



## Original Article

# Perspectives on Group-Based Physical Activity Interventions for Fibromyalgia: A Qualitative Study

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## Abstract

**Objectives:** Fibromyalgia is a chronic condition characterised by persistent pain, fatigue, and poor sleep, with major impacts on quality of life, psychological wellbeing, and disability. Physical activity is a cornerstone of management, and the National Institute for Health and Care Excellence recommends supervised programmes tailored to individual needs. Yet, people with fibromyalgia frequently face barriers to physical activity, and few studies have explored experiences of group-based interventions. This study examined the perspectives of adults with fibromyalgia on group-based physical activity to identify challenges and inform future practice. **Methods:** Two focus groups were conducted with participants (n=8) recruited from Musculoskeletal and Pain Management Services in NHS Ayrshire and Arran. Discussions were audio-recorded, transcribed, and thematically analysed by three independent researchers. **Results:** An overarching theme was a lack of understanding of the impact of fibromyalgia and a desire for validation. This was evident across all discussions. Two further themes were identified: the challenges of engaging in physical activity, and priorities for intervention design and delivery. Participants emphasised the need for practitioners who recognise the fluctuating nature of fibromyalgia and who demonstrate empathy, openness, and collaboration. **Conclusions:** Findings highlight the importance of practitioner understanding and patient-centred design in developing acceptable group-based physical activity interventions for people with fibromyalgia.

**Keywords:** Chronic Pain, Exercise, Fibromyalgia, Group-based Physical Activity, Pain Management

## Introduction

### What is Fibromyalgia?

Fibromyalgia syndrome (FMS) is a complex condition characterised by widespread persistent pain, fatigue, poor sleep quality and cognitive difficulties<sup>1</sup>. It affects approximately 2-5% of the global population depending on the criteria used, and the estimated UK prevalence is approximately 5.4%<sup>2-3</sup>. The impact of FMS at the individual and societal levels is significant. Many sufferers report poorer health related quality of life, greater psychological distress, and higher levels of disability than their age-matched controls<sup>4</sup>. People with FMS also have significantly more comorbidities, higher associated healthcare costs, and lower income from employment when compared to age-matched controls<sup>5</sup>.

### Why is PA important in FMS?

The management of FMS is challenging, and, as with many chronic pain conditions, no one treatment has been shown to be universally effective<sup>6</sup>. Clinical guidelines recommend non-pharmacological treatment approaches

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as the mainstay of management. Physical activity (PA) interventions are highly recommended by The European Alliance of Associations for Rheumatology (EULAR) due to their “effect on pain, physical function and well-being, availability, relatively low cost and lack of safety concerns”<sup>7</sup>. PA is defined as “any bodily movement produced by skeletal muscles that results in energy expenditure”, whilst exercise is defined as “a subset of PA that is planned, structured, and repetitive and has as a final or an intermediate objective the improvement or maintenance of physical fitness”<sup>8</sup>. Recent systematic reviews have reported positive effects of PA on pain intensity, physical function, fatigue, balance and sleep quality in people with FMS<sup>9,10</sup>.

The National Institute for Health and Care Excellence (NICE) recommend supervised exercise programmes which “take people’s specific needs, preferences and abilities into account” as part of the management of chronic primary pain conditions like FMS. However, engaging in such programmes can be a major challenge for this population<sup>11,12</sup>. Tolerating the pain associated with being active is often reported as a significant barrier and many sufferers state that they do not believe PA or exercise improves pain, which often results in poor adherence<sup>13,14</sup>. Furthermore, focus group responses outlined by McVeigh et al.<sup>13</sup> suggest that the fatigue associated with FMS is perceived as one of the biggest factors preventing people from taking part in PA, despite the simultaneous report that sixty per cent of respondents felt exercise improved feelings of well-being. Russell et al.<sup>11</sup> emphasised the need for healthcare professionals to “appreciate the enormity” of the challenges faced by people with FMS and “approach exercise prescription with empathy and understanding”.

### **Aims and Objectives**

Although evidence and clinical guidelines endorse supervised physical activity (PA) programmes as a core component in the management of FMS<sup>7</sup>, people with the condition often encounter considerable barriers to participation. Yet, few qualitative studies have explored experiences of group-based PA interventions specifically. This study sought to address this gap by recruiting adults with FMS to share their perspectives on group-based PA, with the aim of developing a deeper understanding of current challenges and informing the future design and delivery of such interventions.

