to be developed:

We still don't have a lot of research that gives us that hard evidence, that we would really love. We are getting guidelines that look at primary pain problems that recognise the fact that they are vague, and I would say fibromyalgia is the cheap example of that really. – Participant 9

Nine of the 12 participants discussed the pressure to provide a "fix" and during all interviews there were descriptions of fibromyalgia as "really hard", "stressful" and "difficult", suggesting frustration at being unable to help. However, this frustration was toward the complexity of fibromyalgia and the limited guidance, rather than toward the patient themselves:

I think -to make it far too simplistic- but it's not the condition, it's all that other stuff that goes around it that is the really stressful part. That's the hard stuff. [..]it's bizarre, almost *all the treatments that we offer along the conventional lines are very hard for fibromyalgics to access.* -Participant 1

Once you've tried everything, it's really hard because the barrier isn't necessarily the individual, it's the demands upon them and their circumstances. -Participant 6

It was suggested that participants *wanted* to help PLF, but the limited scope of medical interventions available resulted in them expressing feelings of disappointment or a lack of gratification:

...you have to have a lot of patience and understanding to be able to work with patients with fibromyalgia [...] whatever progress they make is extremely slow. And you don't get that "I did make a difference" type feeling. -Participant 5

*It's not easy. It's not like someone comes in and says "I've got pain in my shoulder" and I say "oh well, I'll inject it", easy-peasy lemon squeezy *laughs* [...] if someone goes away and says "you've been useless" -which they do sometimes- of course I'm disappointed.* -Participant 9

Similarly, participants gave powerful statements about the emotional response they felt when their patients (for various reasons) were unable to engage in self-management strategies. For some participants this evoked a sense of helplessness:

***Absolutely** there is an emotional response to that because the bottom line is, I **want** her to do what she wants to do.* -Participant 4

How do you manage that huge burden of patients coming to you? And they're coming to you with not just pain but suffering as well [...] sometimes there's just ones where you do feel truly powerless to really help. But then you have to just see yourself as just a witness to their pain and suffering. -Participant 1

Participants described recognising the difficult feelings they had around the challenges of managing fibromyalgia, and often they noticed that their approach in clinics was dependent on their mood, motivation and energy levels:

Sometimes I have less ability to be the cheerleader because of my tiredness. It's not very often, but just sometimes [...] there's times, because I'm tired I think "maybe I'm not going to hard sell this". -Participant 3

I suppose I'm quite passionate about what I do, within the energy levels I've got. -Participant 5

Being aware of their limits and the emotional impact of trying to manage fibromyalgia was expressed by many participants, and they discussed how they coped through self-reassurance and distancing themselves from their work:

I have to be able to let go of it. You have to empathise, sympathise, have compassion, but manage to switch off and maintain a distance when you're not speaking to the person. -Participant 11

*...you're shattered, exhausted, rolled over by a steamroller, certainly at the end of a **full** week of that [...] these things deplete your emotional bank balance **a lot** and you have to find ways of perhaps being a little bit less empathic and a bit more compassionate, and it's difficult... and knowing your limits and knowing the patients' limits* -Participant 1

We have to live with what we do. If you feel you've done your best for that person again, that's one of the lessons I think you learn as a (clinician) very quickly. You just have to do your best. And when you sleep at night, that's what you have to just remember. -Participant 8

Theme 2. Wanting to Get it ***Right***

10 of the 12 participants expressed awareness of negative past experiences PLF had, including in healthcare:

What I do find is there's a lot of distress involved when a patient of fibromyalgia finally presents to the pain clinic. More often than not, there has been at least once, if not more, lack of validation of the symptoms. -Participant 10

I think you have to be an advocate for someone as well, because people are coming feeling alienated or negative about some of the interactions they've had with medical professionals. -Participant 2

As a result of this, they described striving to offer an alternative, more positive experiences for PLF in how they approached their clinic, but first emphasised the importance of rectifying difficult or invalidating experiences people had:

Your interactions should have a degree of sensitivity. Which is appropriate to the circumstances for any consultation isn't it? But yes, undoing some of the damage, that is the one difference that's definitely there. -Participant 10

I guess on the one hand, I'm a bit kind of like "oh, I've got to undo all this." -Participant 3

One participant highlighted wanting to come across as "on their side", perhaps reflecting how the clinicians might be at pains to be perceived differently to others who have provided negative experiences:

...they might not have been listened to previously?[...] I listen to them, seem like I'm on their side. -Participant 11

All participants spoke about the importance of building alliance with their patients. They suggested this was a key element to working successfully with PLF due to the level of engagement required for self-management:

When you're validating the things they're saying. When people feel safe and they feel respected and understood, they're much more likely to engage because they believe, and they trust you. I think that's it. It's gaining people's trust. -Participant 6

Mostly it's a lot of listening and empathising I find. And only once they feel like "I can see a change" and they feel like they've been sufficiently heard and believed, built up enough rapport. They're ***then*** *prepared to engage with what I'm trying to offer.* -Participant 5

Again, participants appeared conscious of the possible hopelessness or concern PLF may have about their condition, and therefore many of them spoke about providing hope, so they could motivate their patients and give the best chance for them to improve:

*I say to them "four years ago none of us knew COVID existed. And here we are, four years later" and so I always give people **hope**. I think hope should always be part of the ingredients used.* -Participant 8

*I do say "if all I'm going to tell you is 'well, this is good as it gets and wish you all the best and bye now.'" I say: "I couldn't **be** in a job like that. I'm in this because I know people **can** make changes, people **can** improve their quality of life."* -Participant 3

Theme 3. Overt and Covert Narratives

The participants overtly expressed themes of not perceiving fibromyalgia as any different to other pain presentations, whilst also describing how they noticed covert ideas and assumptions about fibromyalgia which they consciously tried to put aside.

Subtheme: Looking Beyond the Label

During the interviews, some participants seemed to reject that their perceptions of PLF could be discussed as a whole due to how uniquely it affects each individual; half of the participants expressed their perspective that very disparate people could not be grouped into one homogenous group:

I have people who have fibromyalgia who run marathons and I have others that struggle to get out of bed and might spend eight hours a day in bed. So, there's huge variation, it seems hard to call it the same condition. -Participant 1

I can see five or six people in one day that have all got a diagnosis of fibromyalgia, for each of those people -there will be similarities, of course there will- but the effect it has on their life, how they feel about it, how they think about themselves will be different. The areas that are tricky for them are likely to be different for every single one of those people. -Participant 4

Throughout the interviews all participants discussed challenges but made clear that these were not unique to fibromyalgia, again indicating how they do not perceive fibromyalgia to be different to other conditions. They acknowledged how stereotypical narratives can be damaging:

That's sad actually, because that's not true. Really not true. You can have an awkward patient ***with*** *back pain, you can have an awkward patient* ***with*** *fibromyalgia and the problem is not the '****with****' bit, it's the 'awkward patient' bit. It's the human being, they're just challenging, and some people sadly are.* – Participant 8

there'll be people with fibromyalgia that make my heart sink. But then there'll be people with other kind of pains that make my heart sink. And there are people with fibromyalgia that I think "oh gosh, they're really engaged. Really moving forward" really, like I would for anyone else. So, I would get a varied emotional response from people with fibromyalgia, just like I would with anyone else with any other health condition. -Participant 7

Almost all the participants made explicit their neutral feelings about fibromyalgia. As such they expressed how they would not treat people with fibromyalgia any differently to anyone else, suggesting there is minimal difference in their interactions with PLF than with people with other pain presentations:

I guess I don't particularly think I see people with fibromyalgia any differently [...] I don't think that there ***is*** *particularly anything that you do differently* -Participant 2

I don't think I'd change what I do because of what it says on a piece of paper, that person's diagnoses. [...] Because I'm just having a conversation with somebody. So, how can it differ? I don't really know how it can differ. -Participant 12

To me -call them what you will- they deserve attention, and they deserve support [...] To me it doesn't make a difference to the way they should be managed or treated. -Participant 8

However, participants also discussed how they needed to consider adaptations, or felt that treatment as usual did not quite fit for PLF, which appears to be at odds with the overt narratives given:

...people with fibromyalgia didn't seem to find that (general pain management groups) met their needs. And the feedback we were getting was that they weren't really scratching where they were itching. – Participant 6

... maybe the interventions or the treatment needs to be adapted to meet their needs. - Participant 7

One participant demonstrated some uncertainty in their perceptions of fibromyalgia, or perhaps found it difficult to find the right words to discuss a potentially sensitive topic:

I'm not sure whether I could identify whether there's a difference. I guess just in general -well, I don't know though, I was going to say maybe in general people with fibromyalgia are... I don't know. – Participant 6

Subtheme: Beneath the Surface of the Interaction

Participants shared how despite similar considerations needed for all patients, they recognised there was *something* which made them feel there were additional factors to hold in mind during encounters with PLF:

I don't think it's just a fibro thing. But I think because we see more of them, I think they might get more of a -I don't know- label in our heads. We need to be careful that we don't ostracise them. -Participant 3

I wouldn't want anyone to have the message that pain is somehow not real. I mean it cuts across all pain conditions that I see, but I do think there is ***something*** *a bit different about patients with a diagnosis of fibromyalgia. And I don't know whether it's something to do with* ***how*** *it's diagnosed, that it's a diagnosis of exclusion.* -Participant 4

As a result, it seemed that the participants felt the interpersonal dynamics in their clinics were more important with PLF, and this was described as weighing on their minds prior to meeting new patients:

It's quite easy to sit there and think "they're not going to be on board, we're not going to achieve a rapport". So, there is a certain amount of worry at the beginning of a clinic. How are you going to get on with someone you've never seen before? What are they expecting? What can I do for them? And with fibromyalgia that's large really. -Participant 9

Participants shared how they may be susceptible to unhelpful ideas and assumptions about fibromyalgia, and highlighted how they tried to put these to one side so to not negatively impact on the interaction with their patients:

What I feel is it's not just the patient who carry their baggage into a consultation. The healthcare provider also carries their baggage. If I'm not convinced of the reality of struggles or reality of the pain, somewhere my body language is going to show that. My impatience is going to show itself. […] *maybe more flippantly we say, "oh this one's a heart sinker." When I'm going to meet a "heart sinker", who am I kidding? Is my body language not going to somewhere be showing?* -Participant 10

I'm trying not to make a judgement about (who I can help), because I know there's definitely research that suggests if clinicians have negative thoughts about patient outcomes, regardless of what the patient thinks, there's more likely to be negative outcomes [...] it's having awareness of biases that you might have in respect to that. But you suddenly can't switch that off, can't you? You can't switch it off in your brain. -Participant 12

One participant discussed how they try hard not to make assumptions about PLF:

I try really hard not to (make assumptions), but I can't prevent myself from doing it to some extent. But I try hard not to. -Participant 9

And later chose to return to this topic, possibly as the conversation allowed space for them to reflect or to be open about their experiences. They recognised that their preconceived ideas might play a more central role in their perceptions of PLF until meeting them in person:

*I'll be completely honest with you now, I do make assumptions. Of course I make assumptions *laughs*, but often someone comes through the door [...] they say "hi" and they smile and you think "ah, that's great." And that's real. Until you get past that point where you get that recognition of each other as human beings* -Participant 9

Other participants also spoke about *consciously* making an effort to ensure they are inclusive in their fibromyalgia clinics:

So, I consciously make an attempt not to you know, treat my patients in a different manner. -Participant 10

Similarly, one participant suggested they may have to put more energy and effort into clinics for PLF:

Participant: *I find I can be quite tired at the end of a session. It can make me fatigued *laughs*.*

Interviewer: *Okay, why do you think that is?*

Participant: *Maybe I'm working harder, I don't know… I don't know.* -Participant 12

Discussion

This qualitative research highlighted alternative clinical perceptions of fibromyalgia to those in existing literature (e.g., Mengshoel et al., 2017; Colmenares-Roa et al., 2016; Amber et al., 2014; Ghazan-Shahi et al., 2012), and corroborate findings by Scott et al. (2023), whereby respectful and supportive attitudes towards PLF were found via Q-methodology. This study extends Scott's findings, through offering possible understanding of supportive perceptions. Throughout the present study's findings, the participants described a desire, and a conscious effort made, to provide positive healthcare experiences for PLF. They expressed awareness of negative past experiences or stereotypes, and some recognised their own ideas and assumptions about fibromyalgia.

The theme "fibromyalgia as a personal challenge" demonstrates the personal and emotional response participants described when they felt unable to help their patients and suggested a genuine desire to move PLF forwards with self-management. These challenges appeared to be due to a lack of professional gratification as well as an empathic approach, feeling upset for their patients by how little could be done at times. This was partly a frustration at the limited research and guidance on how to manage fibromyalgia, and it became evident that it was the circumstances around fibromyalgia which made it feel difficult, rather than the patient themselves. This contrasts with evidence demonstrating dismissive attitudes from some healthcare professionals and the idea that PLF are "malingerers" (Briones-Vozmediano et al., 2018; Hayes et al., 2010) and corroborates findings from Ashe et al. (2017) who described how the validation PLF received at the pain clinic contrasted with interactions with other healthcare professionals. These differences may be due to cultural norms, as well as guidance bodies which may inform care in alternative ways in other countries, as this is the first study of its kind with UK pain clinicians. In addition, the sample in this research may have expressed a more empathic perception of PLF due to having specialist knowledge in chronic pain and working in a secondary care setting; some evidence has indicated how knowledge and understanding can help to reduce stigma in mental health (Simmons et al., 2017; Martínez-Zambrano et al., 2013), a phenomenon which may be applied to the present study. Indeed, Scott et al. (2023) also recognised the link between positive attitudes towards PLF and how pain clinicians' training emphasises a holistic mind-body approach to understanding pain (e.g., Butler & Moseley, 2015). Furthermore, those who have *chosen* to specialise in chronic pain are likely to feel more confident and have a better understanding of fibromyalgia; Perrot et al. (2012) identified that primary care clinicians were amongst those reporting the least confidence and the greatest difficulties in managing fibromyalgia, whilst secondary care rheumatologists were the most confident. Scott (2023) also suggested that this difference may be due to clinical exposure to PLF, which may help to dispel misconceptions.

Despite this empathic stance potentially offering PLF better healthcare experiences, participants described how investing empathy resulted in greater vulnerability to the emotional impact of the complex challenges. This led to hopelessness in some cases, and participants recognised the need to distance themselves from their work with PLF, a boundary required to avoid burnout (Demerouti, 2015), but also one which may feel uncomfortable given their desire to help. Although it was not explicitly stated in this study, it may be that clinicians pre-emptively create psychological distance between themselves and their new patients living with fibromyalgia, so to limit the personal impact.

Theme two, "wanting to get it *right*" highlights the participants' awareness of unhelpful beliefs and attitudes towards PLF and shows how they made efforts to seem "on their side". This again indicates their willingness to help, whilst emphasising the need for allyship and alliance through trust and active listening. Allyship has been considered an important element to address social inequalities, targeting oppression, implicit bias and microaggression (Sumerau et al., 2021). These ideas have been used in healthcare in the NHS (e.g., Iwu et al., 2022), and Noone et al. (2022) encourages clinicians to advocate for others and confront their own biases. For PLF, who experience healthcare inequalities as well as social ostracism, building allyship may be a key tool identified by the participants in this study to improve healthcare experiences. This also corroborates research demonstrating the power of the therapeutic alliance in fibromyalgia (e.g., Varinen et al., 2022; Grahl et al, 2022; Matthias et al., 2010) but offers a further layer in recognising PLF as a stigmatised group in need of allies. Despite not specific to fibromyalgia, it appears that healthcare providers are becoming more aware of inequalities their patients may face. Research advocating for equality is contemporary, whereas some research indicating negative clinical perceptions of fibromyalgia are from around 14 years ago, and therefore these perceptions may be outdated since understanding has progressed. Recent guidance by the Royal College of Physicians has made explicit that fibromyalgia is *not* “all in the head” indicating a move to discredit stigmatising ideas (Royal College of Physicians, 2022). The findings of the present study and other recent similar findings (e.g., Scott et al., 2023; Ashe et al., 2017) may reflect this shift in our understanding of fibromyalgia.

The final theme, “overt and covert narratives” identifies a conflict between not treating PLF differently based on their diagnosis and recognising internal judgements and extra considerations for fibromyalgia. The “overt” narratives within the subtheme “looking beyond the label” demonstrates how participants felt generalisations could not be made and therefore they discussed both treating PLF individually, as well as no differently to others. This is in line with contemporary findings highlighting improved outcomes for PLF when care is individualised (e.g., Kundakci et al., 2022; Stellman et al., 2023). However, it is also important to consider the findings with the caveat of social desirability bias. This can be common in qualitative research, particularly when the topic being discussed is potentially controversial or sensitive (Bergen & Labonté, 2020). Grimm (2010) suggests social desirability occurs when there are widely accepted attitudes or norms, and therefore perhaps participants’ portrayals may be linked to the theme “wanting to get it *right*”. They endeavoured to rectify poor past experiences for PLF, and this may have contributed to giving the impression that fibromyalgia was no different to other presentations. This appeared an honestly held belief but was incongruent with the idea that extra considerations were needed for PLF, as suggested in the subtheme “beneath the surface of the interaction”. There may be several reasons for this incongruence; on a conscious level, participants may have experienced dissonance between these conflicting ideas (Festinger, 1957), causing discomfort and encouraging responses which gave a more desirable impression (Paulhus, 1984). Alternatively, participants may have described opposing ideas due to an unconscious level of bias, for example, self-deceptive enhancement (Paulhus, 1984) or implicit bias (Greenwald & Banaji, 1995).

The subtheme "beneath the surface of the interaction" demonstrated how several participants felt there *was* something different about fibromyalgia, and there were extra considerations to be made. As such, the importance of interpersonal dynamics was considered, including references to process factors such and potential bias when bringing "baggage" into the room. It seemed that ideas and beliefs perhaps from others, or previous experiences with PLF might influence the interaction. For example, one participant discussed the effect on their body language if they were to think of their patient as a "heart-sinker". Additionally, this theme highlighted how participants reflected on possible judgments and assumptions they made, attempting to bring unhelpful ideas into awareness. They described consciously making efforts to avoid ostracising PLF, therefore inferring recognition of differences and additional considerations to be made. As such, the act of doing things especially for PLF, results in a contradiction of not treating PLF any differently (as described in "looking beyond the label"). Participants appeared to express the need for equality for PLF (in that they would receive the same treatment as others). However, their narratives describe an *equitable* experience, in that they consider more for PLF, so they have equal opportunity to having positive healthcare experiences. Aligning with the theme "wanting to get it *right*" and developing alliance, Pugh (2023) considers equitable healthcare to be a key part of allyship.

Clinical Implications and Future Research

The participants in this study highlighted their perceptions around fibromyalgia as a challenging condition which impacted on them personally, and as a result they noticed how they reassured themselves or sought distance from their work. Despite this, they reported how they wanted to make a difference to PLF by providing positive healthcare experiences. In order to maintain this balance, one participant recognised the need to be "*a little less empathic and a bit more compassionate*". McNally et al. (2019) emphasise the difference between empathy and compassion, suggesting empathy in healthcare requires the clinician to feel what their patient feels. Whilst valuable, this may become emotionally exhausting for the clinician; a recent meta-analysis identified the complex relationship between components of empathy and clinician burnout (Delgado et al., 2023), and this appears to be echoed by the present study. Instead, compassionate care is encouraged by the NICE guidelines for chronic pain (NICE, 2021) and is key to people feeling respected and understood in healthcare (Crawford et al., 2014). Indeed, compassionate and inclusive leadership is becoming increasingly emphasised within the context of the NHS (NHS, 2023). Finally, Perez-Bret et al. (2016) described compassion in healthcare as the understanding of another's suffering, and willingness to help and find a solution. Whilst a compassionate approach may be useful for the clinicians in this study, solution finding will no doubt be supported by further research on improving our understanding of and treatment for fibromyalgia (Wilson et al., 2022).

It was considered that specialist knowledge and understanding may be partly responsible for participants' supportive stance, and as such, further training and education on fibromyalgia could contribute to improving healthcare experiences. Research from Scott et al. (2023) and Perrot et al. (2012) supports this idea. Scott identified an attitude in their findings from participants who did not specialise in chronic pain management, around lacking confidence in specialist skills to support PLF. Perrot indicated over a third of their participants were not confident to treat and manage fibromyalgia, with over half feeling they had inadequate training on the condition. Additionally, considering this in line with compassionate care, Crawford et al. (2014) highlight how compassion may be improved in healthcare through training, as well as communication and collaboration.

Considering the findings as a whole, this study highlighted the meeting of external attitudes, beliefs, stereotypes, and negative past experiences, versus participants wanting to discredit and rectify these. This resulted in a conflict of recognising assumptions and making conscious efforts to treat PLF equally, while also not acknowledging differences within professional encounters with PLF. It could be hypothesised that this occurred due to a combination of complex processes; since this is an area which has not been explored, it is important that future research seeks to provide clarity, as evidence indicates how clinicians' perceptions can influence healthcare provision (Fitzgerald & Hurst, 2017), particularly in care for PLF (Doebl, 2020; Briones-Vozmediano et al., 2018; Hayes et al., 2010). Future research may identify possible psychological processes which underlie this conflict of ideas. For example, using methodology which would allow complete anonymity of participants and encourage less sociably desirable responses such as surveys or quantitative manipulation research.

Recognition of interpersonal dynamics and process factors have been an important element of the findings; bringing these ideas into awareness may encourage open discussions and induce positive change in healthcare for PLF. Opportunities for reflective practice may be useful to encourage awareness of covert narratives, as Noone et al. (2022) suggest, confronting personal biases is key to building allyship in healthcare. In addition, it is hoped that the findings demonstrate how the clinicians strive to provide positive healthcare experiences, and that making additional considerations or treating PLF differently is not negative or discriminatory, when the aim is to provide an equitable service.

Strengths and Limitations

This research was qualitative in nature and therefore a degree of caution should be taken when interpreting findings (Willig, 2017). The aims were not to infer absolute meanings to be generalised to a wider population, rather the authors' interpretations of the data may highlight issues that are relevant to healthcare clinicians working with PLF in a specific geographical area. Although recruiting from three different sites attempted to compensate for this, there may be differences with regard to the diversity of the sample, and the applicability of the findings to the rest of the UK and more broadly.

It is possible that the methods of recruitment meant that only those who held supportive views of fibromyalgia were willing to participate. This may have yielded skewed findings which did not reflect unhelpful attitudes previously demonstrated in some of the literature. In addition, the methods of data collection may have resulted in social desirability (Larson, 2019). It was considered by the authors whether focus groups may have given participants permission to speak more freely on difficult topics had they heard others with similar views to their own; alternatively, this may have resulted in a more guarded response so to not be perceived as controversial by others. Ultimately during the development of the research, interviews were deemed to be a more private space for clinicians to share their experiences.

Despite these limitations, the qualitative nature of this research allowed for depth in the findings and perceptions of PLF were identified which were new to the literature. This is important because the underpinnings of these perceptions have been considered and may offer clinical implications as discussed. Furthermore, the participant group included a range of professional backgrounds which may attempt to reflect the varied roles within a specialist pain multi-disciplinary team and therefore may be more readily applicable to service contexts.

Conclusions

The present study sought to consider specialist pain clinicians' perceptions of fibromyalgia, and whether these influenced the patient-professional encounter. RTA produced three themes, suggesting fibromyalgia was perceived as a personal challenge to participants, but partly due to the desire to do their best for people living with an often-stigmatised condition, with limited intervention guidance. Participants seemed to strive to look beyond the label of fibromyalgia, however recognised additional considerations they made, and the importance of interpersonal dynamics. Overall, the findings indicate these pain clinicians held a supportive perception of PLF. It is recommended that equitable provision of healthcare may be suitable, as well as building allyship and providing compassionate care. Future research may guide this through further exploration of the dissonance between not making assumptions based on labels, while also considering the additional needs of PLF. Further training to expand knowledge and understanding of fibromyalgia may be of benefit to provide positive healthcare experiences.

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Chapter 5. Additional Methodology and Design

This additional chapter aims to supplement the methods section of the empirical paper. The rationale for the methodology, ontology, epistemology, and analysis process will be discussed in further detail to provide justification for decisions made throughout the research.