## **Methods**

### **Design**

This qualitative report used focus groups to explore and understand the perspectives of adults living with fibromyalgia and their views on group based physical activity interventions. Two focus groups, each lasting 60 minutes, were conducted at a community health centre in Ayrshire, Scotland. Each group included four adults

with lived experience of Fibromyalgia. The facilitator was an experienced physiotherapist with expertise in musculoskeletal conditions and experience of working within Pain Management services (MP). The facilitator was supported by two assistants, one Specialist Pain Management Physiotherapist (EM) and one Physiotherapy Assistant Practitioner (WC), both with extensive experience in working with people with Fibromyalgia and in facilitating group discussions. The assistants recorded the focus groups using a dictaphone supplied by the University of Strathclyde and took field notes on non-verbal cues and poignant discussion points to assist the researcher in the analysis.

Thematic analysis (TA) was undertaken to identify and analyse patterns within the focus group discussions. TA is an easily accessible and theoretically flexible interpretative approach to qualitative data analysis with the potential to produce a rich and detailed account of the data<sup>15</sup>. TA is a relatively easy and quick method to learn, can be useful for producing qualitative analyses that support policy development, and allows participants to be involved in the research as ‘collaborators’ as opposed to ‘subjects’<sup>16</sup>.

### **Recruitment**

Eight participants (7 females; 1 male) were purposively sampled from the caseloads of physiotherapists working in the Musculoskeletal and Pain Management services within NHS Ayrshire and Arran, Scotland, United Kingdom. Participants eligible for inclusion were those who: 1) were over 18 years of age; 2) had a diagnosis of Fibromyalgia (in line with ACR 2010 criteria for diagnosing Fibromyalgia<sup>17</sup>); and 3) had attended some form of group-based physical activity intervention prior to taking part in the study. Participants were all under the care of a Physiotherapist either within the Musculoskeletal Physiotherapy department or the Pain Management Physiotherapy team at the time of recruitment. The ratio of male to female participants appears to be representative of the wider population in terms of the published literature, however, as Wolfe et al.<sup>2</sup> explains, there are still significant challenges in the diagnosis of the condition. They state that “The perception of fibromyalgia as almost exclusively (≥90%) a women’s disorder is not supported by data in unbiased studies”. Future studies may yield different outcomes in recruitment patterns as diagnostic criteria are adjusted.

Physiotherapists within NHS Ayrshire and Arran Musculoskeletal and Pain Management Services were provided with an information sheet (Appendix 1) outlining the research study and the above inclusion/exclusion criteria. They were asked to identify potential participants at their initial assessment if they met this criterion and to provide them with a Participant Information Sheet (PIS - Appendix 2). After participants had read the PIS, written consent was obtained allowing the researcher to contact them by telephone to discuss further and they were invited

to take part in the study. Before taking part in the focus group, written informed consent was obtained, in person, by the researcher, at the focus group location. Participants were made aware they could withdraw at any time.

### **Data Collection**

A topic guide (Appendix 3) was developed based on the research objective of exploring and understanding the perspectives of adults living with fibromyalgia and their views on group based physical activity interventions. The structure and content of this guide did not change between focus groups but was designed to enable the facilitator to engage flexibly with the participants. Emphasis was placed on ensuring the participants were encouraged to interact and explore ideas, whilst the guide included probes to encourage participants to elaborate on their responses and to allow them the opportunity to provide clarification and detail. The topic guide was developed by facilitator (MP) and reviewed by the research team (FM, CD and AM). Demographic information was collected at the recruitment stage. Focus groups were audio recorded and transcribed verbatim independently by a reputable transcription company and checked for accuracy against the audio recording by the researcher (MP). All data were collected, managed, and stored securely according to the Data Protection Act (1998) and in accordance with NHS research ethics guidelines. Participant data (including demographic data, electronic copies of consent forms and focus group transcriptions) were stored securely on the researchers encrypted University of Strathclyde OneDrive.

### **Data Analysis**

Focus group transcripts were analysed using thematic analysis (TA) as described by Braun and Clarke<sup>16</sup>. Six stages of analysis were followed: 1) data familiarisation; 2) generating initial codes; 3) generating initial themes; 4) developing and reviewing potential themes; 5) refining, defining and naming themes; and 6) writing up.

#### **Step 1 – Data Familiarisation**

The first stage involved the lead researcher (MP) independently reviewing transcripts and audio recordings using an active listening approach to gain a deep understanding of the data. Transcripts were imported into NVivo 14<sup>18</sup> for data management and pseudonyms were assigned to ensure anonymity. The researcher repeatedly read the transcripts, noting reflections on both the data and the analytical process, following Byrne's<sup>19</sup> guidance.

#### **Step 2 – Generating initial codes**

The researcher systematically coded the transcripts, assigning descriptive and interpretive labels to data segments relevant to the research question. Data with multiple meanings were coded in several ways to capture depth and nuance. Coding was iterative, with overlapping

codes merged and irrelevant ones discarded as familiarity with the dataset increased. The initial coding framework was reviewed by members of the research team (MP, FM, and CD) to ensure comprehensiveness and consistency.