Rationale for Methodology

Rationale for a Qualitative Framework

The aim of this research was to understand the perceptions of specialist chronic pain clinicians on fibromyalgia. As discussed within the introduction of the empirical paper, much of the existing literature highlights negative experiences people living with fibromyalgia (PLF) have received within healthcare (e.g., Mengshoel et al., 2017), as well as negative attitudes from clinicians, or limited confidence to work with PLF (e.g., Colmenares-Roa et al., 2016; Perrot et al., 2012). There were several reasons which indicated that understanding pain clinicians' perceptions of fibromyalgia would be valuable; firstly, it was identified that perceptions, attitudes, and beliefs can influence the patient-professional encounter in various health conditions (e.g., Kay et al., 2018; Fitzgerald & Hurst, 2017; Phelan et al., 2015). Quantitative methodology is useful when there are variables to be tested and compared, large samples to understand, and topics which can be generalised (Watson, 2015). Seeking to understand a personal, unique, and nuanced phenomenon such as individuals' perceptions, may be limited through quantitative research which would seek to quantify an answer with factual information (Hammarberg et al., 2016). Instead, this research allows for further exploration of a sensitive topic, acknowledges how dialectic perspectives may be held at the same time, and has freedom to explore this.

Secondly, pain clinicians' perspectives are lacking within the evidence base, despite one study from patient perspectives that experiences for PLF at specialist pain clinics were extremely valuable (Ashe et al., 2017). A qualitative approach seeks views on a focused topic, and in particular, use of semi-structured interviews creates opportunities for participants to discuss issues which are important to them, and questioned further when necessary (Alsaawi, 2014). It was therefore deemed that qualitative methodology would provide rich insight into an under-researched area.

During the development stage of this research, the primary author (OF) identified a research study via the Fibromyalgia Action website [FMA] (2015) by a Clinical Psychology Doctorate student at Staffordshire university. This study recruited clinicians from various healthcare services including primary care, rheumatology and chronic pain clinics, to explore their attitudes toward PLF using a Q-methodological approach, and has subsequently been published (Scott et al., 2023). OF met with Scott in May 2022 to discuss the findings of their research, and it was indicated that whilst supportive attitudes were found toward PLF, in depth qualitative interviews would likely provide background to, and further understanding of this phenomenon which contrasted with previous findings within the literature.

Rationale for Reflexive Thematic Analysis

Thematic analysis is a way of identifying, analysing and interpreting patterns within all features of a qualitative dataset (Clarke & Braun, 2017). Organising data into themes is accessible and therefore can be a useful starting point for an area of research which has not yet been explored. It has also been identified as a useful method for researchers early on in their qualitative research journey (Braun & Clarke, 2006). Willig (2013) argues that qualitative research design must be coherent, in that the method makes sense given the research question and the purpose of the project. Reflexive thematic analysis (RTA) (Braun & Clarke, 2019) is an approach to analysis of qualitative data which recognises the researchers' role in shaping and forming themes, through interpretations based on their theoretical knowledge, experiences and positionality. Braun and Clarke (2019; 2022) highlight the role of the researchers in creating and developing the codes and themes, rather than the themes "emerging" from the data as if pre-existing prior to analysis. The RTA approach is therefore aligned with the authors' social constructionist, interpretivist ontology and epistemology. Furthermore, RTA is flexible with regard to its epistemological and ontological framework and coding strategy (i.e., inductive or deductive), acknowledging the "inescapable" subjectivity in data analysis (Braun & Clarke, 2020), which would not be in line with a positivist, objective epistemology and ontology for example.

RTA was selected because the research aimed to gain an overview of the issue, being an area which had not yet been researched; alternative approaches such as interpretive phenomenological analysis (Smith, 1996) would have provided rich, in-depth case analyses which although useful perhaps once more research has been carried out in the area, was not deemed necessary at this stage (Pietkiewicz & Smith, 2014). The methodological approach chosen is appropriate for an anticipated sample size of more than 10 participants, and a heterogeneous sample (staff from various disciplines, with varying levels of experience), allowing for diversity to be captured across the dataset (Braun & Clarke, 2020).

Semi-structured Interview Topic Guide

The topic guide was developed in collaboration with five members of the target participant population during the initial stages of the research development. Three focus groups were carried out with a physiotherapist, occupational therapist, clinical psychologist, specialist nurse and a consultant anaesthetist, all working in a National Health Service (NHS) chronic pain management service. None of these clinicians were subsequently recruited as participants in the study.

During the focus groups, discussions took place around clinicians' general reflections on their clinical experiences of fibromyalgia to consider what could be important to explore further within the research interviews. They discussed challenges, as well as successes and pleasures of working with PLF, and acknowledged stereotypes and attitudes around the diagnosis. The clinicians also shared how they adapt their approach to support PLF in their clinics and noted how this impacted on them. OF considered what questions might be asked to draw out significant perceptions of fibromyalgia given the topics discussed within the focus groups, as well as having reviewed relevant literature. This helped to develop the initial topic guide with guidance from the research supervisors; questions needed to be specific enough to guide the conversation, but broad enough that participants had freedom to discuss what was important to them, rather than being led by the topic guide. The topic guide was then shared with the clinicians who gave feedback on the detail of questions, as well as the sensitivity. Minor amendments were made, and the topic guide was submitted with the research protocol for ethical approval. No amendments were requested during the ethical review.

Ontology and Epistemology

The authors' ontological stance is interpretivist, which suggests that phenomena between people as social entities are created from perceptions, and consequent actions

(Bryman, 2016). This ontological stance fits with the research background and aims to understand pain clinicians' perceptions of fibromyalgia, and whether these influence the patient-professional encounter. An interpretivist ontology acknowledges the social construction of meaning and how reality cannot be separated from an individual due to its subjective nature, which can change over time or contexts; this stance allowed the authors to hold in mind the complexity of people as social beings, and to consider multiple realities, whilst also recognising their own role within the research and how this would influence the course of the findings.

The authors' epistemological stance is social constructionist, which suggests that what we accept as reality is subjective and fluid. It is individually formed through experiences and social processes and understood in terms of social, cultural and historical context. This stance acknowledges the nuances of human experiences, and allows for interpretation of qualitative data, rather than to provide a generalisable and rigid perspective on a complex topic.

The ontological and epistemological stance were pertinent throughout the research; they influenced the methodology in terms of the approach taken and the tools used to acquire knowledge. They were held in mind during data collection and referred to throughout data analysis. For example, when considering multiple meanings a participant may have been attempting to convey, and when considering the purpose of multiple data coders and the value of member reflections. The research proposal made clear that data would not be additionally coded by another author due to the epistemology and ontology setting out that reality is subjective and bound by context. Therefore, seeking inter-rater reliability would have been inappropriate (Braun & Clarke, 2022). Additionally, member reflections (Tracy, 2010) were sought to consider whether the research questions had been addressed through the methodology and in the findings, and whether the findings were sensitively conveyed, rather than to seek confirmation or validity of the findings. OF was also careful to write both the empirical research and systematic review papers with the epistemological and ontological stance throughout, for example recognising the authors' roles within the research, acknowledging the subjectivity of the findings and ensuring candour in the applicability of the findings to wider contexts.

Enhancing the Quality of Analysis

Trustworthiness Framework for Qualitative Research

Lincoln and Guba's (1985) framework for validity and reliability of qualitative research was followed to ensure trustworthiness and rigour of the analysis process.

Credibility

Given the authors' social constructionist epistemology, recognition that multiple realities exist was key to the process of this research. The authors were aware that their experiences and own perceptions would influence the findings, and therefore discussions about these took place prior to data collection. The authors' preunderstandings of fibromyalgia and PLF were that it was a complex condition with multiple layers to understand. As such they reflected on their varied experience, at times expressing negative feelings associated with their skills and ability to best support PLF to self-manage the condition. The authors also considered their beliefs that fibromyalgia seems to form a strong part of identity, perhaps due to the long process of receiving a diagnosis and the key role of peer support groups, although there were ideas that peer support and fibromyalgia identity could form a bidirectional relationship. These viewpoints were recorded in a reflective journal and returned to following interviews to consider how they may have influenced the discussion, and during the analysis stage where assumptions and ideas which aligned with preunderstandings were discussed in research supervision meetings. This process helped to bring to the surface and hold in mind how interpretations may be subject to the authors' biases and encouraged discussions of alternative viewpoints.

Regarding the authors' experiences, all three are white British women, under 45 years of age, and have previous experience working in the same chronic pain management clinic in the NHS, under the discipline of clinical psychology. Although this research focused on a population within the NHS, it is important to consider that services have unique ways of approaching their caseloads and therefore the authors' experiences of working with PLF were likely to be different to clinicians from other services. Additionally, given that all three authors were female and white British, this may have impacted on recruitment and how participants were related to and understood; the majority of the participants in this research were also white British, and/or female. It is also important to note that most people diagnosed with fibromyalgia are female (Marques et al., 2017), and therefore the perspectives of the (majority) female participants and the interpretations of this by female authors were important to hold in mind. Finally, some of the authors' unique life experiences were discussed, for instance none had close friends or family members that they were aware had a diagnosis of fibromyalgia.

Dependability

Throughout the research process records were securely kept, ensuring a clear audit trail of decision making. For example, OF wrote their ideas and interpretations in the reflective journal during analysis of each transcript, and these ideas were discussed in research supervision meetings, with additional notes and new ideas recorded. During the coding stages of analysis, extracts were often given multiple codes in order to allow for multiple interpretations and were then refined using an iterative approach, returning to transcripts following discussions and subsequent coding. If inconsistencies arose within the data, these were flagged to ensure they were returned to and accounted for within the overall analysis. When coding trees and thematic maps were amended following meetings, previous versions were referred back to and kept to indicate changes based on researcher decisions.

Confirmability

As with a social constructionist epistemology, neutrality is not necessarily achievable and therefore emphasis was placed on confirmability of the results instead. This was ensured through prolonged involvement with the data, taking an iterative approach and ensuring original extracts were returned to when coding trees were created to develop overall themes. This approach helped to consider the meanings the participant was trying to convey, rather than basing analysis on the most recent interpretation. In addition, rich verbatim extracts were used to support the findings, although several extracts supported the themes, due to word limits it was only possible to include key extracts for each. Often, indications of how many participants' accounts contributed to a theme were included within the results section.

Participants' transcripts were returned to them and they were offered to provide comments and invited to be involved with the analysis process through member reflections (Tracy, 2010). They understood that this was not to ensure validity or "truth" of the results, but to help consider whether they adequately addressed the research questions, and to ensure these were sensitivity conveyed (Glesne, 2011). Braun and Clarke (2023) encourage this approach over "member checking", as it emphasises reflexivity and collaboration, over verification of findings, and does not infer a truth to be found. Two participants expressed interest, however due to other commitments, only one was able to contribute. This participant reviewed the analysis at two stages and following both, their feedback was considered and guided the next steps. The first review was following initial grouping of codes and development of preliminary themes. The participant felt that the coded extracts and preliminary themes “matched”. They acknowledged the positive attitudes apparent in the data and agreed that there may have been a sampling bias of those who were willing to participate. The second review was once themes had been further developed and extracts had been narrowed down to best represent the themes. The participants’ feedback indicated that the research question had been addressed, and they shared some of their thoughts around the sensitivity of how these had been conveyed. For instance, they felt a quote could be shortened to avoid embarrassing one of the participants, and this advice was followed.

Transferability

The aims of this research were not to be generalisable to other contexts, rather that the findings may be applicable to similar settings or groups. As such, participant demographics (age, gender and ethnicity) were gathered to give the reader an understanding of the types of participants involved and who the findings may apply to. Furthermore, the participants’ job roles were broadly reported, as well as the length of time they had worked in a specialist chronic pain management service. The participants covered a range of specialism duration, from 10 months to 37 years. Their roles covered many of the disciplines included in a chronic pain multidisciplinary team, meaning that the participant population may be a good representation of chronic pain clinicians. This is not to say that the findings are absolute truths to be applied to all similar services and populations, but that they may be transferrable and help to understand the phenomena. The settings were described as three NHS chronic pain management services in the East and Midlands of England, in order to give context to the findings.

Authenticity

The authors aimed to provide authenticity in their presentation of the participants’ accounts. The data collection method invited participants to discuss matters which were important to them and resulted in a variety of topics being explored within this research. Authors stayed close to the original accounts during analysis, using inductive coding to develop semantic codes. Several extracts were presented within the empirical paper and these offered rich insights into the participants' perceptions of fibromyalgia.

The Reflexive Thematic Analysis Process

Braun and Clarke's (2006) six stage guidance for thematic analysis, and the reflexive thematic analysis (RTA) approach was followed (Braun & Clarke, 2019). Transcripts were automatically created during the interview via *Microsoft Teams* however these were each meticulously reviewed whilst listening to the audio recording to ensure their accuracy and to remove identifiable information. This formed part of the first step of analysis, in becoming familiar with the data; additionally, OF read each transcript prior to coding, to immerse themselves in the data. Transcripts were imported into NVivo and each was coded line by line by OF, with the research questions held in mind. In line with the researchers' ontological and epistemological stance, an inductive approach was used so that the data could drive meaning, rather than a priori frameworks or theoretical perspectives. Despite this, assumptions and interpretations must always be made by researchers, as they take an active role in analysis (Braun & Clarke, 2019), as such, interpretations OF made about the data were considered and recorded in the reflective journal, and then discussed during supervision. Codes were semantic, to keep closely to the original data, however most lines were given more than one code, to allow different meanings to be considered. Once all transcripts were coded, each was returned to, to consider how newly developed codes might apply to earlier transcripts, and to ensure consistency of coding. See appendix L for an extract from a coded transcript as an example. The research protocol specified that a second data coder would not be used, given the social constructionist and reflexive nature of the research. Instead, when codes were collated (into coding trees), the research team deliberated over the viewpoint, and original data was returned to so that consensus could be reached on how this would be most meaningfully represented in line with what they *assumed* the participant was conveying. This was to provide rich and nuanced insights, rather than to verify meaning and themes (Braun & Clarke, 2022). For example, the code "feeling stuck" could relate to a theme about clinicians' frustrations at limited guidance, frustrations at patients, or the personal impact of working with PLF. The final 125 codes were arranged and rearranged individually by OF, during discussions with the research supervisors when subsequent interpretations of possible themes were considered and following member reflections. The researchers continually discussed their engagement with the data and their role in analysis; consensus was reached to form final themes. Names were agreed, and extracts were selected to best represent the themes. See appendix M for an example of a coding tree and how themes were formed.

Supervision

Once the research supervisors were confirmed, a supervision contract was drawn up and agreed; OF was provided with at least monthly supervision from the initial development stages of the research, through to completion of the thesis portfolio. This ensured that all researchers were up to date, aware of the current stage of the project and involved throughout. Supervision offered opportunity to discuss practical elements of the research process, as well as space to reflect, not only on the course of the research, but also on the personal impact at each stage. Decision making regarding the research at all stages was reliant on supervision to discuss and reach agreement. OF would consider each decision (for example from sample size and analytical frameworks, to agreeing theme names) through reading and the University of East Anglia's (UEA) qualitative forums, and these would then guide discussions in supervision. The supervisors offered advice, guidance and expertise within the areas of qualitative research and chronic pain. Supervision meetings were also heavily used for data analysis, with supervisors providing opportunity to discuss alternative viewpoints, to rearrange and reconsider codes and themes, and to refine findings. Records were kept by OF at each supervision meeting and then shared with supervisors. Further to monthly supervision meetings, the supervisors were available via email and offered ad-hoc support when necessary. Both research supervisors read drafts of each chapter of the thesis portfolio, providing feedback to refine final drafts.

Reflective Journal

OF kept a reflective journal throughout the research process, from the point of developing the semi-structured interview schedule, through to completion of analysis. An example of an extract from the reflective journal can be seen in appendix N. This was to assist with the reflexivity of the research (Braun & Clarke, 2019; 2022), to consciously acknowledge the authors' ideas, opinions, and assumptions so that they could be transparent in the research process, rather than attempting to "bracket these off" as in other methods of analysis (Ortlipp, 2008). This helped to inform the development of the research, as well as to guide the methodology chosen and contributed to an audit trail of decision making in the analysis stages. This was considered particularly important, as with qualitative research, the authors will inevitably influence the course of the research and the findings (Parker, 1999).

Ethical Considerations

Ethical Approval

Ethical approval was granted by the UEA Faculty of Medicine & Health Sciences Research & Ethics Committee (appendix J) and Health Research Authority (HRA) and Health and Care Research Wales (HCRW), REC reference 23/HRA/0086 (appendix K).

Consent

Gatekeepers (four clinical psychologists) were identified at each recruitment site and as per the research protocol, consent was gained from them via emails, confirming they were willing to take on the role. Once approvals were in place to commence recruitment, the gatekeeper emailed their clinical team to invite them to participate, attaching the participant information sheet (PIS) (appendix F) and a recruitment poster (appendix G). OF did not email clinical teams directly to avoid coercion or obligation to participate. Participants emailed OF to express interest, and 48 hours were given to allow participants time to read the participant information sheet before being sent the electronic consent form (appendix H), so that consent was fully informed. They were given the opportunity to ask questions about the study prior to consenting. As per Health Research Authority and Medicines and Healthcare products Regulatory Agency [HRA and MHRA] (2018) guidance, electronic signatures can include those which are typewritten. Participants were made aware and reminded at the interview, and during the debrief that they could withdraw consent at any point prior to data analysis.

Confidentiality

Participants were made aware via the PIS and reminded at interview that information they share would be confidential, unless it was deemed that they or another were at risk of harm, or if poor practice was disclosed. As per the research protocol, they were made aware that in these instances, the interviewer (OF) would discuss this with the participant and escalate to their supervisors. If it was deemed necessary, then the participants' line manager would be contacted to make them aware of risk or practice issues. Fortunately, these issues did not arise for any of the participants.

Participants were made aware via the PIS and reminded at interview about keeping patient information confidential. It was requested that no identifiable patient information was discussed, and pseudonyms should be used where appropriate.

Interviews were carried out remotely via *Microsoft Teams*; OF was the interviewer for all interviews and conducted these in a private space, either in a clinical room at an NHS site, or in the study of their home. No one else was present during interviews and all participants also joined in equally private spaces.

Participants interviews were transcribed by *Microsoft Teams'* automated transcription software. OF removed any identifiable information from the transcripts prior to saving these. Furthermore, transcripts were returned to participants and given a 10-day window to ensure they were satisfied that they would not be identifiable. Data was pseudonymised due to the use of participant identification numbers, which were agreed with the participant at the interview. This was to ensure that their participant identification numbers were not recorded on their consent forms and therefore matched with identifiable information. A small amount of identifiable information was gathered via the consent form, including participants' age, gender, ethnicity, job role and duration having worked in a chronic pain service. These demographics were reported broadly in the empirical paper, to preserve confidentiality.

Data Storage

All data for this research were stored on a password protected UEA OneDrive. Consent forms were stored in a separate password protected folder to minimise the matching of identifiable information to study data, in the unlikely event of a storage breach. Participant identification numbers were recorded on a database which was stored in a separate folder on the OneDrive.

All interviews were audio recorded, these along with transcripts were saved immediately in the OneDrive folder, and original recordings were deleted from the laptop recording device. Once the transcript was finalised and the 10-day window for participants to comment on their transcript had passed, the audio recording was deleted from the OneDrive.

As per the UEA's Information Classification and Data Management Policy, all information was shared between authors via the OneDrive, and a password was created to provide access. All authors complied with the requirements of the General Data Protection Regulation 2018 with regards to the collection, storage, processing and disclosure of personal information and upheld the Regulation's core principles. As per the University of East Anglia's (UEA) research data management policy, data for this research will be stored in the UEA data repository securely and destroyed 10 years after the study has ended.

Potential Burden to Participants

Participants were made aware of the scope and expectations of the research via the PIS. A potential burden of participants was the time taken for the interview (around an hour in duration) and often this was carried out during participants' work hours. Approval had been gained from service leads for this time to be protected, however as a token of appreciation and thank you for their time, each participant was offered a £10 *Amazon* electronic gift voucher, which was emailed to them after the interview.

Due to the potentially sensitive nature of the research, an anticipated possibility was that participants could feel some discomfort in answering all the questions. They were reminded that they did not have to answer anything they did not wish to, and that information was confidential. Additionally, participants were reassured at the initial team meeting which OF joined to introduce the research, and via the PIS that their views would be portrayed as sensitively as possible in the findings. The sensitivity of findings was checked and confirmed by one of the participants.

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Chapter 6. Discussion and Critical Evaluation

This thesis portfolio explored how peer support is experienced by people living with fibromyalgia (PLF) and the impact of this, as well as chronic pain clinicians' perceptions of fibromyalgia, and the influence of this on their interactions during healthcare appointments. This final chapter summarises the main findings of the empirical research and systematic review, before providing a critical evaluation of the findings. Lastly, clinical implications and future research are considered.

Summary of Main Findings

Systematic Review

The contemporary systematic review examined the research relating to peer support for PLF, to explore how this is experienced by individuals and the impact of this. To date, no systematic review of the literature has been carried out on this topic, focusing solely on fibromyalgia. Thematic synthesis (Thomas & Harden, 2008) was used to analyse the results sections of 17 empirical research studies, producing three descriptive themes with five subthemes, and four analytical themes.

The first descriptive theme "The contrast of peer support versus others" was developed from 16 of the 17 studies and indicated how peer support for PLF provided non-judgmental support, empathy and compassion, as well as a sense of community, belonging, and shared identity. This however contrasted with the lack of understanding others seemed to show, and the theme demonstrated frustration and sadness by PLF. As such, the benefits provided by peer support were extremely valued, and this contributed to the analytical theme "The benefits of peer support are emphasised by the drawbacks of the outside world". This analytical theme suggested that peer support is valuable in its' own right but is also emphasised due to the stark contrast between what it provides in comparison to a lack of understanding and sometimes negative attitudes from others. A further analytical theme "Others don't understand: A maintenance loop" hypothesised how the contrast in support from peers versus others' misunderstanding may contribute to a negative cycle which maintains difficult interactions with others, and positive interactions with peers.

The second descriptive theme "Motivation to keep going" was developed from 14 of the 17 studies and demonstrated how peer support provides PLF opportunities to improve the self-management of their condition, through sharing of advice and strategies, as well as by encouraging and empowering one another. As such, it was considered that the peers learnt from one another through experiential knowledge and mutual experiences, and this formed the basis of the analytical theme “Peer social learning”.

The final descriptive theme “Peer groups can be negative” was developed from 11 of the 17 studies and demonstrated some of the drawbacks of peer support, including PLF finding peer groups tended to spread negativity, not feeling able to share openly with their peers, the sharing of misinformation and practical issues such as time for discussion. The analytical theme “Peer support must be just right” considered how peer support for PLF is not a wholly positive experience, and several elements which may make it beneficial, may also present as barriers or disadvantages if not suited to individual needs or context.

Empirical Research

The empirical research provided new insights with findings in an area not previously explored. 12 chronic pain clinicians from three regional chronic pain management centres were interviewed to gain further understanding of their perceptions of fibromyalgia, and how these may influence their clinical encounters with PLF. Reflexive thematic analysis (Braun & Clarke, 2019) was used to analyse the interviews, and resulted in three main themes, with the final theme being made up of two subthemes.

The first theme “Fibromyalgia as a personal challenge” indicated how the participants wanted to help their patients living with fibromyalgia, but challenges such as the limited guidance and the complexity of the condition resulted in a personal, and emotional response. Participants described disappointment, frustration and helplessness, which meant their interactions with PLF were often dependent on their energy levels. In order to manage the challenges, participants described reassuring themselves, and maintaining distance from their work. This finding is in line with research by Briones-Vozmediano et al. (2013), whereby interviews with clinicians revealed their dissatisfaction and frustration with working with PLF, because of difficulties around finding effective treatment. This is in contrast to other research showing how some clinicians direct their frustration toward PLF, rather than the complexity of the condition (e.g., Roitenberg & Shoshana, 2021; Briones-Vozmediano et al., 2018).

The second theme "Wanting to get it *right*" demonstrated the participants' awareness of difficult past experiences PLF may have had, and therefore they described striving to offer an alternative more positive experience, through building the therapeutic alliance.

The final theme, "Overt and covert narratives" identified how the participants overtly expressed how they did not perceive fibromyalgia to be any different to other pain presentations (described in the subtheme "Looking beyond the label"), whilst also recognising covert ideas and assumptions about fibromyalgia which they made efforts to bracket off (described in the subtheme "Beneath the surface of the interaction").

Findings by Ashe et al. (2017) demonstrate how PLF found specialist pain management clinics extremely valuable, for example due to the expertise and support available. The empirical research in this thesis portfolio furthers our understanding of Ashe's work by offering the perspectives of the clinicians.

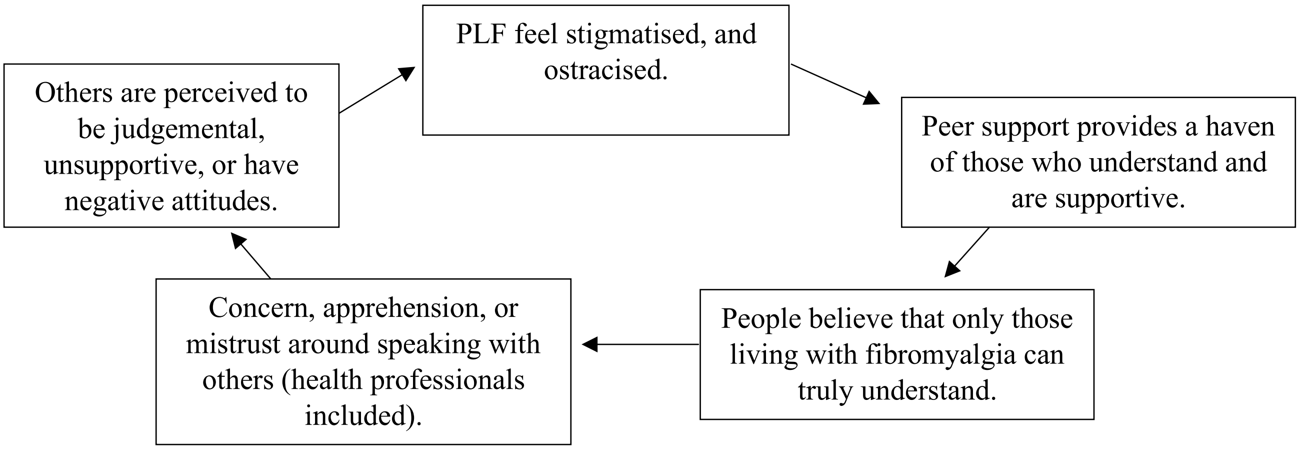
Discussion of Findings

Considering the findings from both the systematic review and the empirical research, there may be additional hypotheses to be drawn. Part of the rationale for the empirical research was to further explore the descriptive theme "The contrast of peer support versus others" and its' subthemes, as well as the two analytical themes linked to these: "the benefits of peer support for fibromyalgia are emphasised by the drawbacks of the outside world" and "others don't understand: a maintenance loop". Exploring clinicians' perceptions of fibromyalgia could be a key element to help understand why the evidence mostly points toward negative experiences for PLF in healthcare (e.g., Diviney & Dowling, 2015; Rodham et al., 2010).

The participants in the empirical research expressed empathic perceptions and supportive attitudes toward PLF, while recognising past negative experiences PLF may have had in healthcare, as well as how this may influence their own beliefs and assumptions about fibromyalgia. As such, the theme "Wanting to get it *right*" seems to link to the analytical theme developed in the systematic review "Others don't understand: A maintenance loop" (figure 6 demonstrates the maintenance loop described in the systematic review).

Figure 6.

A maintenance loop demonstrating a hypothesis around peer support experienced as positive, while others reinforce negative beliefs and expectations.



The participants in the empirical paper appeared to recognise how others might have provided unsupportive or judgemental experiences to PLF in the past, and in the theme "Wanting to get it *right*" describe a desire to rectify past experiences, by forming therapeutic alliance with their patients, thus attempting to break the maintenance loop. This is perhaps furthered by the subtheme "Beneath the surface of the interaction", whereby participants discussed making a conscious effort to avoid ostracising PLF, through awareness of unhelpful ideas and assumptions.

The empirical research discussed the importance of allyship in healthcare inequalities (which it appears PLF face e.g., Wilson et al., 2022), however it is important to be aware of how this may contribute to an "in-group" and "out-group" construct discussed within the systematic review (Tajfel, 1978; Tajfel & Turner 1979). Future research discussed below may help to address this.

Critical Evaluation

Both the systematic review and empirical research used qualitative methodology, due to the exploratory nature of the review and research questions. The thesis portfolio set out to gain further understanding of nuanced topics, which quantitative methodology may have been less likely to capture, as the primary focus for quantitative research is to provide definitive conclusions based on factual information (Hammarberg et al., 2016). This would not be in line with the authors' social constructionist epistemological stance. However, one of the limitations identified within the empirical research was the possibility of social desirability bias due to the way in which participants were recruited and data was collected (e.g., Bergen & Labonté, 2020). Semi-structured interviews offer opportunity to gain depth of information on a topic but removes anonymity of participants from the researcher and therefore may impact on their freedom to be openly truthful (Grimm, 2010). This may mean that only those who had positive perceptions of PLF to share were willing to participate, and / or that those who participated offered only socially desirable perspectives. As such, a quantitative methodology may have offered alternative findings, for example if participants were able to complete measures anonymously. Furthermore, Scott et al. (2023) used Q-methodology, a statistical approach to understand clinicians' perceptions of fibromyalgia, which allowed for nuances to be captured despite its' systematic approach. However, the first author (OF) liaised with Scott and agreed that qualitative interviews would provide further depth to their findings (which identified generally positive perspectives). In addition, a strength of this research was the apparent willingness to share and honesty that participants showed, for example when discussing the emotional impact of their work, the energy and motivation levels they require, and their awareness of preconceived ideas and beliefs.

A further consideration is the impact of the ontological and epistemological stance of the authors, and whether alternative findings would have been developed with a different stance. Indeed, for both the systematic review and empirical research, only OF coded the data, with the justification being that an additional data coder would have added little benefit, given the authors were not searching for a known "truth" within the data (Braun & Clarke, 2022). Despite collaboration during the stages where themes were developed, it is possible that another coder may have viewed the data from a different perspective. A positivist epistemological stance would have influenced the findings with regard to how prior known "truths" influenced the course of analysis. For example, the post-hoc application of psychological theories in both the systematic review and empirical research may have instead been used as a-priori, to guide interview questions and interpretation of data.

Savolainen et al. (2023) argue that positionality should not influence research processes, and that instead methodological rigour ensures integrity in truth seeking. However, given that it was not the intention of this portfolio to obtain "truth", it is important to provide transparency in the authors' positionality, which may have influenced how data was collected and analysed. All three authors are white, British females, under the age of 45 and able-bodied. Each has experience working with PLF in a chronic pain management service under the discipline of clinical psychology.

Systematic Review

As discussed, the systematic review synthesised only qualitative evidence and therefore may lack the rigour associated with quantitative meta-analysis (Ahn & Kang, 2018). Despite this, Stegenga (2011) argues that subjectivity remains even within meta-analysis. As such, the aims of this qualitative systematic review were to provide new insights from a social constructionist epistemology, and therefore focused on future research rather than clinical implications and recommendations.

The search did not include MeSH terms, and therefore may have overlooked important evidence. However, search terms were used based on their prevalence within relevant publications; additionally, reference lists were hand-searched to attempt as thorough a search as possible. The systematic review included studies which were available in English and published in peer reviewed journals. It is likely that research in other languages would offer further, or alternative findings which could be useful to inform future research, but may not be applicable to the United Kingdom (UK) in a National Health Service (NHS) context due to differences in cultural norms and healthcare policies and guidance. Having said this, none of the included studies were based in the UK, and therefore one of the key limitations is the applicability of the findings to the NHS. To compensate for this, detailed extracts from the research were used to allow the reader to judge applicability to other contexts. The choice was made to only include published, peer reviewed research so that rigour could be ensured, however the Critical Appraisal Skills Programme tool ([CASP], 2018) identified methodological and ethical limitations with some of the included studies. As such, if the systematic review were to be repeated, then grey literature may offer additional insights. Particularly as research often does not get published when results are inconclusive, or insignificant, however these kinds of findings are important to be aware of when synthesising a potentially valuable topic. Some of the studies had an absence of discussion around their ethical approvals, and it is important that caution is taken when applying these findings to the NHS, where rigorous processes are followed to ensure research is ethical.

Finally, the systematic review included studies with heterogenous methods of data collection (sourcing online content, interviews, and focus groups). While this may not be an issue for qualitative synthesis, the included studies varied in the depth of information provided on peer support for PLF. Although all met inclusion criteria for having meaningful information about peer support, the aims of the studies varied between focusing specifically on peer support, versus focusing on another phenomenon where peer support was a relevant factor. Some elements of findings such as peers sharing misinformation in the descriptive theme “Peer groups can be negative” were specific to online forums and social media. Therefore, having focused on in-person groups, or specific peer support groups may have offered findings more applicable to NHS settings. Despite this, peer support in any format was reviewed given that there had been no prior systematic review exploring the impact of peer support for PLF and therefore offered contemporary findings and a useful starting point for future research.

Empirical Research

The empirical research included participants from a variety of professional disciplines (consultant anaesthetists, nurses, occupational therapists, physiotherapists and clinical psychologists). This may be viewed as both a strength and a weakness of the research. The sample was heterogenous when considering their professional backgrounds and length of time working in a specialist pain management clinic, which may have resulted in tenuous themes to be developed from the data. However, it was agreed in the development stages of the research that it would be key for all disciplines to be invited to participate, due to the systemic nature of the multidisciplinary team in NHS pain management services. Narrowing recruitment to only one profession may have resulted in more discipline specific themes, but as a new area of research it was deemed important to capture all clinicians’ perceptions of fibromyalgia. A strength of this research is the fact that it achieved this aim, gathering clinicians’ perceptions from a variety of disciplines at three sites across the East and Midlands of the UK (however the fourth site generated no participants, despite several recruitment attempts). It was stated in the protocol that if differing perceptions arose between disciplines, then this would be captured through the themes. However, there were no substantial differences of perceptions across the disciplines which were note-worthy. As such, this research highlighted the homogeneity of ideas in a broad sample, and therefore opened opportunities for future research, to understand why clinicians from specialist pain management clinics appear to have differing perceptions of fibromyalgia to those in the research such as general practitioners and rheumatologists (e.g., Hayes et al., 2010; Ghazan-Shahi et al., 2012).

Caution Interpreting Findings

Considering the GRADE-CERQual (Lewin et al., 2018) ratings of the systematic review findings, it is important to raise caution when interpreting and applying these to wider contexts. Confidence in the review findings ranged from moderate to low, mainly due to variation in the depth of the data and minor methodological limitations in the original studies. Furthermore, the analytical themes were based on interpretations of the data, applying theoretical knowledge, and developing hypotheses about the processes underlying the descriptive themes. Alternative themes may be drawn by different authors, depending on their theoretical stance. It is also worth noting that the hypothesised analytical themes may be refuted or supported by further research. For example, the descriptive theme “Peer groups can be negative” may offer evidence which contests the analytical theme “Others don’t understand: A maintenance loop”. However, this descriptive theme (“Peer groups can be negative”) requires readers to draw tentative conclusions, as it is made up of a wide range of disadvantages which were raised in original research, and therefore only gives a broad overview of a topic which likely requires further depth.

The authors’ social constructionist epistemological stance directed this thesis portfolio. The findings of the empirical paper set out to share the participants’ perceptions of fibromyalgia, and the authors acknowledge that these findings are context driven and may change over time. As such, it has been highlighted that absolute meanings cannot be drawn and widely applied without careful consideration of the context being applied to. It is also important to draw conclusions from the findings with the aforementioned possibility of a social desirability bias in mind.

Theoretical and Clinical Implications

The empirical paper highlighted how the participants recognised the stigma associated with fibromyalgia (e.g. Quinter, 2020) and the negative past experiences PLF may have had as a result of this (e.g., Mengshoel et al., 2017; Diviney & Dowling, 2015). As such, they expressed a desire to provide a positive healthcare experience for PLF, through alliance and allyship. These tools have been shown to be powerful in healthcare inequalities, and several

NHS trusts have implemented guidance around "being an ally" (e.g., Iwu et al., 2022). PLF may benefit from increased recognition of the challenges they face, and it was considered that the participants' specialist knowledge may be one reason why empathic perceptions were expressed. Therefore, further training for other healthcare providers may help to reduce some of the unhelpful attitudes often demonstrated in the research. Healthcare inequalities and bias are widespread issues, being shown to be present in other health conditions and across professions (e.g., Kay et al., 2018; Phelan et al., 2015) and therefore the findings from this research may be useful to consider across specialities. In addition, existing practices within services may be drawn upon and utilised further; reflective practice sessions may help to encourage awareness of covert narratives, for example Noone et al. (2022) suggests that confronting personal biases is a crucial element of building allyship in healthcare.

The authors considered the conflict between the findings in the theme "Overt and covert narratives" to be a result of a need for equitable care for PLF. This means making reasonable adjustments and additional considerations for PLF so that they have equal opportunity to have positive healthcare experiences. The participants seemed to strive to provide this for their patients living with fibromyalgia, but also recognised the challenge and personal impact this had. Considering the findings in line with existing research, compassionate care is thought to provide less emotional identification with patients than empathic healthcare (McNally et al., 2019). Taking a compassionate stance may support clinicians to feel more able to manage the emotional and personal impact of the work. Furthermore, this is in line with the NICE guidelines for chronic pain (NICE, 2021), and research highlighting the benefits of compassionate healthcare (Crawford et al., 2014).

The systematic review highlighted some of the advantages and drawbacks in how PLF experience peer support, and the impact of these. Peer support was mostly experienced as positive, providing several benefits which may be taken advantage of by healthcare providers in that it is cost-effective and feasible to implement. Furthermore, NHS trusts are increasingly including "experts by experience" or peer support workers in their interventions, which provides vicarious positive experiences and social role models, in line with social learning theory (Bandura, 1971; 1972). Despite the positives, the systematic review identified how peer support is a nuanced resource, echoing findings in existing literature reviews regarding how some of the positive aspects can equally have negative consequences (Watson, 2017). Careful triaging when offering access to formal peer support groups within services may help to ensure better experiences for individuals. Practical issues around peer support within services were also highlighted by the systematic review findings, indicating enough time and resource to be available to services providing space for formal peer support groups. With regard to less formal peer support such as through social media or online forums, these may provide PLF benefits such as feeling understood and supported. Clinicians may share information about relevant sources of peer support to PLF, while also showing candour in highlighting possible drawbacks.

When considering the overall findings of this thesis portfolio, it may be important to be mindful of the theoretical implications on clinical practice, including “in-group” and “out-group” constructs proposed by social identity theory (Tajfel, 1978; Tajfel & Turner 1979). Continued negative experiences within healthcare may contribute to clinicians becoming part of an “out-group”, meanwhile positive experiences with peers may form an “in-group”. It is well known that those in the in-group are given a more positive regard (through a cognitive bias favouring the in-group), than the out-group. If this is the case, then it will be important for PLF to feel understood and supported by clinicians, not only to provide a more positive healthcare experience, but also to help breakdown the less favourable attitudes toward the out-group, and to break a possible maintenance loop of negative experiences.

Future Research

One of the analytical themes in the findings of the systematic review hypothesised a maintenance loop of negative experiences in healthcare for PLF. The findings of the empirical research suggested participants’ desire to provide an alternative experience, and therefore potentially strived to break the maintenance loop suggested in the systematic review. Although other studies have suggested similar maintenance loops between patients and professionals (e.g., Byrne et al., 2023; Rowe et al., 2019), this is the first to consider broader challenges within healthcare for PLF. As such, future research may explore this concept further; although clinicians’ perceptions of fibromyalgia provided some insight, understanding patients’ perceptions *of clinicians* through in-depth qualitative interviews may help to understand the interpersonal dynamics which influence the patient-clinician encounter. Further research would also be useful due to the hypothetical nature of the maintenance loop; it is likely that people’s experiences are unique depending on the context and circumstances and therefore an individualised, holistic approach will be advantageous in understanding PLF.

The findings of the empirical paper suggested the participants held empathic perceptions of PLF. It was considered that this may be a result of specialist knowledge and training, as well as compassionate care. Compassion in healthcare has been described as understanding others' suffering, and willingness to help find a solution (Perez-Bret et al., 2016). Specialist knowledge may help to improve healthcare experiences for PLF, for example participants in a study by Ashe et al. (2017) valued the knowledge and experience of pain clinicians and therefore training for all clinicians will likely prove beneficial. However, guidelines for fibromyalgia treatment remain to be vague (Faculty of Pain Medicine, 2020), and therefore the "willingness to find a solution" will no doubt be supported by robust guidelines, through ongoing research to improve our understanding of and treatment for fibromyalgia.

It was unclear whether the conflict between the participants' overt and covert narratives in the empirical research were a result of psychological processes such as cognitive dissonance (Festinger, 1957), and impression management (Paulhus, 1984), self-deceptive enhancement (Paulhus, 1984), implicit bias (Greenwald & Banaji, 1995), or multiple complex processes involved. It is important that ideas, beliefs, assumptions, and biases are brought to our attention, as research has identified how these can influence patient care (e.g., Kay et al., 2018; Fitzgerald and Hurst, 2017; Phelan et al., 2015). Recognition of interpersonal processes have been useful through qualitative research, however further research may seek to clarify the underlying processes between "overt" and "covert" narratives, perhaps through methodology which would allow anonymity of participants and therefore potentially less likely to yield socially desirable results (Bergen & Labonté, 2020). One approach could be to conduct an experimental manipulation study exploring clinician bias, for example using case vignettes whereby diagnostic descriptions are changed, e.g., "fibromyalgia", "chronic widespread pain", or "organic pain". Clinicians' attitudes and readiness to treat the patient may be quantified through formal measures such as the physician version of the Illness Invalidation Inventory (Kool et al., 2010) and the Difficult Doctor-Patient Relationship Questionnaire (Hahn et al., 1996).

The systematic review identified benefits and drawbacks of peer support for PLF, and this may inform the use of peer support in NHS services. The NHS long term plan (NHS, 2019) discusses self-management for long term conditions; for fibromyalgia, the NHS suggests self-management includes support groups, and encourages peer support (NHS, 2022). Despite this, the NICE guidelines (NICE, 2021) do not refer to peer support, and a lack of guidance may result in minimal formal provision of peer support within services. Furthermore, formal provision of peer support may help to monitor the elements which were highlighted by the systematic review as unhelpful for PLF. Given the findings indicating the nuances of peer support, it is key that development of guidance is collaborative in order for peer support to be a success and beneficial to individuals. Therefore, participatory action research may be useful to home in on the challenges and benefits, allowing providers and PLF to work together. For informal sources of peer support (e.g., social media, online forums), there may be a degree of caution from healthcare providers to signpost, due to their unregulated nature. Future research may be useful to explore clinicians' views to understand whether these sources are encouraged or whether there are differing opinions on their value.

As discussed, the systematic review included research with heterogenous data collection methods, and those which specifically evaluated peer support as well as studies for which peer support was a relevant factor. A systematic review of the literature in future may focus specifically on individual aspects, rather than grouping these together so that context specific conclusions can be drawn (e.g., online peer support, formal peer support within services, groups whereby peer support becomes an inevitable element).

Overall Conclusions

This thesis portfolio offers valuable contributions to the knowledge base for care for PLF. The systematic review provided a contemporary synthesis of qualitative research to understand that peer support for PLF is generally positively experienced and suggests the impact of this on clinical practice. Direction for future research is suggested to refine formal peer support interventions for PLF. The empirical research indicates how the participants from specialist chronic pain management services held perceptions that resulted in wanting to provide positive experiences in healthcare for PLF. This was despite limited guidance and treatment options, as well as the challenges of stigma associated with the condition. The findings provide alternative perceptions of fibromyalgia to much of the existing research and offers recommendations for future research as well as implications for clinical practice.

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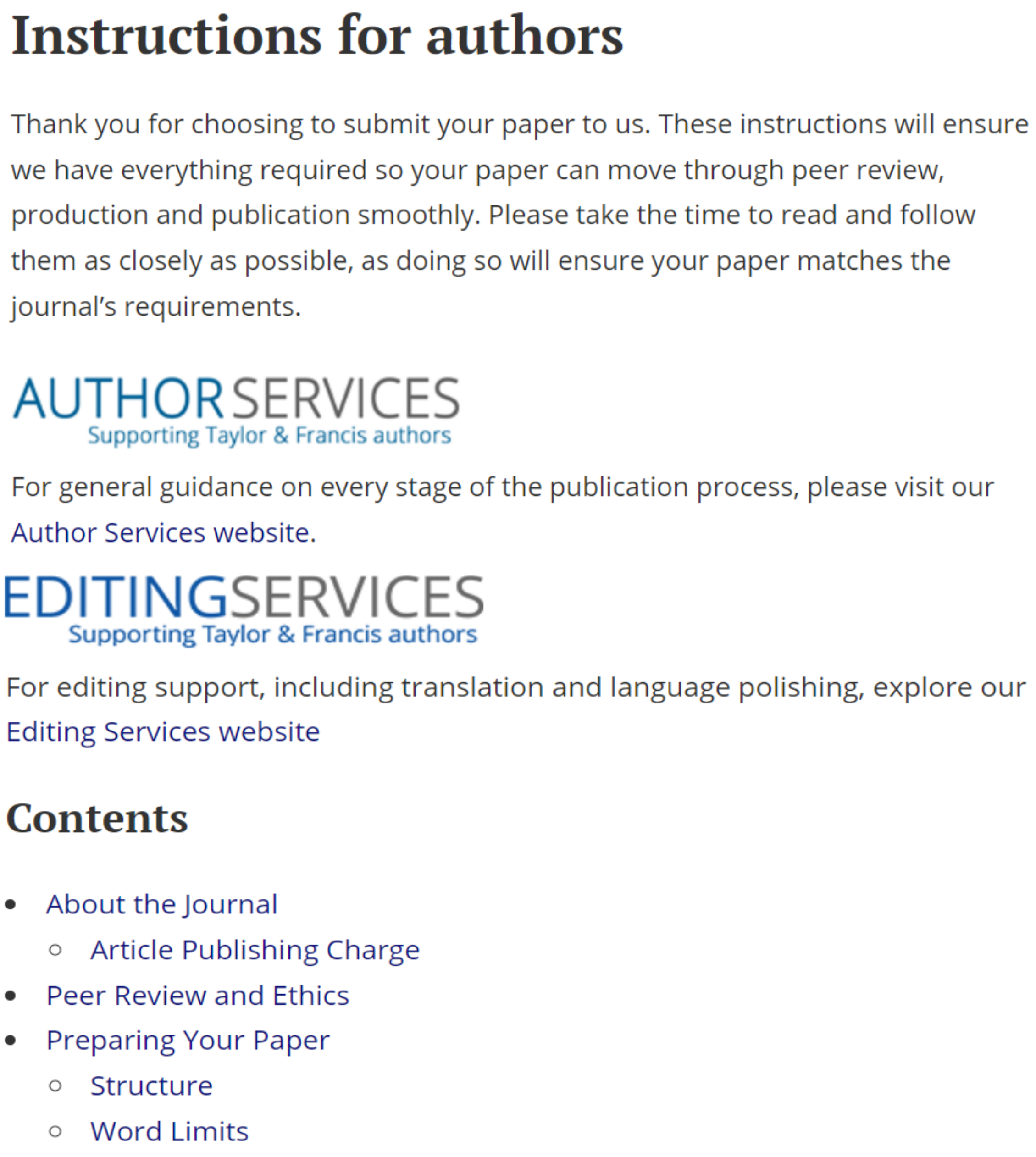
Appendices

Appendix A. Author Guidelines for Manuscript Preparation for International Journal of Qualitative Studies on Health and Wellbeing