#### **Step 3 – Generating initial themes**

The researcher (MP) reviewed and analysed coded data to identify connections and shared meanings across the dataset. Related codes were grouped to form preliminary themes and subthemes, ensuring that emerging patterns meaningfully reflected participants' perspectives on physical activity interventions and experiences of living with fibromyalgia.

#### **Step 4 – Developing and reviewing potential themes**

Themes and subthemes were reviewed collaboratively (MP, FM, and CD) to ensure they accurately represented the dataset and conveyed coherent meaning. Following Braun and Clarke's guidance, MP initially evaluated each potential theme by considering its distinctiveness, coherence, and relevance to the research question. Themes lacking internal consistency or meaningful contribution were revised, merged, or redefined. This process reflected Patton's<sup>20</sup> dual criteria for judging categories—ensuring internal homogeneity within themes and external heterogeneity between them. Final themes and subthemes were reviewed and refined through team discussions until consensus was achieved.

#### **Steps 5 & 6 – Refining, defining and naming themes and Writing up**

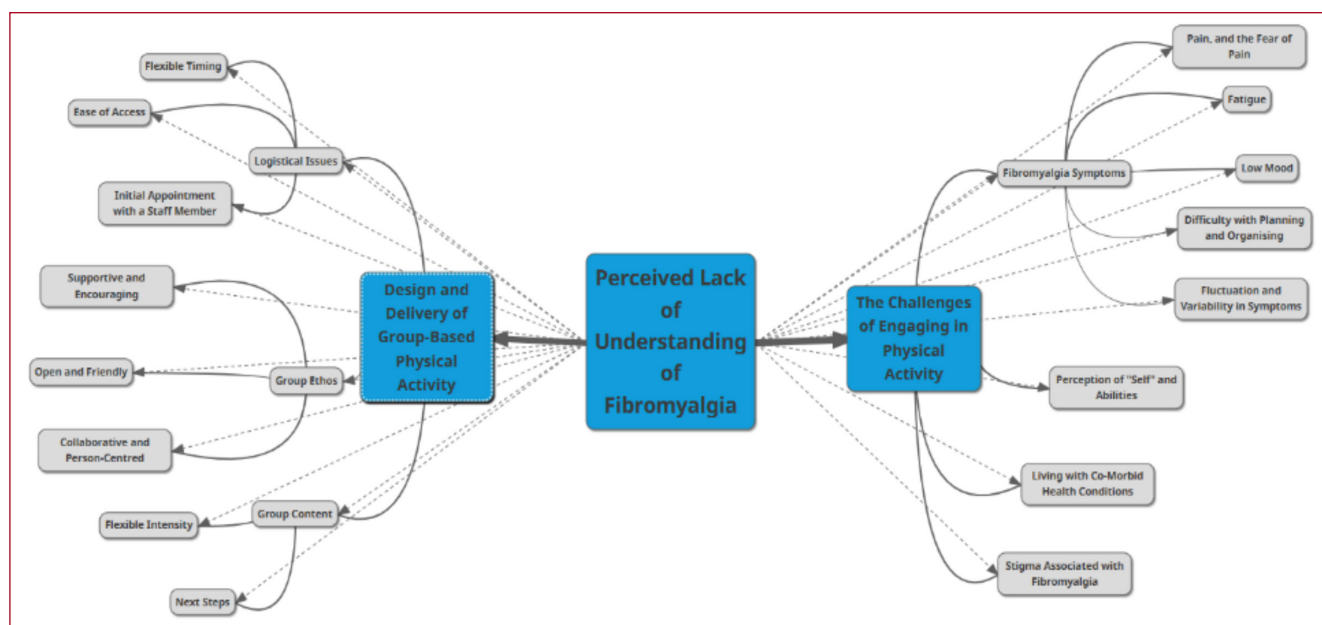
Themes and subthemes were refined through detailed analysis by MP, with representative data extracts selected to illustrate each theme's meaning in relation to the research question. An analytical approach was adopted in presenting these extracts, contextualising participants' accounts within the wider literature. As thematic analysis is interpretive<sup>21</sup>, the write-up aimed to move beyond description to offer theoretically informed insights into the data.

The writing process was iterative and intertwined with ongoing analysis. Themes were reviewed in relation to one another to determine their sequence and ensure a coherent narrative, following Cooper et al.'s<sup>16</sup> recommendation that themes build upon one another while retaining internal consistency and independent meaning.

#### **Reflexivity Statement**

Following Braun and Clarke's<sup>16</sup> guidance, I approached the analysis with openness to subjectivity, recognising that complete neutrality is neither possible nor desirable in qualitative research. Reflexivity was central to maintaining transparency and acknowledging the influence of my own experiences.

As a musculoskeletal physiotherapist with experience



**Figure 1.** Mind map of themes and subthemes.

in pain management and group-based exercise delivery, my interpretations were inevitably shaped by my clinical background and prior interactions with people living with fibromyalgia. These experiences, along with my broader personal and professional context, may have influenced both participant responses and my interpretation of patterns within the data. To mitigate this, I engaged in peer review and critical reflection with co-authors, maintained field notes throughout analysis, and iteratively revisited codes and themes.

While my understanding is informed by my desire to improve the lives of people with fibromyalgia, I view this integration of professional insight and participant experience as a strength that deepens the interpretive process and enhances the authenticity of the analysis.

## Results / Discussion

Eight participants with lived experience of fibromyalgia took part in two in-person focus group discussions (N=4 in each) between December 2023 and February 2024. Most of the participants identified as female (7/8) with a mean age of 57 (range: 38–74). See Table 1 for participant demographic information.

### Themes and Subthemes

Figure 1 shows the themes and subthemes that were generated through thematic analysis.

### Perceived lack of understanding of FMS

The main overarching theme that the TA process produced was the perceived lack of understanding of the impact of fibromyalgia by others and a desire to feel validated and understood. This theme permeated all aspects of both focus group discussions and was interwoven within the underlying themes and sub-themes. The two other main themes were the challenges of engaging in physical activity (PA) and the important aspects of design and delivery of group-based interventions.

In relation to group-based PA interventions, participants highlighted the need for organisers and facilitators to recognise and appreciate the challenges they face in managing the symptoms of FMS. Participants expressed frustration at the lack of understanding of how being physically active can impact upon their ability to undertake their normal activities of daily living:

*Thomas (43): "I would say that's a big thing for me. Because as you say, you could do physical activity, and it could just be walking. But come that night or come the next day, I cannot put my feet out the bed. Even in bed moving, turning, it's agony."*

Susan, 74, discussed how she felt healthcare practitioners sometimes lack understanding of the impact of the condition, and how she felt this can lead to the individual feeling "dismissed" by clinicians:

*Susan (74) "I went to see the GP, and the way I was explaining it to people, 'it's as if somebody's taking the*



Participant	Sex	Age	Pseudonym
Group 1			
P1	Female	74	Susan
P2	Female	66	Mary
P3	Female	59	Louise
P4	Female	38	Debbie
Group 2			
P1	Female	49	Donna
P2	Female	58	Aileen
P3	Male	43	Thomas
P4	Female	55	Sarah
	Mean Age	57	

**Table 1.** Participant Demographics.

*top of my head off and pouring acid through my skeleton.’ And he said ‘so which joint is it you think you need help with?’ You know, how can I make this clearer, it starts there (gesturing to head) and it reaches my toes... and of course it doesn’t show up on a blood test, so you can’t have it then, can you. And I think there’s still... and the pressure GPs are under, something – as they see it – vague like that, you’re just going to be dismissed. And I think that’s a huge issue for most people.”*

This perceived lack of understanding, and the feeling of being “dismissed”, has been discussed in previous studies examining the experience of living with fibromyalgia<sup>23-26</sup>. Mengshoel et al.<sup>27</sup> reported on the findings of several studies on the topic, stating that people with FMS “struggled to convince physicians that their illness was not imaginary or psychological, in order to become a worthy patient.” Participants in these focus groups reported a strong desire to feel believed about their symptoms and viewed this as an important precursor to considering PA recommendations from a health professional. When asked about important factors about how group facilitators behave at PA interventions Susan and Louise replied:

*Susan (74): “It’s being believed...and non-judgemental”*

*Louise (59): “And for you guys, you know what people suffer from with fibromyalgia. You’re aware of the pain, debilitating disability, you know what people suffer.”*

Participants highlighted the need for collaborative, person-centred approaches to PA interventions, run by practitioners who understand the impact of fibromyalgia, are non-judgmental, and take account of individual differences in ability and symptom experience among participants: *“that person-centred approach within the group setting, that’s your bull’s eye.” Thomas (43)*

### The challenges of engaging in PA

A key subtheme that was evident across both focus group discussions was the difficulty in engaging with general PA when living with Fibromyalgia. Participants reported that although they valued PA, living with Fibromyalgia presents many challenges to participating in it consistently, including: 1) the symptoms and their variable and fluctuating nature [pain/fear of pain, low mood, fatigue, difficulty planning and organising]; 2) their perceptions of themselves and their abilities; 3) the stigma associated with the condition; and 4) living with other health conditions which often co-exist with Fibromyalgia [such as osteoarthritis and depression]. These findings are consistent with previous research describing similar challenges experienced by people with other Fibromyalgia and other chronic pain conditions<sup>27-29</sup>.

#### Fibromyalgia symptoms

The experience of fibromyalgia symptoms was reported to have a significant impact on participants’ ability to be physically active. Participants highlighted challenges including 1) pain and the fear of pain; 2) fatigue; 3) low mood; 4) difficulty with planning and organizing; and 5) difficulty managing the variable and fluctuating nature of the symptoms.