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    - Structure
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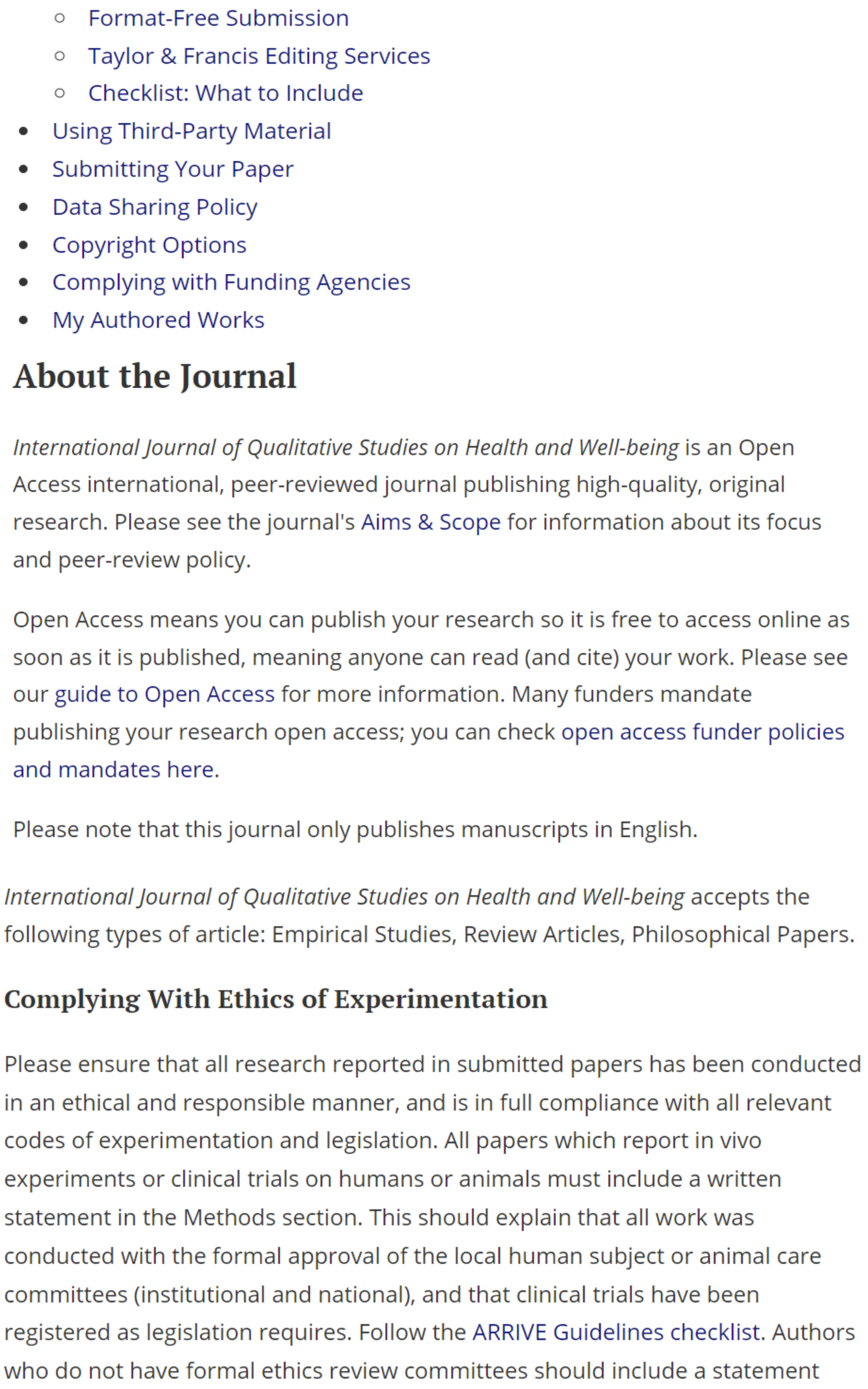

  - Format-Free Submission
  - Taylor & Francis Editing Services
  - Checklist: What to Include
- Using Third-Party Material
- Submitting Your Paper
- Data Sharing Policy
- Copyright Options
- Complying with Funding Agencies
- My Authored Works

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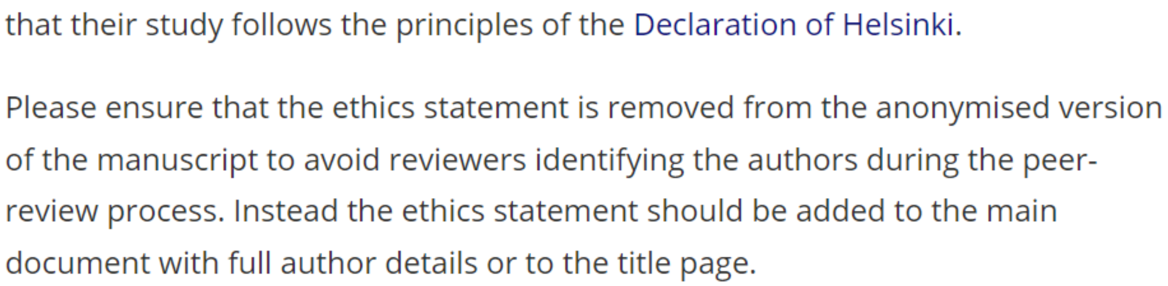

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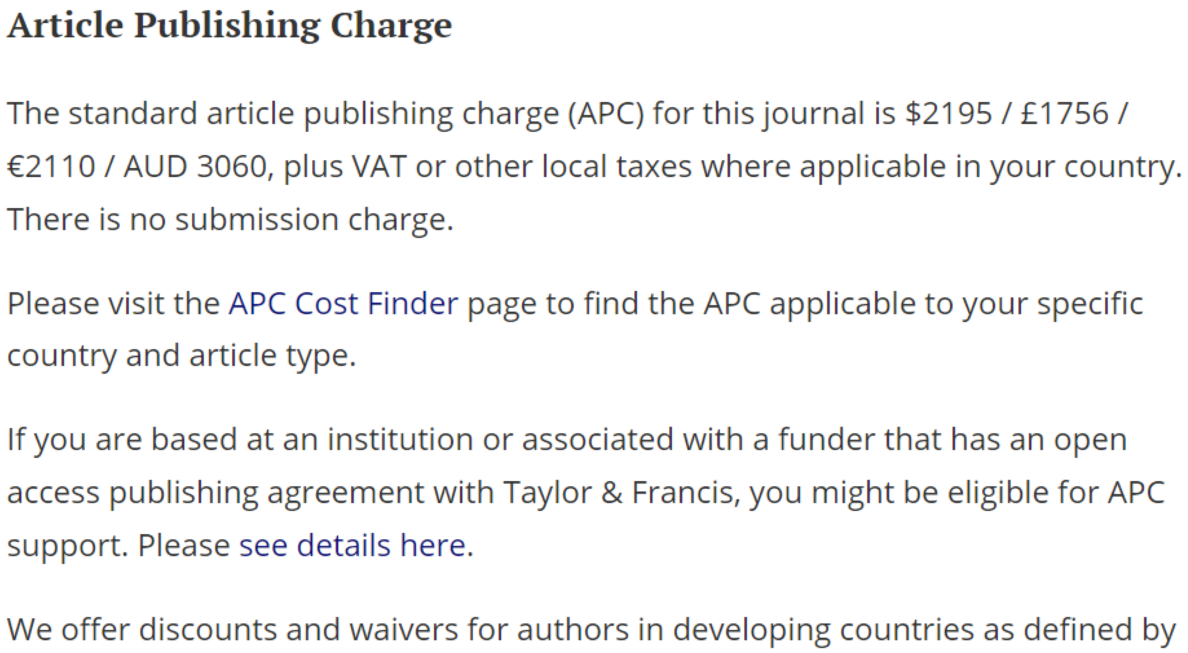

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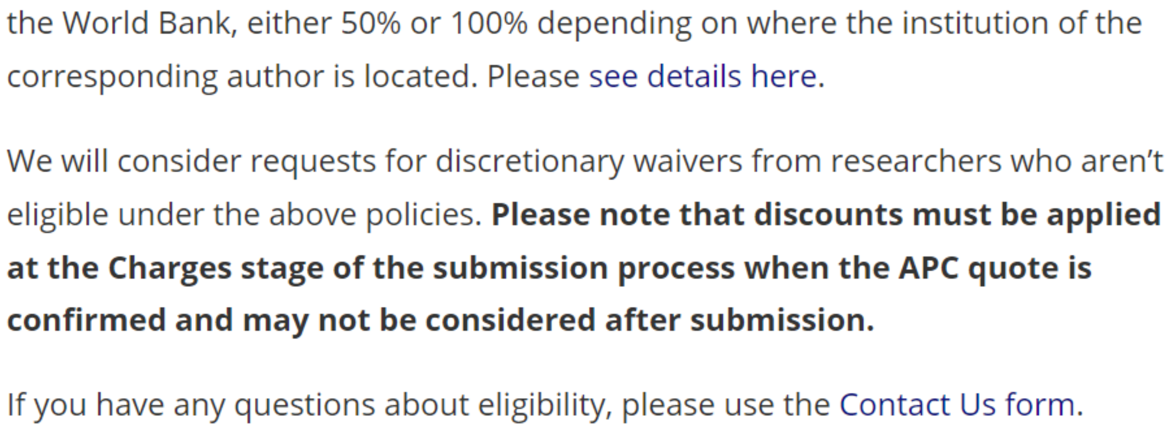

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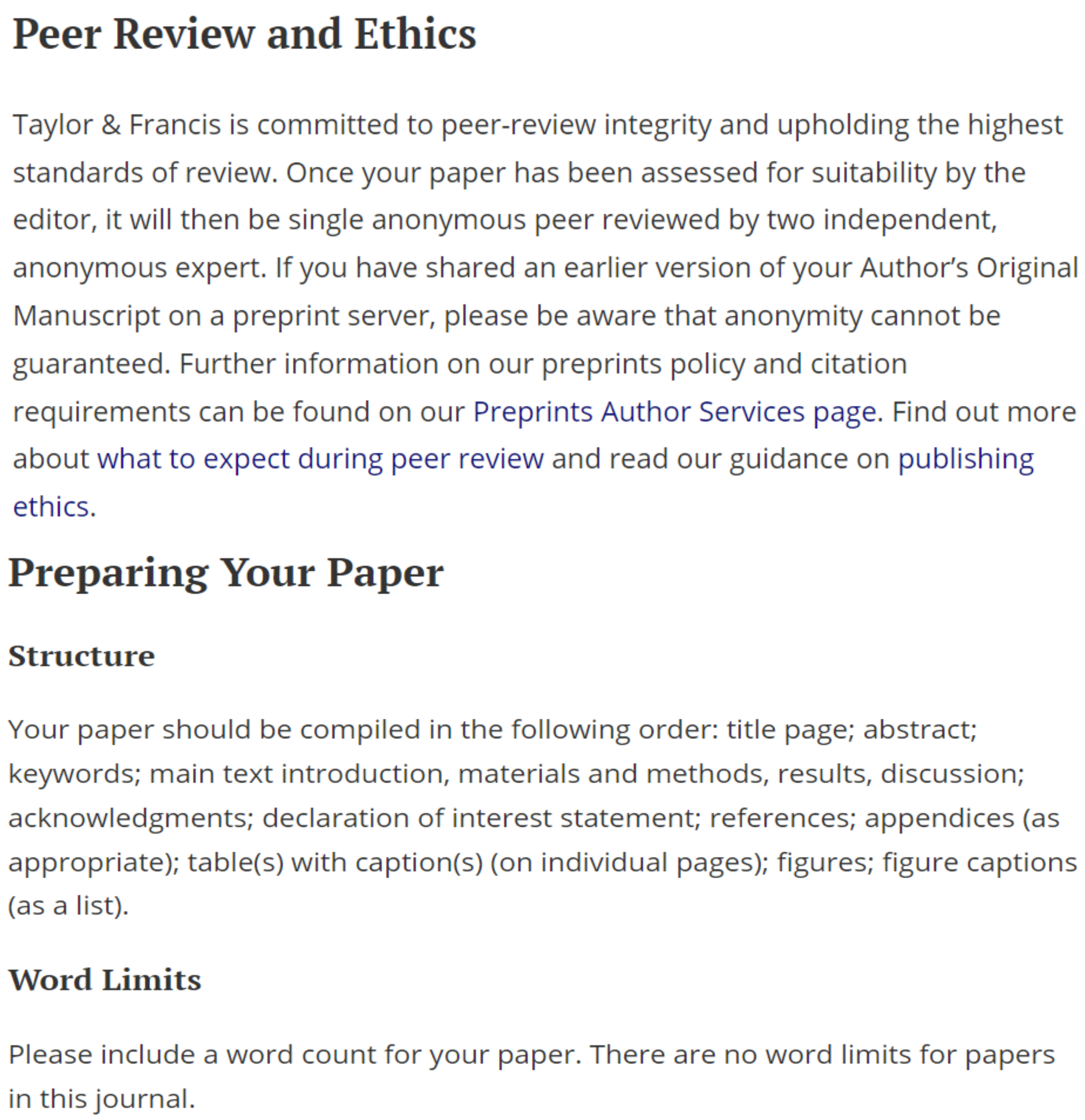

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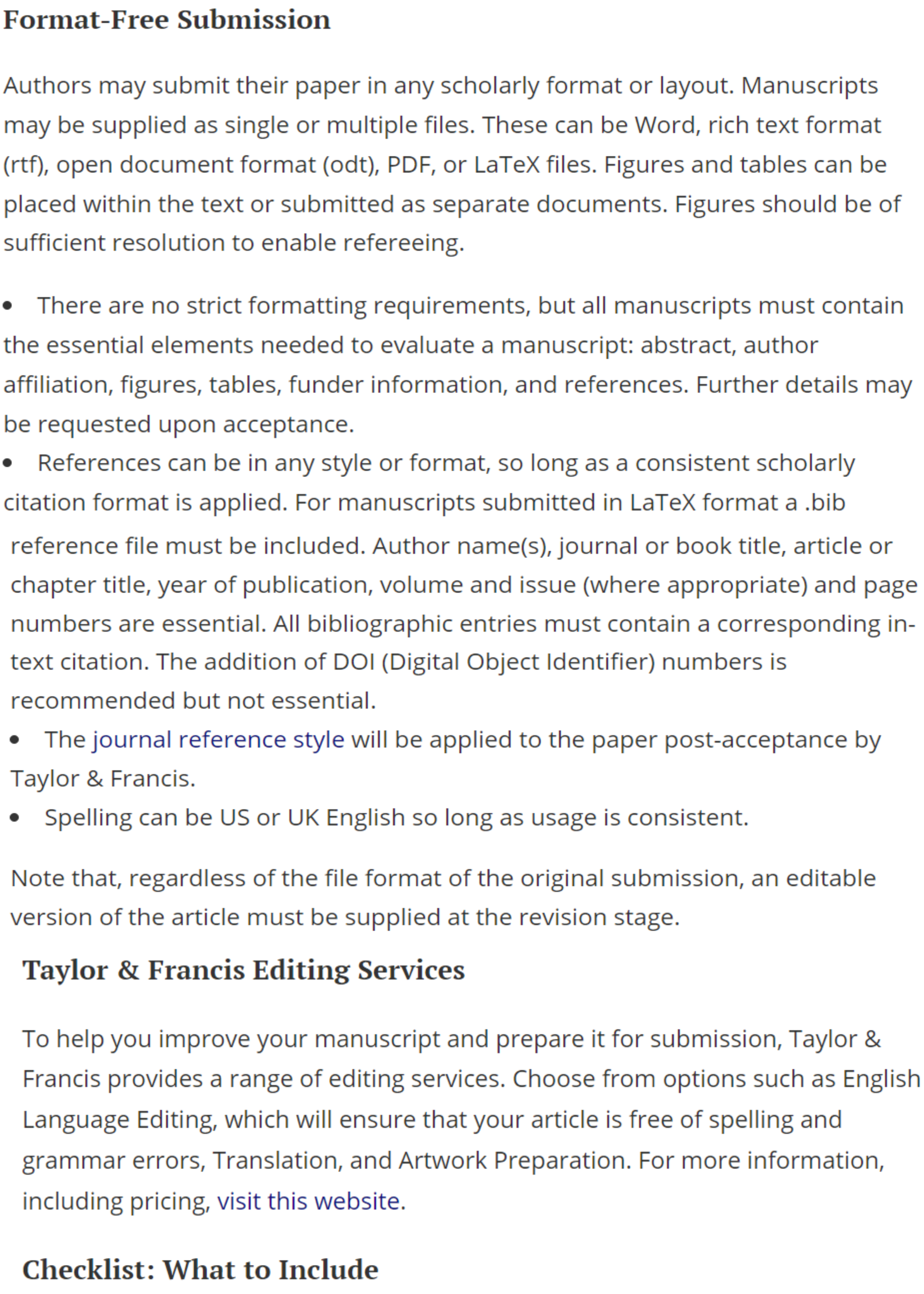

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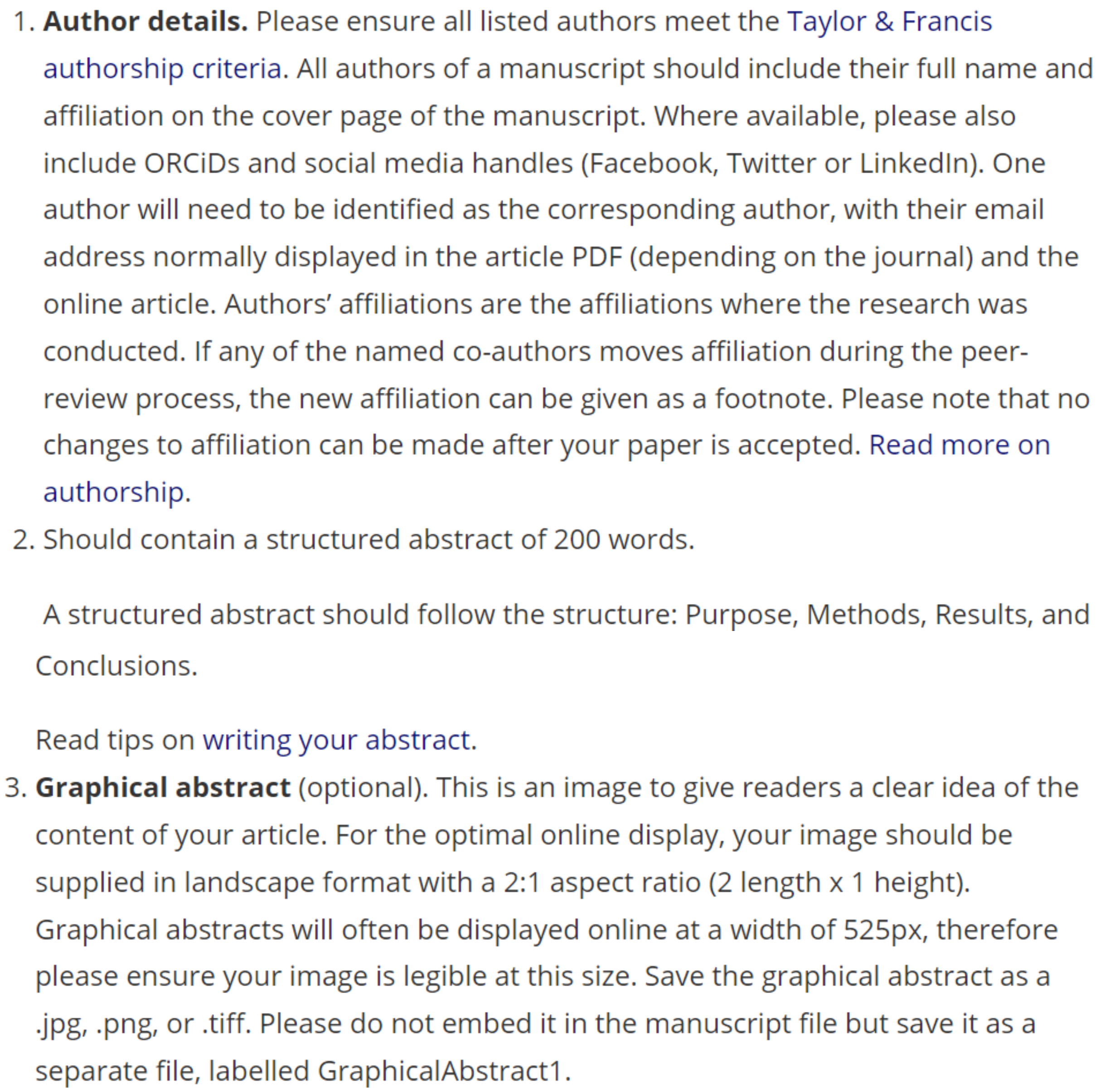

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   A structured abstract should follow the structure: Purpose, Methods, Results, and Conclusions.

   Read tips on writing your abstract.
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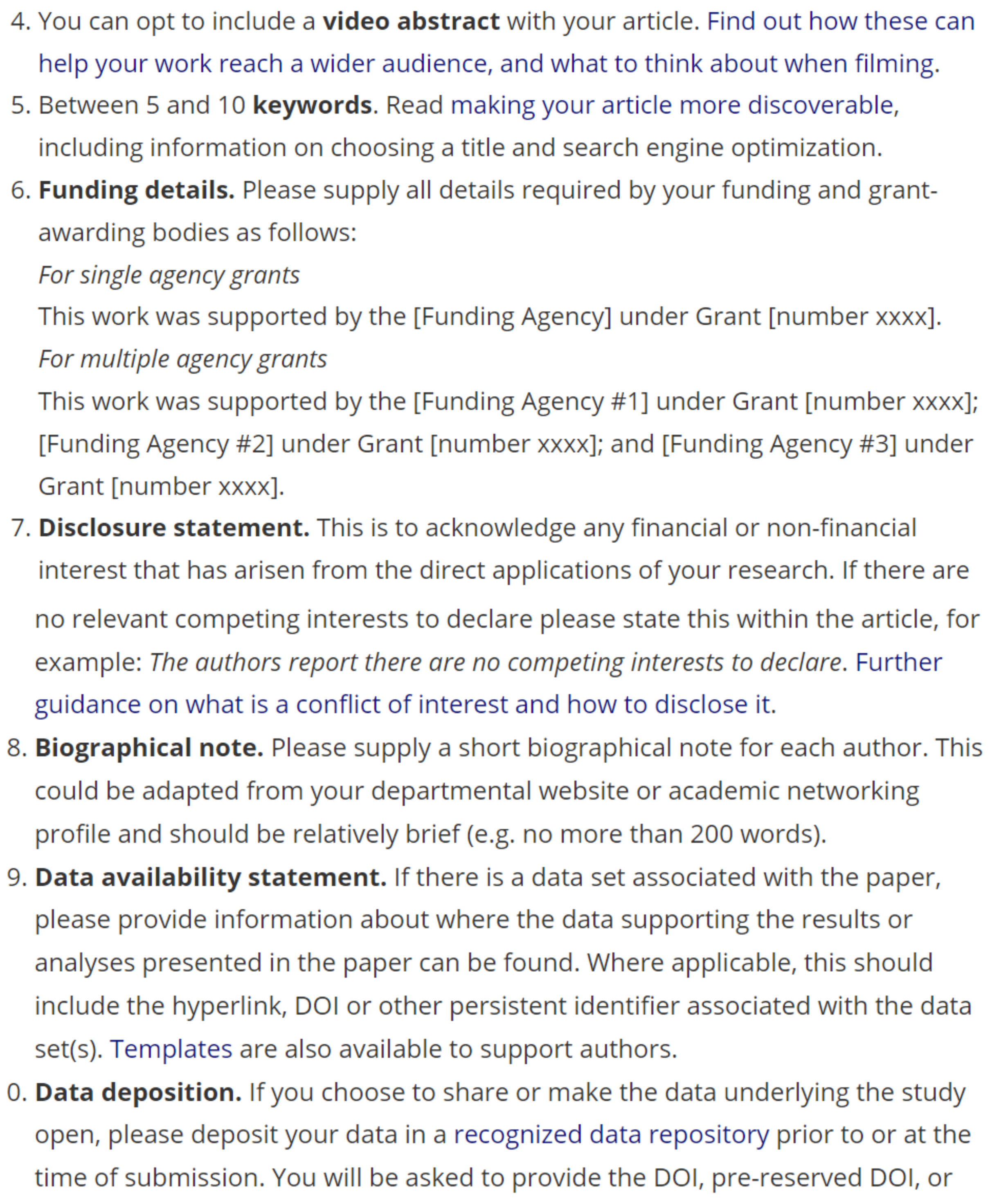

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9. **Data availability statement.** If there is a data set associated with the paper, please provide information about where the data supporting the results or analyses presented in the paper can be found. Where applicable, this should include the hyperlink, DOI or other persistent identifier associated with the data set(s). Templates are also available to support authors.