#### Pain and the fear of pain

Pain, and particularly, the fear of causing pain through being active, was a major challenge for most of the participants. When asked what factors act as barriers to being active, participants stated:

*Sarah (55): “The fear of the pain.”*

*Thomas (43): “I think you’re right, it’s the fear of how you’re going to be.”*

*Debbie (38): "I think it's more in my head now, just from experience. If I do too much I know it's...I'm going to end up sore or I might cause a flare up, so I'm a bit scared to do too much now."*

*Louise (59): "It is, it's a scary thing."*

Similar findings regarding the fear of pain and causing 'flare ups' were reported by Russell et al.<sup>11</sup>. Participants in their study highlighted the frustration at the lack of understanding of the impact that being physically active had on people with FMS, particularly on the part of those recommending and delivering PA interventions. Mary described her fear of pain following an extremely long period of what she described as a flare up lasting nine months, stating: *"And it's the fear of...for me, it's the fear of flare up. I mean, I couldn't do another nine months. I absolutely couldn't do that."* Mary (66)

### Fatigue

Excessive fatigue was an experience all participants described as posing a challenge to being physically active:

*Louise (59): "I think the fatigue that you get with fibro, it is just so debilitating. It's not even if you fall asleep, you wake up refreshed. You wake up, you think, oh God, I am knackered."*

Elevated levels of fatigue in people living with FMS are well documented<sup>30-32</sup>, and two participants noted fatigue as a particular challenge in the context of balancing work and attending group-based PA:

*Louise (59): "And again, I don't think I could make every class. Although I'm saying, you know, it'd be good to have evening classes, but I come in from work and some days I am absolutely gubbed."*

*Debbie (38): "I'm a wee bit like yourself, Louise. I work full-time and I struggle to get through my day at work and I really...I couldn't do, like, a class at night."*

This echoes the findings of Humphrey et al.<sup>30</sup> and Oncu, Başoğlu & Kuran<sup>33</sup> whose interviewees explained how fatigue affected them at a physical and psychosocial level, impacting their motivation to perform desired activities and interfering with their ability to concentrate and think clearly.

### Low mood

Neumann et al.<sup>34</sup> found that people with FMS report lower quality of life than both healthy individuals and those with generalised chronic pain<sup>35</sup>, and self-efficacy and self-esteem are often reduced<sup>36,37</sup>. The combination of pain, low mood, and low confidence can make contemplating physical activity particularly daunting. Mary and Louise reflected on experiences of feeling "stuck" by their symptoms, a form of pain-avoidance behaviour<sup>38</sup>:

*Mary (66): "I had that for nine months...by the time it came to April...I'd lost it with my mental health. It was horrendous. There was nothing you can do. You just have to sit it out."*

*Louise (59): "Sometimes your mental health can be so drastically low that nothing's going to help it."*

### Difficulty with Planning and Organising

'Brain fog' is commonly reported in people with fibromyalgia, describing subjective cognitive difficulties with memory, concentration, and organisation<sup>39</sup>. Participants described how these challenges affect daily life:

*Louise (59): "Trying to process everything...that's how fibro affects me...every day, or the day before, I'm looking at what I have on tomorrow, to psych myself up."*

Planning and organising also posed challenges for attending group-based PA:

*Thomas (43): "It's not just attending the session. You need to get up, get dressed, organise transport, eat, take medication...it's like an eight-hour workday just to attend."*

Participants emphasised that session designers should account for the effort required just to attend. This aligns with Russell et al.<sup>11</sup>, who highlighted the need for greater understanding of FMS's impact on daily activities. Lower-intensity, participant-tailored exercise may improve adherence and reduce pain<sup>40</sup>. Using a 'preferred intensity' model could allow participants to adjust activity to their current symptom severity, supporting a more personalised approach to group-based PA.

### Fluctuation/Variability in Symptoms

Participants highlighted that fibromyalgia symptoms vary between individuals, which can make group-based PA challenging:

*Mary (66): "Your fibro will be different from mine...for me, it's not so much about pain. It's about a hundred and one different things."*

They also commented on how challenging it can be living with symptoms that fluctuate from day to day:

*Susan (74): "You can have a good day managing quite a bit, and the next day just getting out of bed feels like a fight...trying to explain that to someone else is difficult."*

### Perception of "self" and abilities

Participants reflected on challenges in accepting limitations in tasks they previously managed, often expressing frustration and loss:

*Sarah (55): "Why can I not do this, why can I not do that...we used to walk for miles with the dogs, and I miss that so much...I have to take my frame, which I absolutely hate."*

*Susan (74): "It affects you...you feel like a failure...trying your best and then thinking, I can't do this."*

This change in self-perception and frustration at reduced physical ability has been described as a loss of personhood<sup>41</sup> and is common in people with fibromyalgia. However, some participants reported increased acceptance, reduced self-criticism, and greater confidence after attending group-based PA:

*Susan (74): "I found it hugely beneficial...it's actually making me braver about tackling things I would have thought, oh maybe not, I'll just stay at home. I'm braver."*

*Mary (66): "It's about how you view yourself...going out*

for walks...made me feel a bit better, partly because I had decided to do something, and partly because the flare-up was easing."