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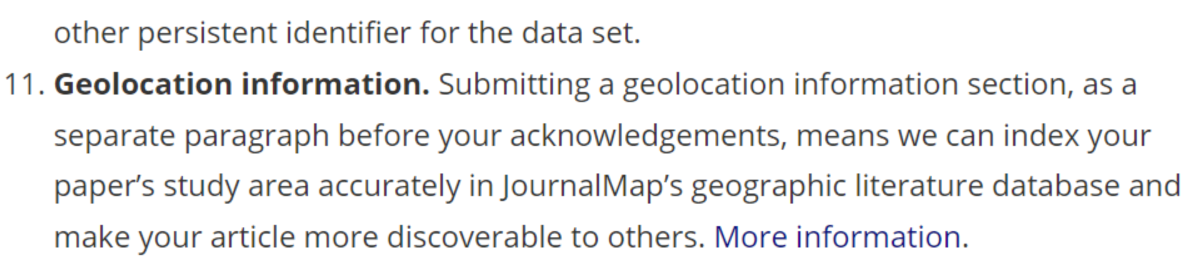

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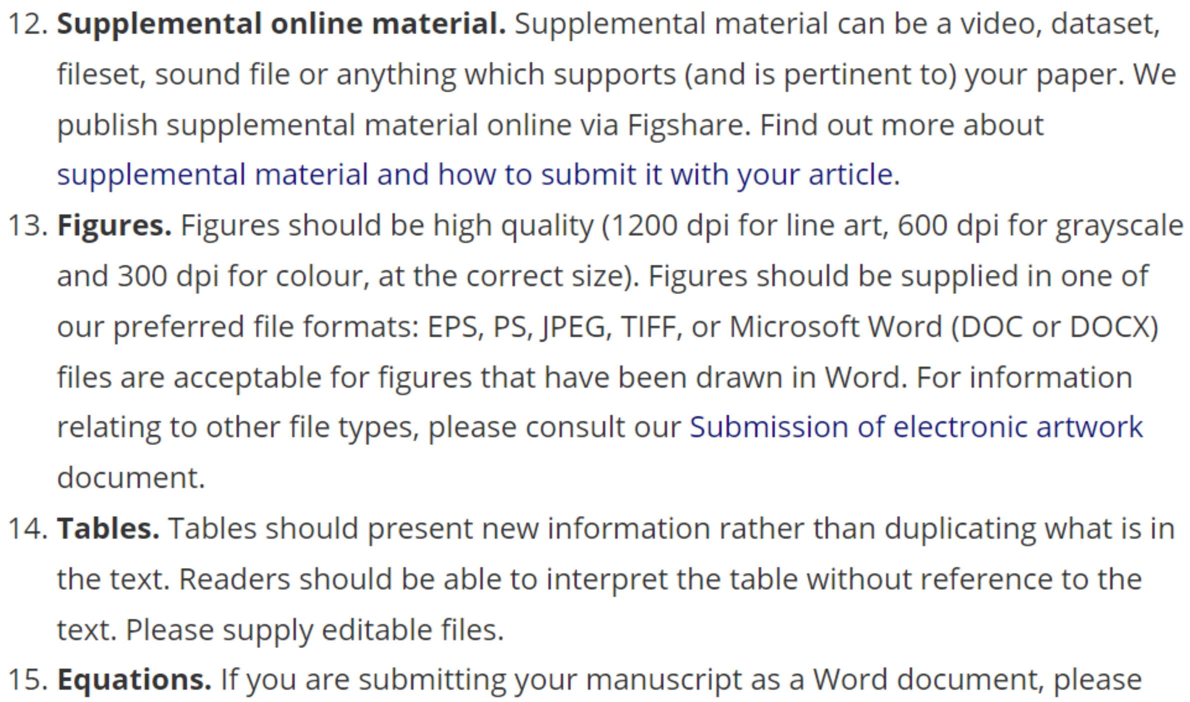

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13. **Figures.** Figures should be high quality (1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour, at the correct size). Figures should be supplied in one of our preferred file formats: EPS, PS, JPEG, TIFF, or Microsoft Word (DOC or DOCX) files are acceptable for figures that have been drawn in Word. For information relating to other file types, please consult our Submission of electronic artwork document.
14. **Tables.** Tables should present new information rather than duplicating what is in the text. Readers should be able to interpret the table without reference to the text. Please supply editable files.
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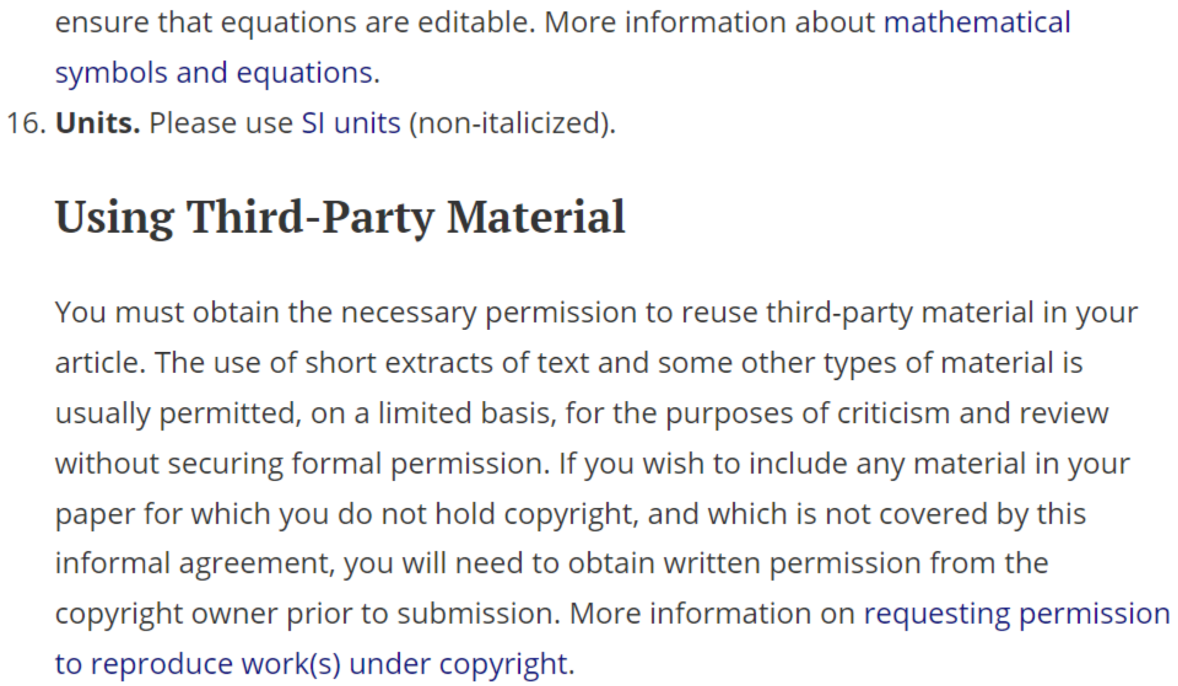

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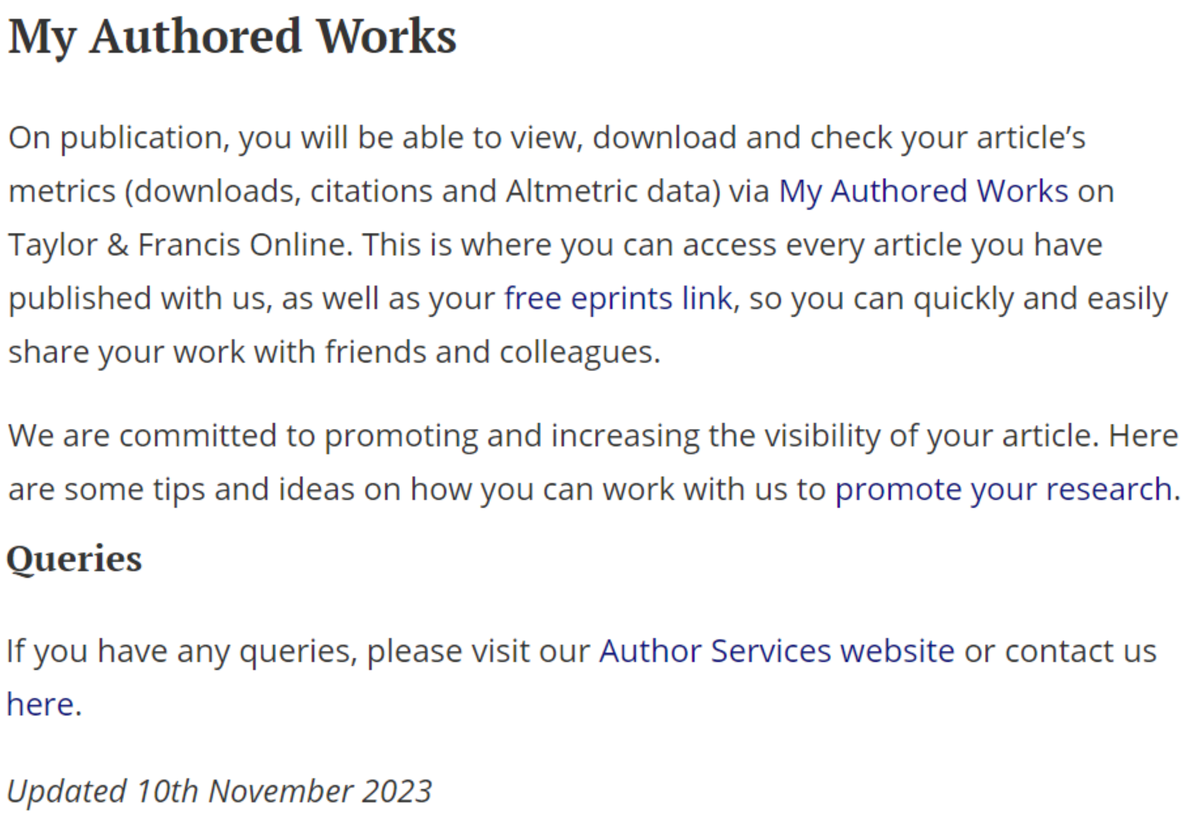

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Updated 10th November 2023

Appendix B. Systematic Review Screening Tool

Review question:

Inclusion criteria (based on SPIDER):

- Sample = adults living with fibromyalgia. Any gender, any country
- Phenomenon of Interest = peer support (in any format)
- Design = qualitative studies
- Evaluation = the impact of peer support on participants (e.g. how it made them feel, what their thoughts were, whether anything changed as a result).
- Research type = Qualitative or mixed methods. Published studies, those available in English and full text format. Studies published in the last 20 years.

Title:

Author names / DOI:

Journal:

Year:

	Include	**Exclude**
Sample	People living with fibromyalgia	People living with fibromyalgia as well as other conditions
		People who are not living with fibromyalgia
Phenomenon of interest	Peer support is the focus of the study	Peer support is not discussed within the study
	Peer support is an element discussed within the study	Another intervention is discussed
Design	Qualitative	Quantitative
	Mixed methods (with the qualitative aspects relevant to peer support)	
Evaluation	There is meaningful discussion on the impact of peer support on participants	No discussion or very limited* discussion of the impact of the peer support
Research Type	Published in a journal	Not published / “grey” literature
	Published in an academic book	Not an empirical paper (e.g., a review, opinion paper, or report).
	Empirical studies	Not available in English
	Available in English	Published before 2003

	Published in the last 20 years (2003-2023)	Not available in full text format (i.e., conference reports)
	Full text format	

*Limited discussion is defined by the review team as the evaluation criteria only being referenced in one sentence within the results section, or referenced vaguely, without the depth to extract meaning.

Overall decision: ☐ **Included** ☐ **Excluded**

Notes

Appendix C. Critical Appraisal Skills Programme Tool

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

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:

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:

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:

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?

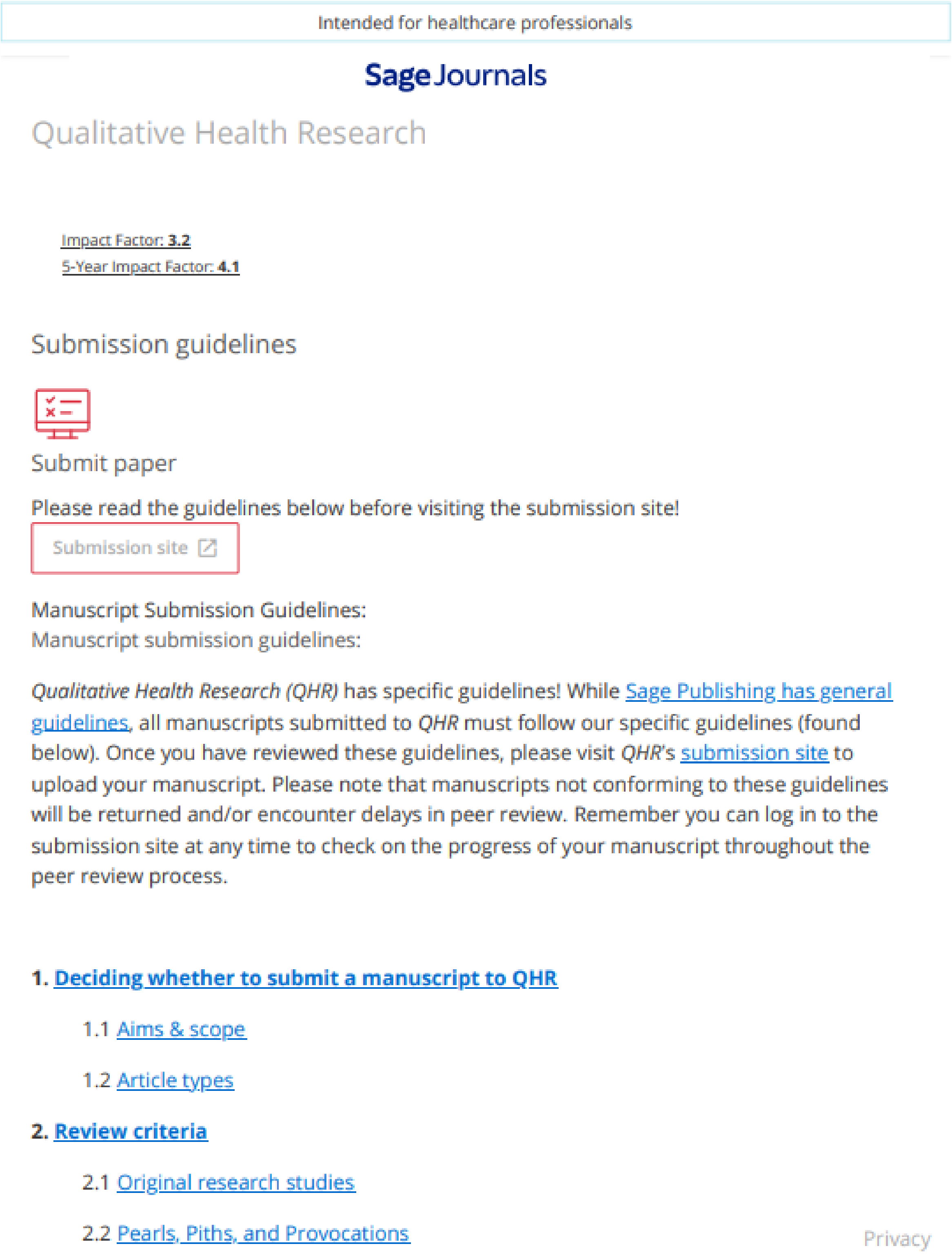
10. How valuable is the research?

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 D. Author Guidelines for Manuscript Preparation for Qualitative Health Research



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Qualitative Health Research

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5-Year Impact Factor: **4.1**

Submission guidelines

Submit paper

Please read the guidelines below before visiting the submission site!

Submission site

Manuscript Submission Guidelines:
Manuscript submission guidelines:

Qualitative Health Research (QHR) has specific guidelines! While Sage Publishing has general guidelines, all manuscripts submitted to *QHR* must follow our specific guidelines (found below). Once you have reviewed these guidelines, please visit *QHR*'s submission site to upload your manuscript. Please note that manuscripts not conforming to these guidelines will be returned and/or encounter delays in peer review. Remember you can log in to the submission site at any time to check on the progress of your manuscript throughout the peer review process.

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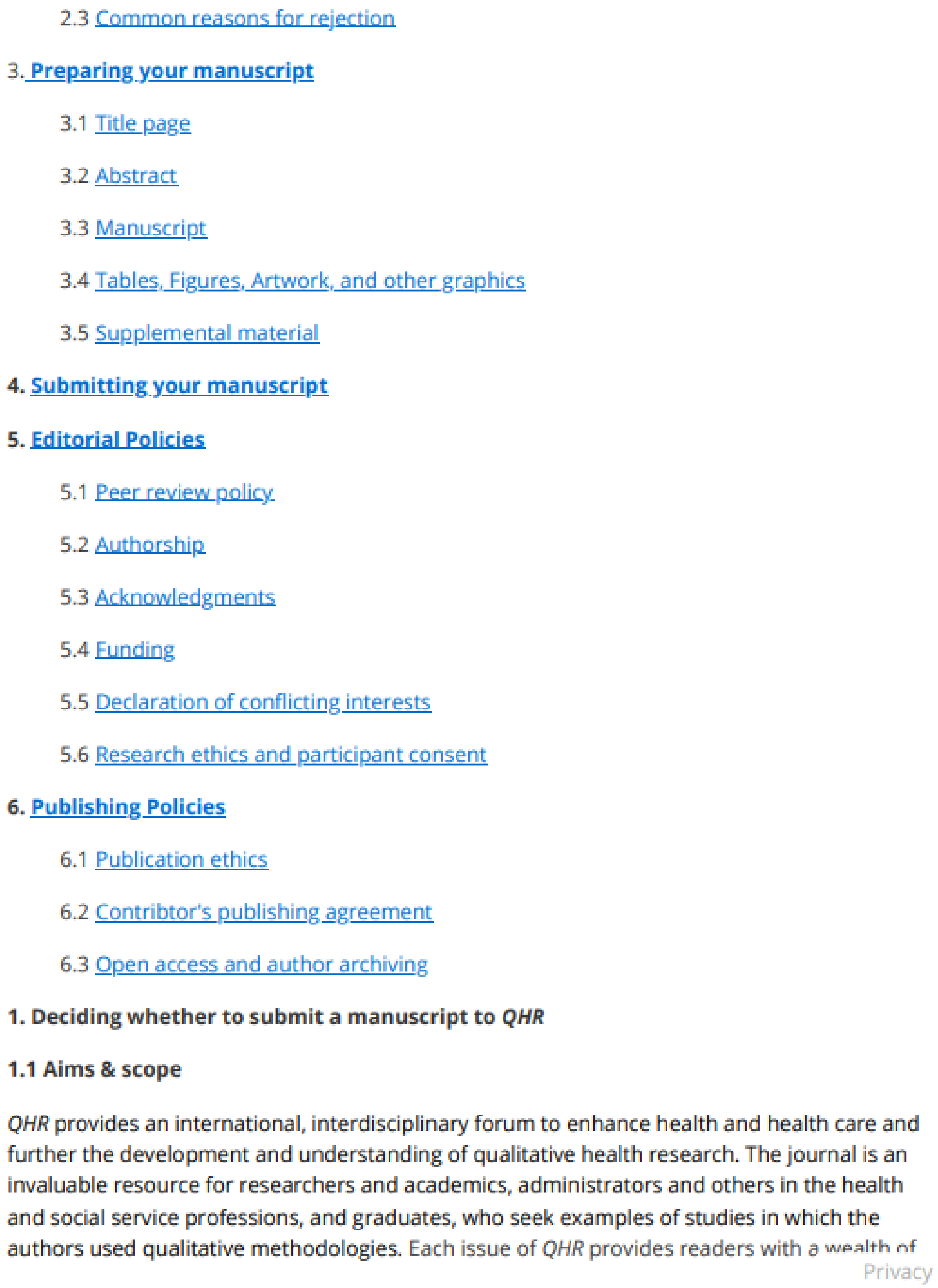

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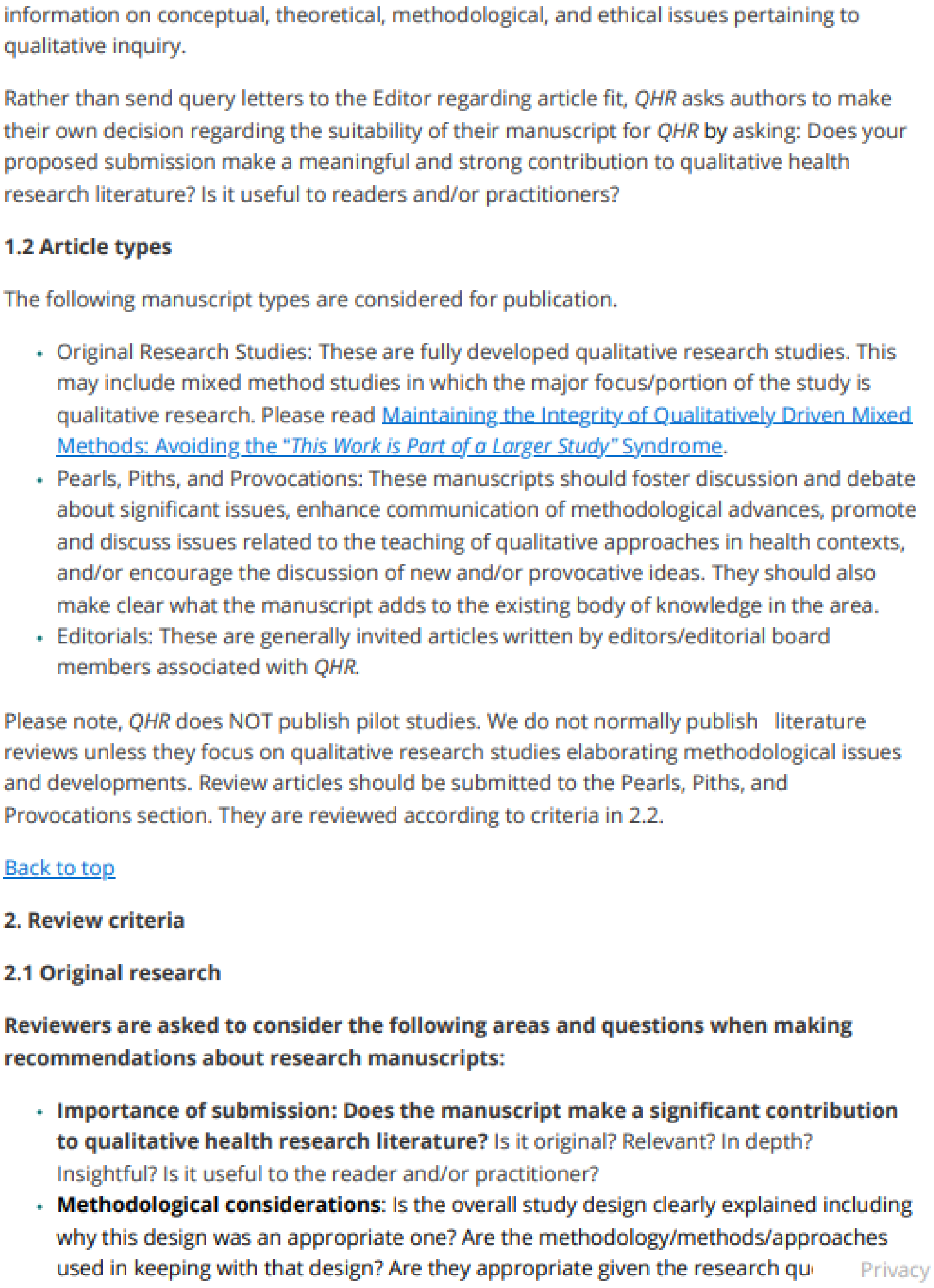
1. Deciding whether to submit a manuscript to *QHR*

1.1 Aims & scope

QHR provides an international, interdisciplinary forum to enhance health and health care and further the development and understanding of qualitative health research. The journal is an invaluable resource for researchers and academics, administrators and others in the health and social service professions, and graduates, who seek examples of studies in which the authors used qualitative methodologies. Each issue of *QHR* provides readers with a wealth of



information on conceptual, theoretical, methodological, and ethical issues pertaining to qualitative inquiry.

Rather than send query letters to the Editor regarding article fit, *QHR* asks authors to make their own decision regarding the suitability of their manuscript for *QHR* by asking: Does your proposed submission make a meaningful and strong contribution to qualitative health research literature? Is it useful to readers and/or practitioners?

1.2 Article types

The following manuscript types are considered for publication.