Thomas, the only participant who had previously attended a Pain Management Programme, reflected on adapting his approach to challenges:

*Thomas (43): "The stepping stones allow you to take a step back...if you can't make that step forward, that's not a failure...Pacing is important...when you change that perspective, it changes how you look at something...you're not looking for an issue, you're looking for a solution."*

Thomas describes using graded activity and fostering self-efficacy to manage 'pain-avoidance' and 'pain-persistence,' approaches that can influence engagement in PA and, if unmoderated, contribute to chronic pain<sup>42</sup>. This insight is particularly relevant for group-based PA, as it may help address frustrations expressed by participants like Sarah and Susan. Sarah, for example, demonstrates 'persistence behaviour,' attempting to ignore pain and physical limitations, which can result in overactivity and flare-ups<sup>38</sup>.

#### *Stigma associated with FMS*

As noted in the above section discussing pain and fear of pain, most of the participants could identify with experiences of feeling as though other people do not understand what it is like to live with Fibromyalgia or as though they have not been believed regarding the impact of the condition. There was a general sense of participants feeling invalidated:

*Thomas (43): "Yeah, your pain's in your head, it's not fibro, you're just...you're imagining this, you know. I've had that said to me."*

*Susan (74): "There's definitely a, kind of, you're a malingerer, you almost can see the word flashing across people's (gesturing to forehead)...it's 'cause they just do not understand what you're dealing with."*

*Mary (66): "You look fine. They'll say you look fine. You look absolutely fine. How, what's wrong, and you're like... [sigh]."*

*Louise (59): "And that's the worst thing ever."*

The stigma associated with FMS is well documented<sup>27,43-45</sup>; indeed, the term "fibromyalgia" was introduced to replace the earlier stigmatising label "psychosomatic rheumatism"<sup>1</sup>. Controversy over defining, diagnosing, and treating the condition persists, and some have even questioned its existence<sup>46-48</sup>. Participants reflected these experiences, echoing themes identified by Quintner et al.<sup>43</sup>: 'pain invisibility' (Mary: "you look absolutely fine"), 'moralising attitudes' (Susan: "you're a malingerer, you almost can see the word flashing"), and disbelief about the reality of pain (Thomas: "you're imagining this, you know. I've had that said to me").

Facilitators of group-based PA should be aware of this stigma and prioritise empathy and validation. Peer support within groups can help participants feel heard and understood.

*Donna (49) described this benefit: "It's nice to actually get to speak to people who are in similar circumstances... It also makes you feel heard, and that's a massive thing... people go, 'what's that?'"*

#### *Living with co-morbid Health Conditions*

Many participants reported coexisting health conditions, including osteoarthritis, obesity, depression, anxiety, and other musculoskeletal issues, which compounded the challenges of engaging in physical activity.

*Thomas (43): "...any time that you don't feel right...I was in my bed for three days...normally fit and healthy people would be up and about, but I had widespread pain."*

*Louise (59): "I've got fibromyalgia, a bulging disc, arthritis in my hands, elbows, knees, and ankles...It's really difficult walking."*

Thomas summed up the need to consider PA in the context of everything that the individual is going through:

*"It absolutely needs a holistic approach. You need to look at the whole thing. You can't just look at, oh this is fibro, or, this is arthritis. It has to be the holistic approach."* (Thomas, 43)

This reflects much of the literature on person-centred management of complex conditions like FMS. Masi et al.<sup>49</sup> reported that a person-centred approach to care more effectively addresses the biopsychosocial aspects of FMS than traditional biomedical clinical methods. Thomas also highlighted the importance of recognising that:

*"...not everybody's able to do what everybody else is... You're thinking of an activity-based session for people when it should be a people-based activity session for the group."* (Thomas, 43)

#### **Design and delivery of group-based PA**

Participants reported aspects of the design and delivery of group-based PA they deemed important. They highlighted factors associated with the logistics of the group including: 1) flexible timing; 2) easy access to the premises; and 3) having an initial appointment with a staff member who will be at the group.

They also outlined some key considerations related to the content of the group: 1) incorporating flexibility in the intensity of PA; and 2) finishing with a 'next steps' session.

Finally, they commented on the impact of the ethos of the group, particularly emphasizing the importance of the group being delivered in a non-judgmental way with these key attributes in mind: 1) supportive and encouraging; 2) open and friendly; and 3) collaborative and person-centred.

#### *Logistical Issues*

##### *Flexible timing*

Participants commented on the challenges of finding group-based PA options that were held at a time that suited them and that they were able to access easily. Many noted the difficulties of attending groups held during working hours:

Mary (66): "A lot of grans look after their grandchildren now, so I can't... I do school run in the morning and in the afternoon, but a lot of the classes were at the wrong time for me. So the likes of the healthcare professionals I think need to take that into account when they're looking to do it."

Debbie (38): "I've had problems getting away for hospital appointments and even, like, coming to these groups. And it's a shame to say, I can't come to that group that I know is going to help, because my employer's not happy."

Some participants highlighted that individuals have different energy levels at different times, suggesting the importance of having a variety of options:

Thomas (43): "I'm like an old geezer. So it takes me a long time to get going in the mornings, do you know what I mean. But some guys were better in the afternoon. Some guys were better in the morning 'cause they had the energy. And by the time it got to the afternoon, they're sitting like wilted spinach."

Susan (73): "I'm 73, so by the evening, after dinner, I'm thinking, I've had it. I've had enough. I'm tired. And to go out at seven o'clock to go to an exercise class, I probably wouldn't go."

Challenges associated with timing of groups are a widely reported barrier to engaging in group-based PA<sup>50-52</sup> and decision-makers must consider this when planning interventions to maximise uptake and adherence.

#### Ease of access

Access to groups, particularly parking, getting into the venue, and getting organised to attend, was deemed a challenge by some participants:

Louise (59): "I mean, parking for a start, to even get to the class is a nightmare. I've got a blue badge so you can get into the back of the leisure centre, but I've only got that blue badge, like, recently. But when I was going, I didn't. And see trying to get parked, you were miles away, trying to walk...you know, you go to the local leisure centre and you're passed the pool, passed whatever, away up into the...and you're like, I've done my exercise before I even get there."

Having an initial appointment with a staff member who will be at the group

Despite not being mentioned by other group members, one participant made a strong case for the potential benefits of having an initial appointment prior to the group with a member of staff who would be there. They felt this would allow the class to be more effectively tailored to suit individual needs and address potential barriers prior to attending:

Thomas (43): "I think when you're planning the groups... it's maybe worthwhile speaking to the people before you invite them along with a, sort of, screener, you know, what activities do you find difficult, what activities do you enjoy. Because if somebody enjoys something, they're more likely

to want to try and attend it...but the thing about it is, if it's tailored to the people in the group, that person-centred approach within the group setting, that's your bull's eye..."

#### Group Content

##### Incorporating flexibility in the intensity

The participants discussed the importance of having options to adjust the intensity of the PA. Most of the participants had experienced a situation where they felt they couldn't continue with an activity as it was too vigorous:

Debbie (38): "There are things the council runs, and you get into them and you're like, come on. It's all these super fit people and you have got no chance... lifting these medicine balls and I'm like...where do you even start with that."

Susan (74): "I went on that class at the local leisure centre...but it was too vigorous...by halfway through, I was thinking, I've had enough. I really can't keep doing this."

Some of the participants talked about their experiences of attending groups which allowed variation in intensity and how that made them feel more confident to engage in PA:

Debbie (38): "The group I went to had a, kind of, mix of ages in it. And I felt, 'am I in the right class?', like, I feel I can do a lot of this more than some of the other people in the class, but then I had a couple of bad weeks where I actually sat down. And I liked that bit as well, where I actually felt like I couldn't do much, but because I was in the group, it made me go, and I felt better for it after. But I had that choice to sit down. And once you start talking to people and realising they're all the same boat with their pain and things then, no, it didn't bother me at all."

Thomas (43): "So, it's about inclusion as well. Because I...I'm not safe on a bike with balance issues. But I can sit on my bum for the whole day. And if you want me to sit on that and pedal for five minutes, I'm safe...I've got the confidence in myself to be able to do it...And I'm more likely to try it because it's a safer environment sitting down on that bike than it is sitting up on the bike."

##### Finishing with a 'next steps' session

Participants discussed the importance of having some form of 'next steps' if a class is run as a block for a limited time. Some participants had been disappointed with previous experiences where this type of approach wasn't included:

Debbie (38): "I just think it's important that it doesn't only run for so many weeks. It's a continuous thing."

Susan (74): "We started the initial Activ8 thing, it was 12 weeks, I think. But at the end of the 12 weeks they then recommended, right, from here we recommend you go to this. So it wasn't a case of, thank you very much...but...so there was a movement onwards."

Mary (66): "That bit didn't work well for the one I went on because I think...from what I can understand now from the review, they hadn't done that bit as well as they could



have. So, we didn't get moving on to anything. Which I would have liked to have done because I felt I'd had such a good 12 weeks and then nothing."