- Original Research Studies: These are fully developed qualitative research studies. This may include mixed method studies in which the major focus/portion of the study is qualitative research. Please read Maintaining the Integrity of Qualitatively Driven Mixed Methods: Avoiding the "*This Work is Part of a Larger Study*" Syndrome.
- Pearls, Piths, and Provocations: These manuscripts should foster discussion and debate about significant issues, enhance communication of methodological advances, promote and discuss issues related to the teaching of qualitative approaches in health contexts, and/or encourage the discussion of new and/or provocative ideas. They should also make clear what the manuscript adds to the existing body of knowledge in the area.
- Editorials: These are generally invited articles written by editors/editorial board members associated with *QHR*.

Please note, *QHR* does NOT publish pilot studies. We do not normally publish literature reviews unless they focus on qualitative research studies elaborating methodological issues and developments. Review articles should be submitted to the Pearls, Piths, and Provocations section. They are reviewed according to criteria in 2.2.

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2. Review criteria

2.1 Original research

Reviewers are asked to consider the following areas and questions when making recommendations about research manuscripts:

- **Importance of submission: Does the manuscript make a significant contribution to qualitative health research literature?** Is it original? Relevant? In depth? Insightful? Is it useful to the reader and/or practitioner?
- **Methodological considerations**: Is the overall study design clearly explained including why this design was an appropriate one? Are the methodology/methods/approaches used in keeping with that design? Are they appropriate given the research qu

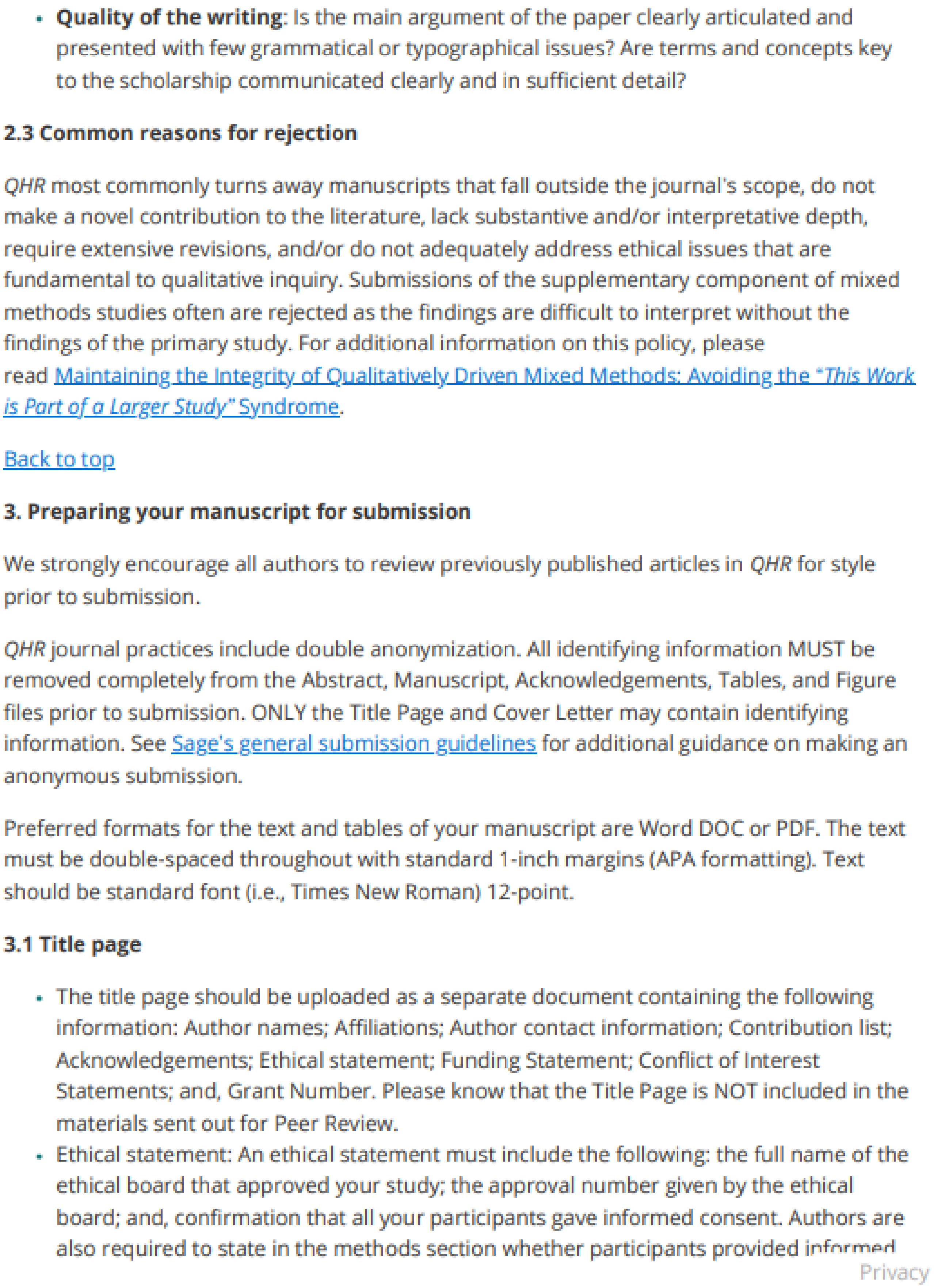
and/or aims? Are they logically articulated? Clarity in design and presentation? Data adequacy and appropriateness? Evidence of rigor?
- **Ethical Concerns**: Are relevant ethical concerns discussed and acknowledged? Is enough detail given to enable the reader to understand how ethical issues were navigated? Has formal IRB approval (when needed) and consent from participants been obtained?
- **Data analysis, findings, discussion**: Does the analysis of data reflect depth and coherence? In-depth descriptive but also interpretive dimensions? Creative and insightful analysis? Are results linked to existing literature and theory, as appropriate? Is the contribution of the research clear including its relevance to health disciplines and their practice?
- **Manuscript style and format:** Is the manuscript organized in a clear and concise manner? Has sufficient attention been paid to word choice, spelling, grammar, and so forth? Did the author adhere to APA guidelines? Do diagrams/illustrations comply with guidelines? Is the overall manuscript aligned with *QHR* guidelines in relation to formatting?
- **Scope:** Does the article fit with *QHR*'s publication mandate? Has the author cited the major work in the area, including those published in *QHR*?

2.2 Pearls, Piths, and Provocations

The purpose of papers in this section is to raise and discuss issues pertinent to the development and advancement of qualitative research in health-related arenas. As the name Pearls, Piths, and Provocations suggests, we are looking for manuscripts that make a significant contribution to areas of dialogue, development, experience sharing and debate relevant to the scope of *QHR* in this section of the journal. **Reviewers are asked to consider the following questions when making recommendations about** articles in the Pearls, Piths, and Provocations section.

- **Significance**: Does the paper highlight issues that have the potential to advance, develop, and/or challenge thinking in qualitative health related research?
- **Clarity**: Are the arguments clearly presented and well supported?
- **Rigor**: Is there the explicit use of/interaction with methodology and/or theory and/or empirical studies (depending on the focus of the paper) that grounds the work and is coherently carried throughout the arguments and/or analysis in the manuscript? Put another way, is there evidence of a rigorously constructed argument?
- **Engagement**: Does the paper have the potential to engage the reader to 'think differently' by raising questions, suggesting innovative directions for qualitative health research, and/or stimulating critical reflection? Are the implications of the paper for the practice of either qualitative research and/or health clear?

Privacy



- **Quality of the writing**: Is the main argument of the paper clearly articulated and presented with few grammatical or typographical issues? Are terms and concepts key to the scholarship communicated clearly and in sufficient detail?

2.3 Common reasons for rejection

QHR most commonly turns away manuscripts that fall outside the journal's scope, do not make a novel contribution to the literature, lack substantive and/or interpretative depth, require extensive revisions, and/or do not adequately address ethical issues that are fundamental to qualitative inquiry. Submissions of the supplementary component of mixed methods studies often are rejected as the findings are difficult to interpret without the findings of the primary study. For additional information on this policy, please read Maintaining the Integrity of Qualitatively Driven Mixed Methods: Avoiding the "*This Work is Part of a Larger Study*" Syndrome.

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3. Preparing your manuscript for submission

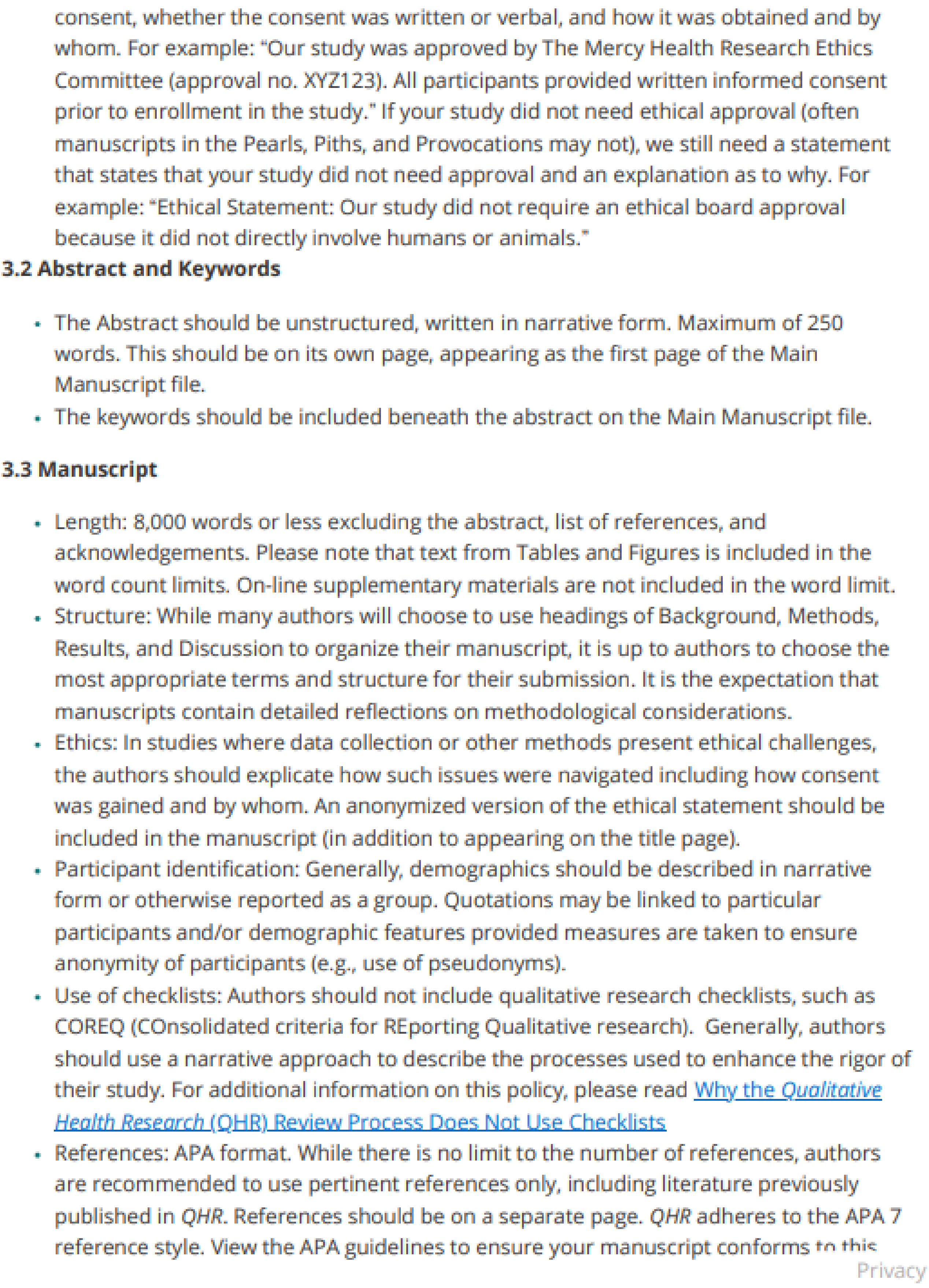
We strongly encourage all authors to review previously published articles in *QHR* for style prior to submission.

QHR journal practices include double anonymization. All identifying information MUST be removed completely from the Abstract, Manuscript, Acknowledgements, Tables, and Figure files prior to submission. ONLY the Title Page and Cover Letter may contain identifying information. See Sage's general submission guidelines for additional guidance on making an anonymous submission.

Preferred formats for the text and tables of your manuscript are Word DOC or PDF. The text must be double-spaced throughout with standard 1-inch margins (APA formatting). Text should be standard font (i.e., Times New Roman) 12-point.

3.1 Title page

- The title page should be uploaded as a separate document containing the following information: Author names; Affiliations; Author contact information; Contribution list; Acknowledgements; Ethical statement; Funding Statement; Conflict of Interest Statements; and, Grant Number. Please know that the Title Page is NOT included in the materials sent out for Peer Review.
- Ethical statement: An ethical statement must include the following: the full name of the ethical board that approved your study; the approval number given by the ethical board; and, confirmation that all your participants gave informed consent. Authors are also required to state in the methods section whether participants provided informed



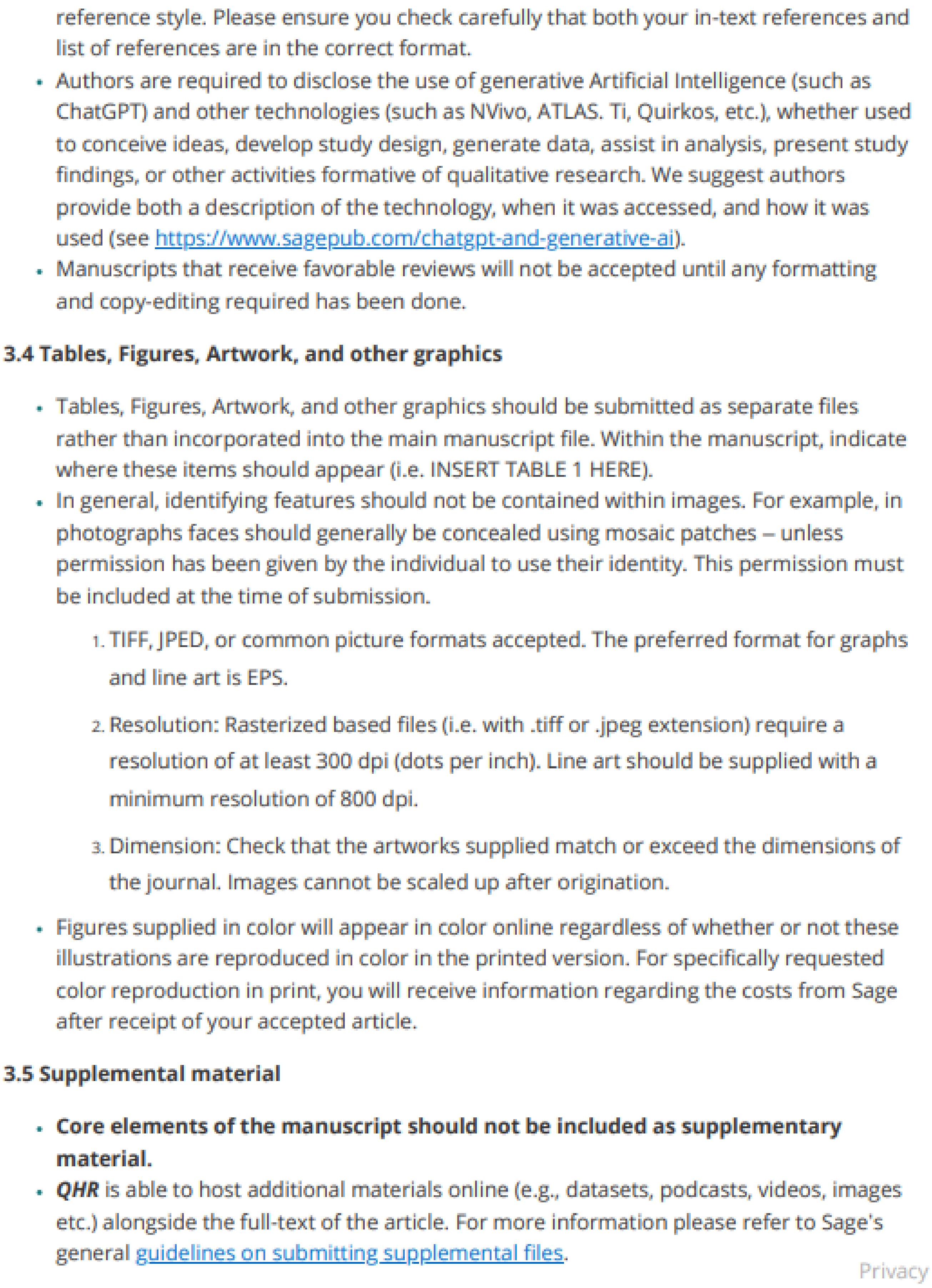
consent, whether the consent was written or verbal, and how it was obtained and by whom. For example: "Our study was approved by The Mercy Health Research Ethics Committee (approval no. XYZ123). All participants provided written informed consent prior to enrollment in the study." If your study did not need ethical approval (often manuscripts in the Pearls, Piths, and Provocations may not), we still need a statement that states that your study did not need approval and an explanation as to why. For example: "Ethical Statement: Our study did not require an ethical board approval because it did not directly involve humans or animals."

3.2 Abstract and Keywords

- The Abstract should be unstructured, written in narrative form. Maximum of 250 words. This should be on its own page, appearing as the first page of the Main Manuscript file.
- The keywords should be included beneath the abstract on the Main Manuscript file.

3.3 Manuscript

- Length: 8,000 words or less excluding the abstract, list of references, and acknowledgements. Please note that text from Tables and Figures is included in the word count limits. On-line supplementary materials are not included in the word limit.
- Structure: While many authors will choose to use headings of Background, Methods, Results, and Discussion to organize their manuscript, it is up to authors to choose the most appropriate terms and structure for their submission. It is the expectation that manuscripts contain detailed reflections on methodological considerations.
- Ethics: In studies where data collection or other methods present ethical challenges, the authors should explicate how such issues were navigated including how consent was gained and by whom. An anonymized version of the ethical statement should be included in the manuscript (in addition to appearing on the title page).
- Participant identification: Generally, demographics should be described in narrative form or otherwise reported as a group. Quotations may be linked to particular participants and/or demographic features provided measures are taken to ensure anonymity of participants (e.g., use of pseudonyms).
- Use of checklists: Authors should not include qualitative research checklists, such as COREQ (COnsolidated criteria for REporting Qualitative research). Generally, authors should use a narrative approach to describe the processes used to enhance the rigor of their study. For additional information on this policy, please read Why the *Qualitative Health Research* (QHR) Review Process Does Not Use Checklists
- References: APA format. While there is no limit to the number of references, authors are recommended to use pertinent references only, including literature previously published in *QHR*. References should be on a separate page. *QHR* adheres to the APA 7 reference style. View the APA guidelines to ensure your manuscript conforms to this



reference style. Please ensure you check carefully that both your in-text references and list of references are in the correct format.

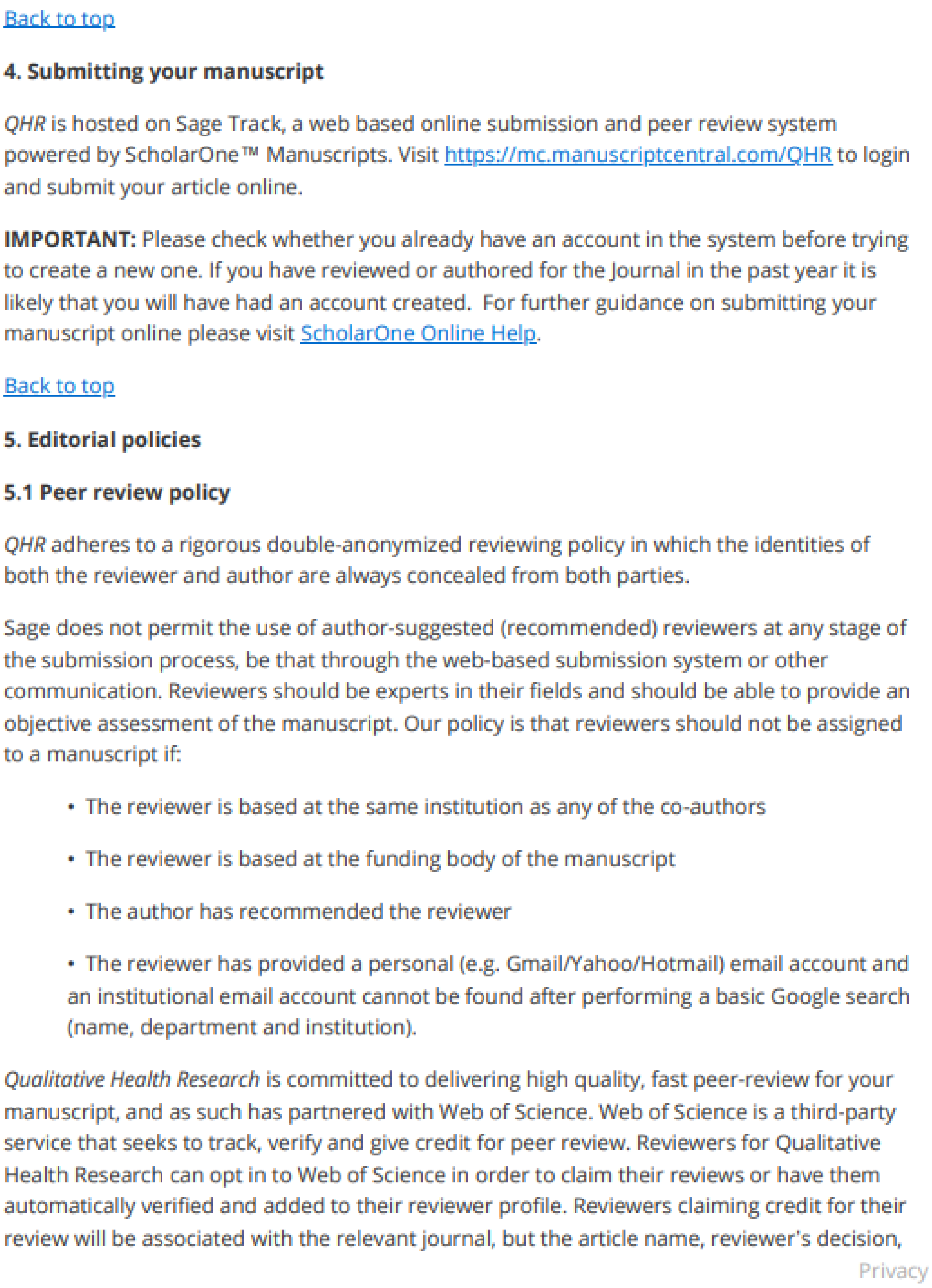
- Authors are required to disclose the use of generative Artificial Intelligence (such as ChatGPT) and other technologies (such as NVivo, ATLAS. Ti, Quirkos, etc.), whether used to conceive ideas, develop study design, generate data, assist in analysis, present study findings, or other activities formative of qualitative research. We suggest authors provide both a description of the technology, when it was accessed, and how it was used (see https://www.sagepub.com/chatgpt-and-generative-ai).
- Manuscripts that receive favorable reviews will not be accepted until any formatting and copy-editing required has been done.

3.4 Tables, Figures, Artwork, and other graphics

- Tables, Figures, Artwork, and other graphics should be submitted as separate files rather than incorporated into the main manuscript file. Within the manuscript, indicate where these items should appear (i.e. INSERT TABLE 1 HERE).
- In general, identifying features should not be contained within images. For example, in photographs faces should generally be concealed using mosaic patches – unless permission has been given by the individual to use their identity. This permission must be included at the time of submission.
    1. TIFF, JPED, or common picture formats accepted. The preferred format for graphs and line art is EPS.
    2. Resolution: Rasterized based files (i.e. with .tiff or .jpeg extension) require a resolution of at least 300 dpi (dots per inch). Line art should be supplied with a minimum resolution of 800 dpi.
    3. Dimension: Check that the artworks supplied match or exceed the dimensions of the journal. Images cannot be scaled up after origination.
- Figures supplied in color will appear in color online regardless of whether or not these illustrations are reproduced in color in the printed version. For specifically requested color reproduction in print, you will receive information regarding the costs from Sage after receipt of your accepted article.

3.5 Supplemental material

- **Core elements of the manuscript should not be included as supplementary material.**
- ***QHR*** is able to host additional materials online (e.g., datasets, podcasts, videos, images etc.) alongside the full-text of the article. For more information please refer to Sage's general guidelines on submitting supplemental files.



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4. Submitting your manuscript

QHR is hosted on Sage Track, a web based online submission and peer review system powered by ScholarOne™ Manuscripts. Visit https://mc.manuscriptcentral.com/QHR to login and submit your article online.

IMPORTANT: Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the Journal in the past year it is likely that you will have had an account created. For further guidance on submitting your manuscript online please visit ScholarOne Online Help.

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5. Editorial policies

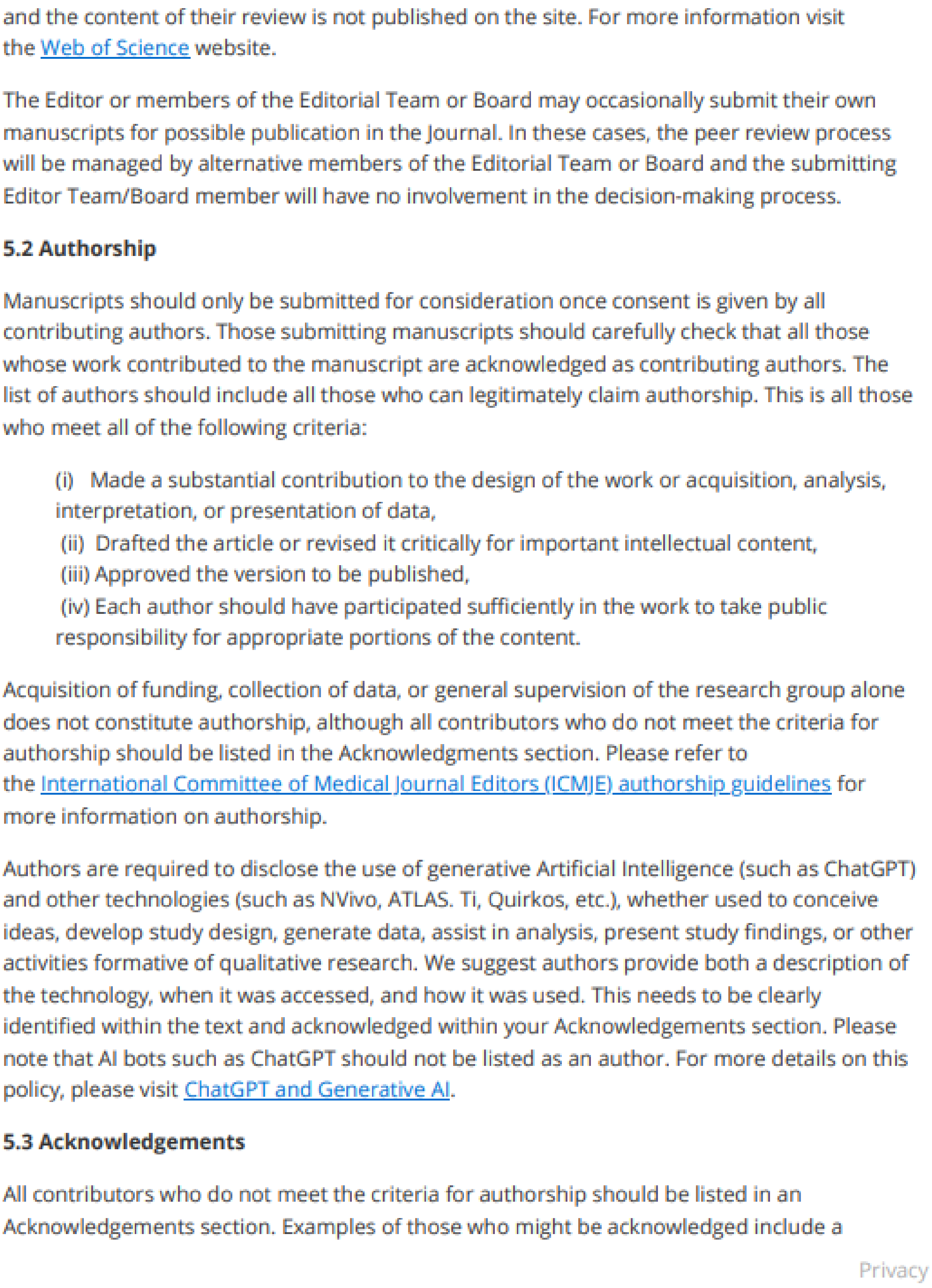
5.1 Peer review policy

QHR adheres to a rigorous double-anonymized reviewing policy in which the identities of both the reviewer and author are always concealed from both parties.

Sage does not permit the use of author-suggested (recommended) reviewers at any stage of the submission process, be that through the web-based submission system or other communication. Reviewers should be experts in their fields and should be able to provide an objective assessment of the manuscript. Our policy is that reviewers should not be assigned to a manuscript if:

- The reviewer is based at the same institution as any of the co-authors
- The reviewer is based at the funding body of the manuscript
- The author has recommended the reviewer
- The reviewer has provided a personal (e.g. Gmail/Yahoo/Hotmail) email account and an institutional email account cannot be found after performing a basic Google search (name, department and institution).

Qualitative Health Research is committed to delivering high quality, fast peer-review for your manuscript, and as such has partnered with Web of Science. Web of Science is a third-party service that seeks to track, verify and give credit for peer review. Reviewers for Qualitative Health Research can opt in to Web of Science in order to claim their reviews or have them automatically verified and added to their reviewer profile. Reviewers claiming credit for their review will be associated with the relevant journal, but the article name, reviewer's decision,



and the content of their review is not published on the site. For more information visit the Web of Science website.

The Editor or members of the Editorial Team or Board may occasionally submit their own manuscripts for possible publication in the Journal. In these cases, the peer review process will be managed by alternative members of the Editorial Team or Board and the submitting Editor Team/Board member will have no involvement in the decision-making process.

5.2 Authorship

Manuscripts should only be submitted for consideration once consent is given by all contributing authors. Those submitting manuscripts should carefully check that all those whose work contributed to the manuscript are acknowledged as contributing authors. The list of authors should include all those who can legitimately claim authorship. This is all those who meet all of the following criteria:

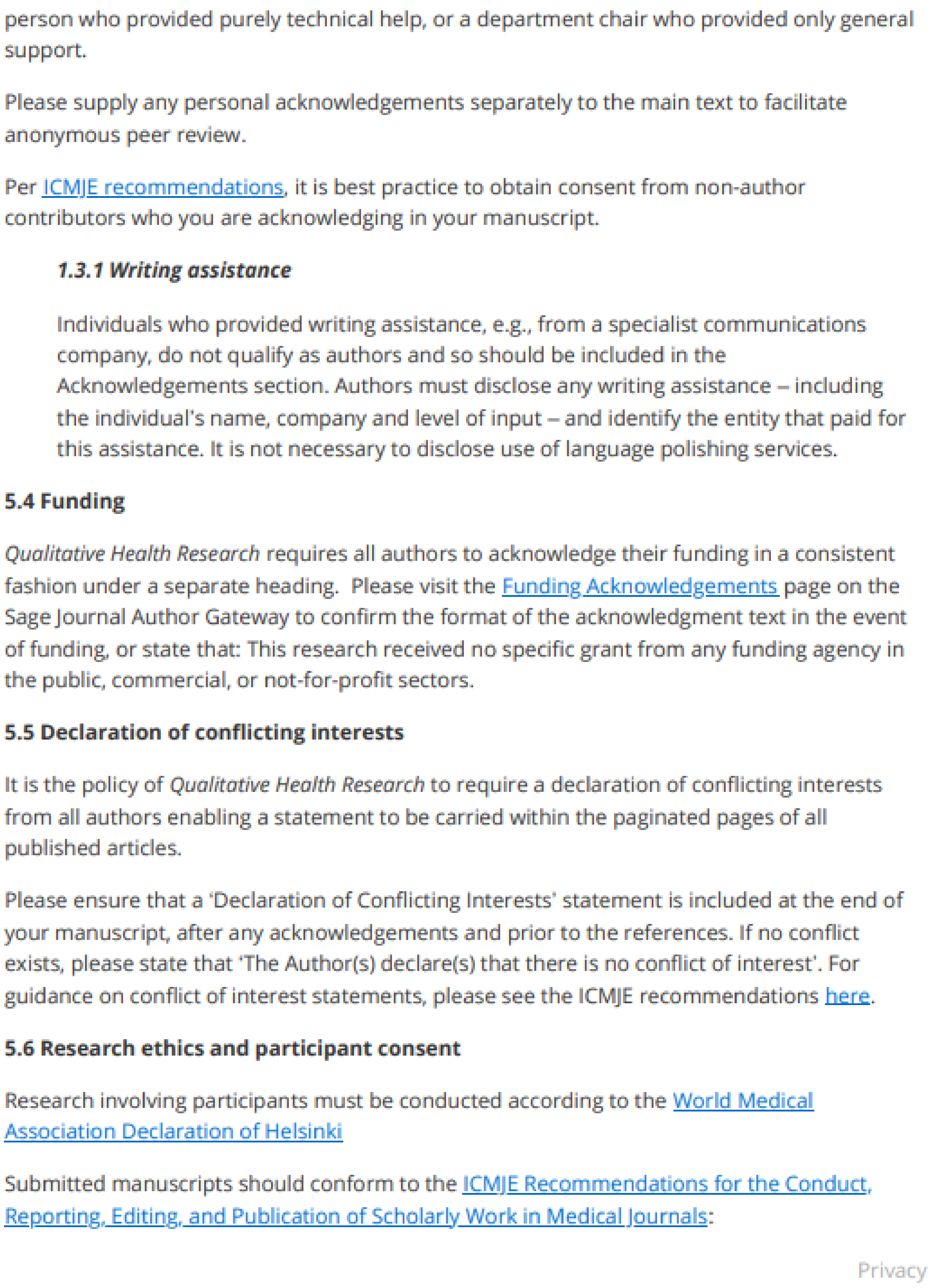
(i) Made a substantial contribution to the design of the work or acquisition, analysis, interpretation, or presentation of data,
(ii) Drafted the article or revised it critically for important intellectual content,
(iii) Approved the version to be published,
(iv) Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content.

Acquisition of funding, collection of data, or general supervision of the research group alone does not constitute authorship, although all contributors who do not meet the criteria for authorship should be listed in the Acknowledgments section. Please refer to the International Committee of Medical Journal Editors (ICMJE) authorship guidelines for more information on authorship.

Authors are required to disclose the use of generative Artificial Intelligence (such as ChatGPT) and other technologies (such as NVivo, ATLAS. Ti, Quirkos, etc.), whether used to conceive ideas, develop study design, generate data, assist in analysis, present study findings, or other activities formative of qualitative research. We suggest authors provide both a description of the technology, when it was accessed, and how it was used. This needs to be clearly identified within the text and acknowledged within your Acknowledgements section. Please note that AI bots such as ChatGPT should not be listed as an author. For more details on this policy, please visit ChatGPT and Generative AI.

5.3 Acknowledgements

All contributors who do not meet the criteria for authorship should be listed in an Acknowledgements section. Examples of those who might be acknowledged include a



person who provided purely technical help, or a department chair who provided only general support.

Please supply any personal acknowledgements separately to the main text to facilitate anonymous peer review.

Per ICMJE recommendations, it is best practice to obtain consent from non-author contributors who you are acknowledging in your manuscript.

1.3.1 Writing assistance

Individuals who provided writing assistance, e.g., from a specialist communications company, do not qualify as authors and so should be included in the Acknowledgements section. Authors must disclose any writing assistance – including the individual's name, company and level of input – and identify the entity that paid for this assistance. It is not necessary to disclose use of language polishing services.

5.4 Funding

Qualitative Health Research requires all authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit the Funding Acknowledgements page on the Sage Journal Author Gateway to confirm the format of the acknowledgment text in the event of funding, or state that: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

5.5 Declaration of conflicting interests

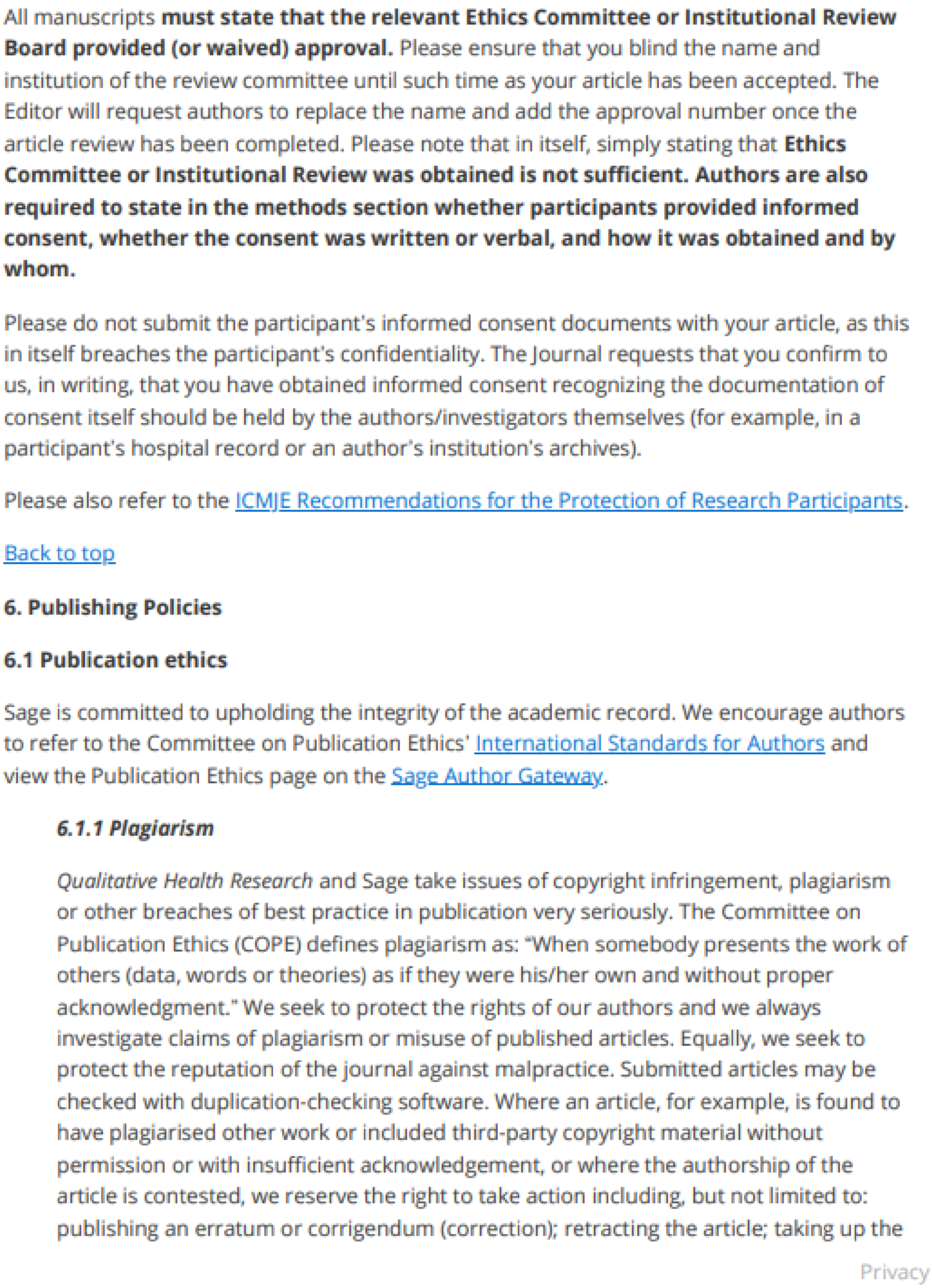
It is the policy of *Qualitative Health Research* to require a declaration of conflicting interests from all authors enabling a statement to be carried within the paginated pages of all published articles.

Please ensure that a 'Declaration of Conflicting Interests' statement is included at the end of your manuscript, after any acknowledgements and prior to the references. If no conflict exists, please state that 'The Author(s) declare(s) that there is no conflict of interest'. For guidance on conflict of interest statements, please see the ICMJE recommendations here.

5.6 Research ethics and participant consent

Research involving participants must be conducted according to the World Medical Association Declaration of Helsinki

Submitted manuscripts should conform to the ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals:



All manuscripts **must state that the relevant Ethics Committee or Institutional Review Board provided (or waived) approval.** Please ensure that you blind the name and institution of the review committee until such time as your article has been accepted. The Editor will request authors to replace the name and add the approval number once the article review has been completed. Please note that in itself, simply stating that **Ethics Committee or Institutional Review was obtained is not sufficient. Authors are also required to state in the methods section whether participants provided informed consent, whether the consent was written or verbal, and how it was obtained and by whom.**

Please do not submit the participant's informed consent documents with your article, as this in itself breaches the participant's confidentiality. The Journal requests that you confirm to us, in writing, that you have obtained informed consent recognizing the documentation of consent itself should be held by the authors/investigators themselves (for example, in a participant's hospital record or an author's institution's archives).

Please also refer to the ICMJE Recommendations for the Protection of Research Participants.

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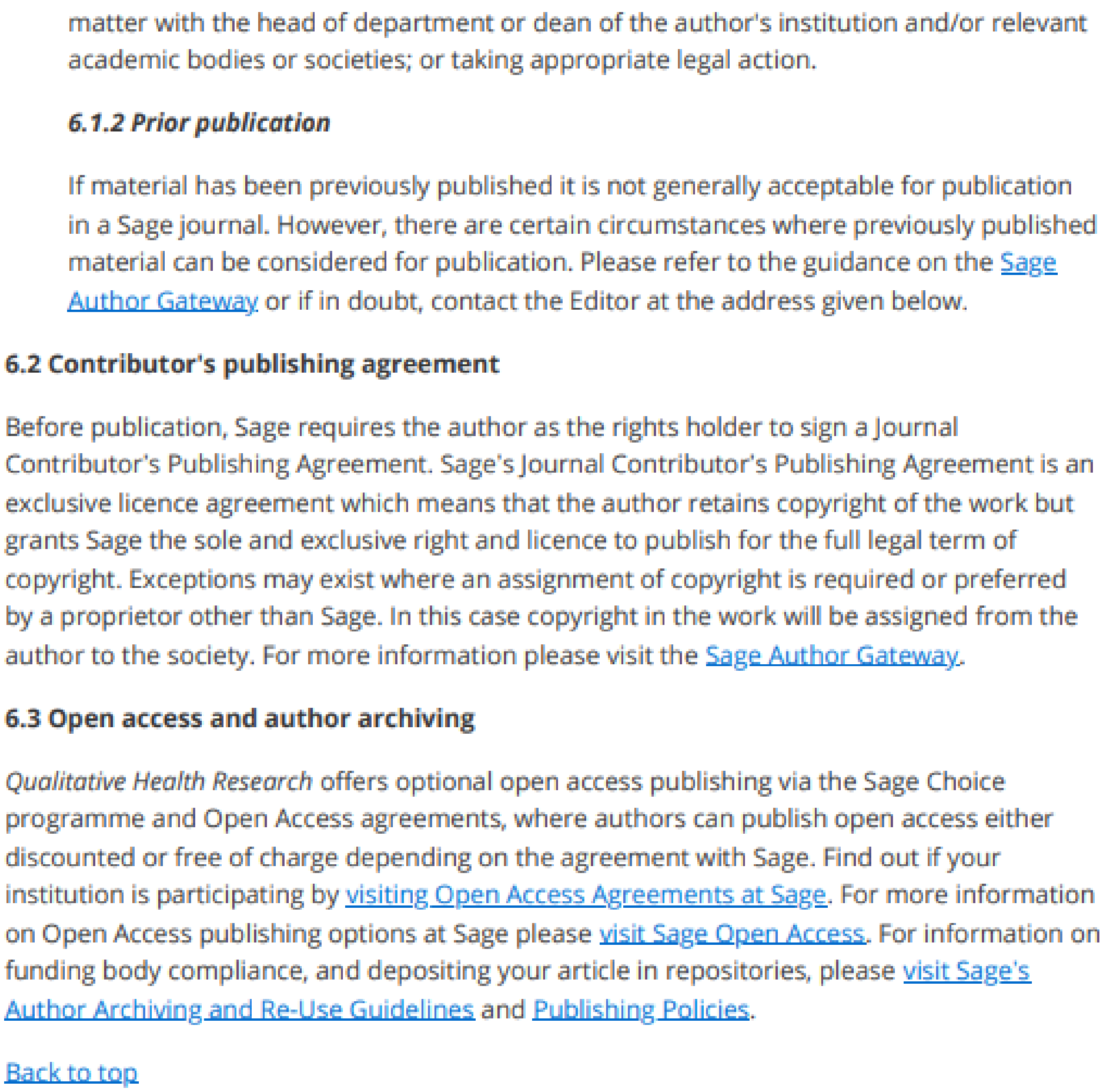
6. Publishing Policies

6.1 Publication ethics

Sage is committed to upholding the integrity of the academic record. We encourage authors to refer to the Committee on Publication Ethics' International Standards for Authors and view the Publication Ethics page on the Sage Author Gateway.

6.1.1 Plagiarism

Qualitative Health Research and Sage take issues of copyright infringement, plagiarism or other breaches of best practice in publication very seriously. The Committee on Publication Ethics (COPE) defines plagiarism as: "When somebody presents the work of others (data, words or theories) as if they were his/her own and without proper acknowledgment." We seek to protect the rights of our authors and we always investigate claims of plagiarism or misuse of published articles. Equally, we seek to protect the reputation of the journal against malpractice. Submitted articles may be checked with duplication-checking software. Where an article, for example, is found to have plagiarised other work or included third-party copyright material without permission or with insufficient acknowledgement, or where the authorship of the article is contested, we reserve the right to take action including, but not limited to: publishing an erratum or corrigendum (correction); retracting the article; taking up the



matter with the head of department or dean of the author's institution and/or relevant academic bodies or societies; or taking appropriate legal action.

6.1.2 Prior publication

If material has been previously published it is not generally acceptable for publication in a Sage journal. However, there are certain circumstances where previously published material can be considered for publication. Please refer to the guidance on the Sage Author Gateway or if in doubt, contact the Editor at the address given below.

6.2 Contributor's publishing agreement

Before publication, Sage requires the author as the rights holder to sign a Journal Contributor's Publishing Agreement. Sage's Journal Contributor's Publishing Agreement is an exclusive licence agreement which means that the author retains copyright of the work but grants Sage the sole and exclusive right and licence to publish for the full legal term of copyright. Exceptions may exist where an assignment of copyright is required or preferred by a proprietor other than Sage. In this case copyright in the work will be assigned from the author to the society. For more information please visit the Sage Author Gateway.

6.3 Open access and author archiving

Qualitative Health Research offers optional open access publishing via the Sage Choice programme and Open Access agreements, where authors can publish open access either discounted or free of charge depending on the agreement with Sage. Find out if your institution is participating by visiting Open Access Agreements at Sage. For more information on Open Access publishing options at Sage please visit Sage Open Access. For information on funding body compliance, and depositing your article in repositories, please visit Sage's Author Archiving and Re-Use Guidelines and Publishing Policies.

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Appendix E. Recruitment Email sent to Pain Clinicians

“Dear Clinicians,

You have been sent this email as you currently work at a chronic pain management service. My colleagues and I are conducting a research study to explore the pain management clinicians’ perspectives on working with patients living with fibromyalgia. This research study has been given favourable opinion by UEA FMH SREC. It is hoped that this research will inform areas of improvement for the management of fibromyalgia, and your involvement is a valued part of this process. If you are interested in participating, then please see the attached participant information sheet and poster advertising the research.

Kind Regards,

Olivia Sutton
Trainee Clinical Psychologist and Chief Investigator

IRAS Project ID: 320204”

Appendix F. Participant Information Sheet

Participant Information Sheet
What are pain clinician's perceptions of patients with fibromyalgia, and does this influence the patient professional encounter?

Please note, this document contains a lot of information to help you decide whether you would like to participate or not. You may wish to read it more than once, or in stages.

We would like to explore your reflections on working with patients living with fibromyalgia, to understand your perceptions, some of the challenges you experience, the dilemmas and how you negotiate these, as well as the aspects you consider are managed well.

What's involved?

As a participant in this study, you would be interviewed by the chief investigator about your experience of working as a clinician in a chronic pain service, with patients living with fibromyalgia. We will ask you questions about your experiences, the difficulties you face, and how you overcome these. We are looking to recruit 15 participants for this research.

Purpose and Background to the Research

There is a wealth of evidence demonstrating the uncertainty around treatment of fibromyalgia, and the resulting dissatisfaction people with fibromyalgia experience. In addition, there are several challenges associated with living with fibromyalgia, including physical problems, mental health difficulties, stigma, and misunderstanding.

It is understood that working with people living with fibromyalgia can cause some apprehension due to the uncertainty around managing the condition and awareness of the difficulties associated with this. There is some evidence which shows different perspectives between disciplines and services; however, perspectives of specialist pain clinicians are lacking in the literature. Some research suggests a more positive experience for fibromyalgia patients in specialist pain management clinics, however preliminary focus groups revealed clinicians' ongoing challenges and concerns. We are seeking to understand your experiences of working with fibromyalgia to further explore perceptions, dilemmas, and challenges for you as a specialist clinician.

The aim of this research is to consider how clinician's perceptions of fibromyalgia play a role in the management of the condition.

What would taking part involve?

If you decide to take part, you will be required to give fully informed consent by signing an electronic consent form before your interview. You will be given at least 48 hours between receiving this information sheet and being asked for consent to ensure you have time to decide whether you want to take part.

You will be required to contact the chief investigator if you would like to take part. This is to ensure you do not feel inclined to participate if you do not wish to. You will then have any questions about the research answered fully. Once you are happy to participate, an interview time will be agreed by you and the chief investigator. The interview will last up to an hour and will take place via *Microsoft Teams.* All interviews will be audio recorded for the purpose of analysis, and then transcribed verbatim via the *Microsoft Teams* automated transcription software. Transcripts will be reviewed and anonymised so no one can identify you; once this is complete you will have a 10-day window of opportunity to provide comment or correction on your transcript. Only the research team will have access to your consent form, audio recording and transcript. Your audio recording will be deleted once your transcript is finalised.

We appreciate the sensitivity of this topic, and therefore we will ensure your involvement is confidential, data will be pseudonymised and quotes will be anonymised. It is hoped that this research will contribute to improvements for management of fibromyalgia and your involvement will inform part of this process, therefore we are open to hearing all perspectives. In addition, the research report will ensure a sensitive portrayal of the matters identified within the research.

You will only be a participant in this study for the duration of the interview. Once this is complete you will be fully debriefed.

What are the possible benefits of taking part?

This study may help to guide services on how to support clinicians to overcome some of the challenges faced when working with patients with fibromyalgia and may be helpful to improve patient care. Your involvement is an important part of this process. However, we cannot guarantee that taking part in this research will result in any benefits to you.

As a thank you for your time, by taking part you will receive a £10 *Amazon* electronic voucher. We will send this to you via email, which you will provide on your consent form.

What are the possible disadvantages and risks of taking part?

We anticipate that risks of taking part will be minimal. However, as your participation may require discussion of sensitive topics you may experience some discomfort (this is not our intention and is subjective to each participant). Should this happen, you have the right to refuse to answer questions. You may also withdraw from the study at any point prior to data analysis, and you do not have to provide a reason for this.

Your information will always be treated confidentially. All data will be accessed via an NHS computer and stored on a UEA password protected OneDrive. Your consent form, participant identification number, and all other study data (i.e., the transcript of your interview), will be stored in separate folders in the OneDrive which will need a password to access. Confidentiality will only be broken if we deem you, or someone else to be at risk. In this instance we will discuss this with you and then amongst the research team. If it is deemed that action needs to be taken, then we may ask to contact your line manager.

The interview will be carried out by the investigator in a confidential space. For your own confidentiality, we advise that you join the remote interview in a private room where you feel comfortable to speak openly about your experiences. Furthermore, as the interviews will require you discuss your clinical experiences, we ask that you do not use patient identifiable information and use pseudonyms if necessary.

Your data will be handled according to the UK Data Protection Act and the General Data Protection Regulation (GDPR, 2018). Once we have finished the study, we will keep some of the data so we can check the results. As per the University of East Anglia's research data management policy, your data will be stored securely and destroyed 10 years after the study has ended.

What if I don't want to carry on?

You may withdraw from the study at any point prior to data analysis and you do not have to give a reason for withdrawing. In this instance, you may contact an investigator to make your wish to withdraw known. You will need your participant number to do this (given to you at the interview).

Who is organising and funding the research?

The chief investigator is Olivia Sutton, a Trainee Clinical Psychologist at the University of East Anglia (UEA), employed by Cambridge and Peterborough NHS Foundation Trust. The research is sponsored by the UEA.

The research team also includes Dr Elisabeth Norton, a Clinical Psychologist working at the Norfolk and Norwich University Hospitals NHS Foundation Trust (NNUH) pain clinic; and Dr Sarah Fish, a Clinical Psychologist working at Norfolk and Suffolk Foundation Trust (NSFT) and a Clinical Lecturer at the UEA.

Who has checked the study?

All research within the UEA is checked by the university's Faculty of Medicine and Health Sciences Research Ethics Subcommittee. This research has been given favourable opinion by the FMH S-REC. Additionally, research taking place within the NHS is reviewed by the Health Research Authority to ensure quality and safety standards are met.

How have patients and the public been involved in this study?

Preliminary focus groups with pain clinicians have guided the development of this research, as well as the topic guide and this information sheet.

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
- Job role
- Duration having worked in a specialist pain clinic
- Age
- Gender
- Ethnicity

People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.
- If you lose capacity at any point whilst the study is being carried out, then the investigators will not take any further information from you, but they will keep information which has already been obtained.

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/
- our leaflet available from www.hra.nhs.uk/patientdataandresearch
- by asking one of the research team
- by sending an email to Olivia.Sutton@uea.ac.uk, Elisabeth.Norton@nnuh.nhs.uk or sarah.fish@uea.ac.uk
- in addition, you may contact the UEA's or your Trust's Data Protection Officer:
    - UEA: David Bridge, dataprotection@uea.ac.uk
    - The Queen Elizabeth Hospital: Dr Antonia Hardcastle, Antonia.hardcastle@qehkl.nhs.uk
    - East Suffolk and North Essex NHS Foundation Trust: FOI@esneft.nhs.uk
    - Stamford and Rutland Hospital / North West Anglia Foundation Trust: nwangliaft.dpo@nhs.net
    - Addenbrooke's / Cambridge University Hospital: information.governance@nhs.net

What will happen to the results of this study?

The results of this study will be included in a full research report as part of a thesis portfolio for a UEA Clinical Psychology doctorate. It is intended that this report will be published to a relevant peer reviewed journal. You can consent to having a summary of the results shared with you via email, once the study is complete.

What to expect during the consent process

Prior to your interview, you will be sent an electronic consent form to read and sign if you wish to participate.

Further information and contact details
Should you have any queries or concerns, please contact the chief investigator Olivia Sutton at Olivia.sutton@uea.ac.uk

Am I eligible to participate?
In order to participate you must be a current clinician working in a specialist pain management service. You need to have worked in the service for at least 6 months. In addition, as this research relies on interviews, you will not be able to participate if you are not a fluent English speaker.

What if there is a problem or something goes wrong?
If you are concerned about anything relating to the research, please speak to someone from the research team and we will try our best to help you.

I you wish to make a complaint about the research or investigators, then please contact Dr Sian Coker, Professor of Psychology with the UEA ClinPsyD Programme (s.coker@uea.ac.uk). Dr Coker is separate from the research team. Alternatively, you may contact an investigator: Olivia.sutton@uea.ac.uk or Elisabeth.Norton@nnuh.nhs.uk or Sarah.fish@uea.ac.uk

What happens next?
Thank you for reading this information sheet. Please contact us if you have any questions.

If you are interested in participating in this research, then please email the chief investigator to express your interest at: Olivia.Sutton@uea.ac.uk with the subject titled: “fibromyalgia research”. You will receive a response no later than one week after your email to answer any questions you may have, and to organise your interview.

Appendix G. Recruitment Poster

Research Opportunity

Pain Clinician’s perceptions of fibromyalgia

We are looking for pain clinicians to take part in research exploring their perceptions on fibromyalgia.

Fibromyalgia is difficult for those who live with it and can be difficult for clinicians to best take care of patients’ needs. The aims of the study are to learn about your experiences and perceptions surrounding working with and treatment for those living with fibromyalgia.

The research involves an interview with the lead investigator, via Microsoft Teams. You will be asked about your experiences and challenges you have come across and how you negotiate these. The interview is estimated to last up to one hour.

If you are interested in knowing more then please email Olivia Sutton, the lead investigator at: Olivia.sutton@uea.ac.uk

NHS

UEA
University of East Anglia

Supervised by Dr Elisabeth Norton and Dr Sarah Fish

07/11/2022 Version 2.0 IRAS ID: 320204

Appendix H. Participant Consent Form

Your participant identification number will be agreed with you at your interview. It will be helpful if you make a note of this, as you will need this if you wish to withdraw from the study.

CONSENT FORM

What are pain clinician's perceptions of patients with fibromyalgia, and does this influence the patient professional encounter?

Name of investigators: **Olivia Sutton (Trainee Clinical Psychologist), Dr Elisabeth Norton (Clinical Psychologist) and Dr Sarah Fish (Clinical Psychologist)**

1. I confirm that I have read and understand the information sheet dated 20/12/2022 (version 4) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	**Initial Box** ☐
2. I understand and consent for my interview to be audio recorded.	**Initial Box** ☐
3. I understand that my data will be stored and handled according to the UK Data Protection Act and the General Data Protection Regulation.	**Initial Box** ☐
4. I understand that my participation is voluntary and that I am free to withdraw at any time (up until the data analysis of the study) without giving any reason, and none of my rights will be affected, in particular my terms of employment.	**Initial Box** ☐
5. Once the study is complete, I would like a summary of the results to be emailed to me at: ____	**Initial Box** ☐
6. I agree to take part in the above study.	**Initial Box** ☐

____________________	____________________	____________________
Name of Participant in full	**Date in full**	**Signature**
____________________	____________________	____________________
Name of Person taking consent in full	**Date in full**	**Signature**

Please scroll down as there is further information on the next page

Amazon voucher

As a token of appreciation for your participation, we would like to offer you a £10 *Amazon* voucher. This will be sent to you via email. Please provide an email address (if this is the same as above then please leave blank): ____

Participant Demographic Information

This information will be used by the investigators to give demographic details of the participants in the research report, to inform the findings. If you do not wish to answer, then please write "prefer not to say".

Job role: ____
Duration working in a specialist pain clinic: _______________________________________
Gender: ____
Age: ____
Ethnicity: ____

---

1 for participant; 1 for researcher.

Appendix I. Semi-Structured Interview Topic Guide

1. What immediately comes to mind when thinking about working with patients living with fibromyalgia?

2. What are the challenges? Why do you think this is?
   What do you do to manage this / How do you respond? Why do you think this is?
   (Prompt for more than one challenge / more than one facet to a challenge

3. What do you enjoy about working with people living with fibromyalgia? How do you know when things have gone well?

4. How do you feel interactions are different with those with fibromyalgia, versus other pain presentations (prompt for: differences in clinic appointments, how you approach your clinic)

5. How does it make you *feel* when you speak with a fibromyalgia patient in your clinic? (prompt for before, during, after – are there differences in each stage?)

6. Are there times when you feel differently about the things you’ve shared today?

Appendix J. Ethical Approval from the University of East Anglia's Faculty of Medicine & Health Sciences Research & Ethics Committee

University of East Anglia

Study title: What are pain clinician's perceptions of patients with fibromyalgia, and does this influence the patient professional encounter?

Application ID: ETH2223-0095

Dear Olivia,

Your application was considered on 17th November 2022 by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee).

The decision is: **approved**.

You are therefore able to start your project subject to any other necessary approvals being given.

If your study involves NHS staff and facilities, you will require Health Research Authority (HRA) governance approval before you can start this project (even though you did not require NHS-REC ethics approval). Please consult the HRA webpage about the application required, which is submitted through the IRAS system.

This approval will expire on **4th March 2024**.

Please note that your project is granted ethics approval only for the length of time identified above. Any extension to a project must obtain ethics approval by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) before continuing.

It is a requirement of this ethics approval that you should report any adverse events which occur during your project to the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) as soon as possible. An adverse event is one which was not anticipated in the research design, and which could potentially cause risk or harm to the participants or the researcher, or which reveals potential risks in the treatment under evaluation. For research involving animals, it may be the unintended death of an animal after trapping or carrying out a procedure.

Any amendments to your submitted project in terms of design, sample, data collection, focus etc. should be notified to the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) in advance to ensure ethical compliance. If the amendments are substantial a new application may be required.

Approval by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) should not be taken as evidence that your study is compliant with the UK General Data Protection Regulation (UK GDPR) and the Data Protection Act 2018. If you need guidance on how to make your study UK GDPR compliant, please contact the UEA Data Protection Officer (dataprotection@uea.ac.uk).

Please can you send your report once your project is completed to the FMH S-REC (fmh.ethics@uea.ac.uk).

I would like to wish you every success with your project.

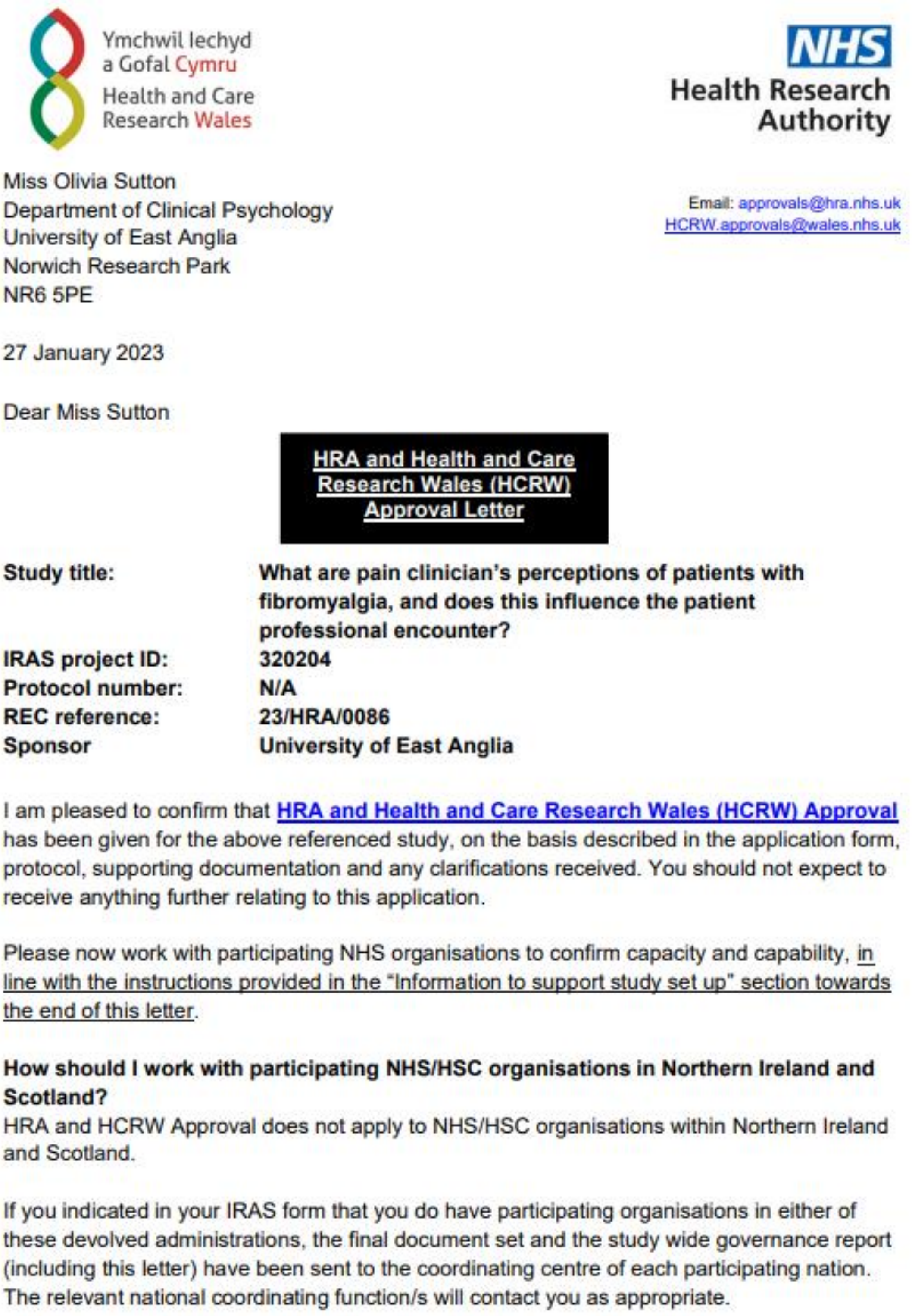
On behalf of the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee)

Yours sincerely,

Paul Linsley

Ethics ETH2223-0095 : Miss Olivia Sutton

Appendix K. Ethical Approval from the Health Research Authority and Health and Care Research Wales



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

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

Miss Olivia Sutton
Department of Clinical Psychology
University of East Anglia
Norwich Research Park
NR6 5PE

27 January 2023

Dear Miss Sutton

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

Study title:	**What are pain clinician's perceptions of patients with fibromyalgia, and does this influence the patient professional encounter?**
IRAS project ID:	**320204**
Protocol number:	**N/A**
REC reference:	**23/HRA/0086**
Sponsor	**University of East Anglia**

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 "*After HRA Approval – guidance for sponsors and investigators*" document on the HRA website gives detailed guidance on reporting expectations for studies with HRA and HCRW Approval, 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 **320204**. Please quote this on all correspondence.

Yours sincerely,
Hayleigh Keating
Approvals Specialist

Email: approvals@hra.nhs.uk

Copy to: *Tracy Moulton*

Appendix L. Example of Transcript and Coding

Key:

- Highlighted text is that which was coded
- (Highlighted text in brackets) were initial codes

Participant

Well, I mean, you know, it's quite important to validate their position (validation). Erm, but actually I quite like, quite like… so, yeah. So it's one of those things that I feel in one session you can from majority people, you can swing them around a little bit (challenging patients' narratives) (selling the treatment).

Investigator

OK.

Participant

So I quite like in our pain management information session, they don't come in as disgruntled as they used to be. But when we have those sessions, you know people come in and kind of go "what's all this about?" and "what are you going to possibly do in an hour?" and "blah blah blah" (patients are frustrated) (selling the treatment).

Investigator

Mm

Participant

And then when they walk out, they're like "oh, actually that was really interesting. Thank you very much." (enjoying turning patients around). So then when they come to the therapy assessment and maybe they're still a bit cheesed off, even after even after that. (patients are frustrated) (patients are sceptical of therapies)

Investigator

Yeah.

Participant

You know, I think if you validate their position and kind of, you know in a way hear what they're saying.(validation) But then I also kind of think I also try to communicate to them that I wouldn't be in my in my job if I didn't think people could turn things around (careful communication) (inspiring hope) , make you know and maybe it's my (removed for confidentiality) or my sense of humour. But I do kind of say "you know, if all I'm going to tell you is 'well, this is good as it gets and take care and wish you all the best and bye now.' I said I couldn't- I couldn't *be* in a job like that."(optimism and positive feelings) (inspiring hope) (advocating and cheerleading)

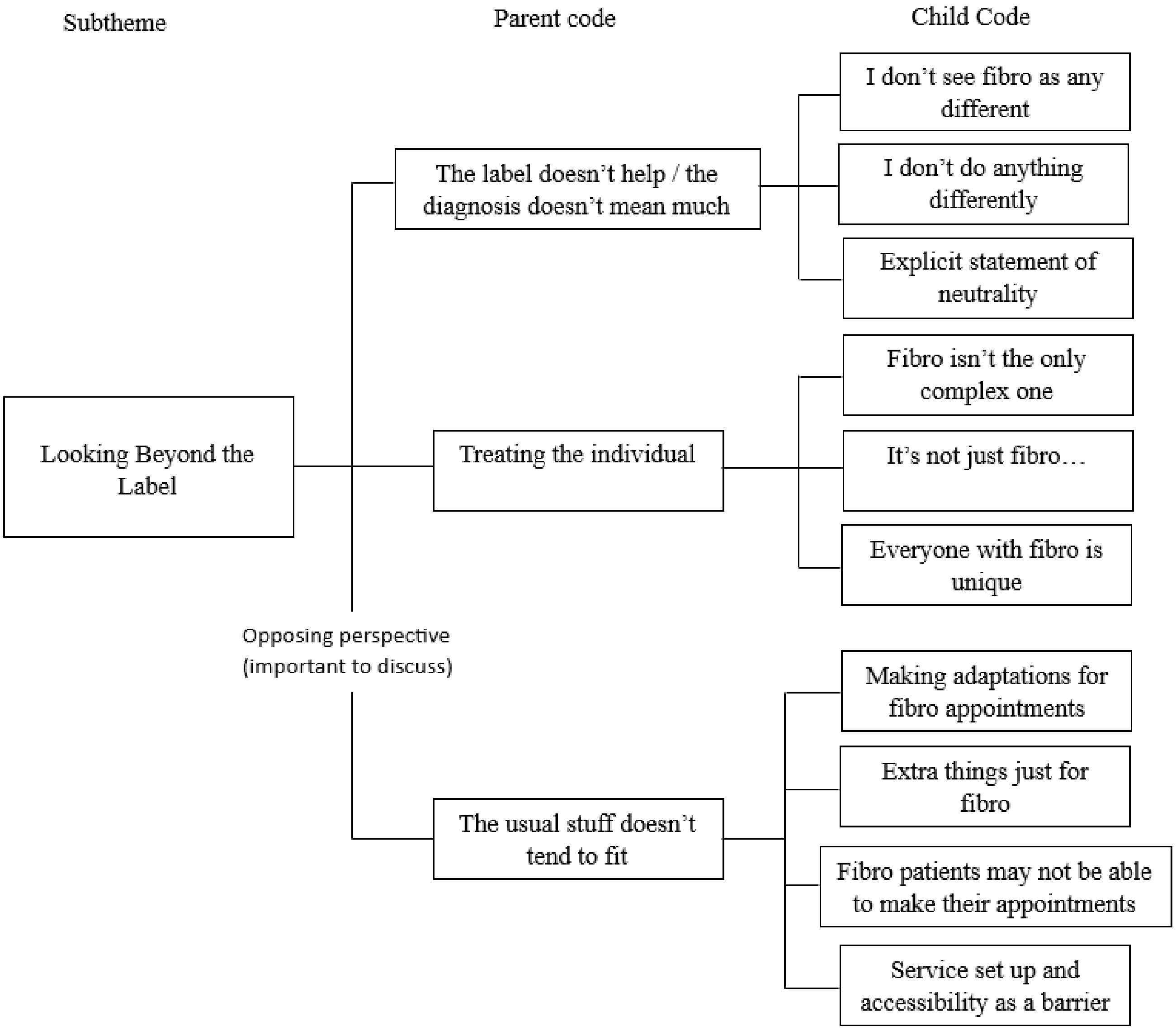
Investigator

No, yeah.

Participant

So I kind of say "you know I'm in this because I know people *can* make changes, people *can* improve their quality of life.(inspiring hope) (optimism and positive feelings) Erm you know, albeit that it's not easy and it's not what you chose and you did not wake up one day and think 'I would like fibromyalgia'"(validation) (empathy, understanding and putting yourself in the patients' shoes).

Appendix M. An Example of a Coding Tree for the Empirical Research



Appendix N. Reflective Journal Extract

The following extract was written immediately following an interview with a participant, at around the mid-stage of recruitment:

This interview was interesting and brought up lots of thoughts and feelings which have been building across each interview I complete. Mainly, a feeling of discomfort when returning to the interview questions after a period of more free-flowing discussion. This seems to be because a few of the participants (including today's) expressed pretty early on in the interview that they feel fibromyalgia is no different to any other pain presentation they treat. So, this means I then feel like I'm challenging people in what I'm asking, when for the entire interview I continue to ask about fibromyalgia *specifically,* and this begins to feel very uncomfortable for me and probably for them too. But I am wondering *why* I feel uncomfortable though. It almost feels as if people feel the need to defend their neutrality on the topic of fibromyalgia, perhaps because they're so aware of the stigma and negative attitudes of others. Today's participant seemed a little bit disgruntled at times that I was asking the questions specifically about fibromyalgia when they had already stated that they do not see or treat people living with fibro as any different to anyone else. This made me feel like I had to justify the question each time, and that I was interested to hear their answers no matter which perspective they hold. It feels like a hard path to tread and I'm not sure why. The interview itself feels quite controversial at times and this seems at odds with the perspective participants are expressing in that fibromyalgia is not a controversial topic / patient group.