#### *The ethos of the group*

##### **Supportive and encouraging**

The group reported that they felt encouragement from peers within a group setting was beneficial in supporting them to engage in PA. Some participants talked about their past experiences of this support network during group-based PA.

*Susan (74): "...because you're getting to know people, it encourages you not to give up. It's, kind of, 'I'll see you next week, are you coming?'...There's a couple of ladies in our class who are widowed so spend a lot of time on their own and I think initially they were slightly wary about saying too much but gradually, kind of...when they realised that everybody was, kind of, in the same situation...it's formed quite a social group...beyond the class. So it has...you know, it is supportive."*

*Mary (66): "And that's great for your mental health as well."*

Similar benefits of peer support in a group setting have been reported by Healy et al.<sup>53</sup> who investigated embedding PA into community support groups. Healy highlighted that both the facilitators and participants felt the social aspects of the group were at least as beneficial and valued as the PA itself, with some participants reporting increased confidence in social situations because of the peer support of the group.

Participants also discussed the benefits of learning from others within the group and sharing experiences with people in a similar situation:

*Donna (49): "I think it's keeping an open mind and listening to other people's coping mechanisms and seeing, you know, is there something that they're doing that I could be trying."*

##### **Open and friendly**

Participants felt that having an open and friendly atmosphere within group-based PA was important. Some of the group reflected on their positive experiences and how this facilitated their continued engagement with PA:

*Mary (66): "I felt that the girls at the group I went to were such a good team that it was actually a joy to go."*

*Susan (74): "It was just a very open and warm, inviting...kind of a, 'we know you've got issues and that's why you're here and we're going to do the best we can to help you'. People are friendly and welcoming. And that matters."*

##### **Collaborative and person-centred**

Having an ethos of collaboration, and taking a person-centred approach, was discussed by most participants as a key element in the design and delivery of group-based PA interventions:

*Donna (49): "I think it's really important to collaborate,*

*you know...talk to people, don't talk at them. You know, like, engage them in conversation."*

Participants highlighted the need to recognise that different people have different needs, and that Fibromyalgia can affect different people in different ways:

*Thomas (43): "For me it's a...you're absolutely spot on with what you're saying, but it's a person-centred approach within a group setting is essentially what you're looking to aim for. Because there are things that I can't do that you guys can do. There are things you guys can't do that I can."*

*Donna (49): "And what works for one doesn't work for another. You know, everybody's pain tolerance is different. You know, everybody's coping mechanisms are different and it's just finding things that you can change that...you know, small steps at a time but it's things that work for you."*

*Interviewer: "Do you think the...so the person that's leading it or taking the class or whatever it is has to be able to recognise the individual differences and everybody's abilities are also going to be different?"*

*Donna (49): "I think that's really important that they can take on that...something that Sarah could do, I can't do, and vice versa. And, you know, to have a lead who understands that everybody's abilities are different."*

*Thomas (43): "Not everybody's able to do what everybody else is."*

The desire for an individually tailored and person-centred approach to PA is commonly reported in those living with FMS and other chronic pain conditions<sup>54-56</sup>. It is recognised as a key component in the management of FMS and is included in the original<sup>57</sup> and the revised European League Against Rheumatism (EULAR) guidelines<sup>6</sup>. However, achieving this within a group setting can be challenging. Organisers must consider the individual needs and abilities of participants within the group when designing the intervention. Using co-production methods, whereby people with lived experience are consulted in the very early stages of design and included in the decision-making processes<sup>58</sup>, may be an effective way of achieving a more person-centred intervention approach as Thomas alluded to *"I think when you're planning the groups...it's maybe worthwhile speaking to the people before you invite them along"*.

## **Conclusion**

Physical activity (PA) is strongly recommended for people living with fibromyalgia (FMS), yet engagement remains low despite well-documented benefits. This study explored adults' experiences of group-based PA through focus groups and thematic analysis, identifying three main themes: perceived lack of understanding of FMS, challenges in engaging in PA, and considerations for the design and delivery of group-based interventions. Participants highlighted the importance of feeling believed, treated with empathy, and having a collaborative, person-

centred approach to support consistent participation. They valued interventions delivered by practitioners who understand fibromyalgia, are non-judgmental, and account for individual differences in ability and symptoms.

A limitation of this study is that the type of group-based PA participants engaged in was not recorded, which may influence individual experiences. Future research could explore diverse forms of PA in depth, as well as the use of co-production methods to design interventions with people with lived experience. Co-produced interventions may enhance relevance and acceptability, though alternative approaches beyond group-based formats should also be considered to address the challenges in promoting PA for this population.

### Ethics Approval

*Ethical approval was obtained from NHS Ayrshire & Arran Research and Development Department (R&D Ref No. 2023AAO39; IRAS Ref No. 326639).*

### Consent to participate

*All participants provided written informed consent obtained in person by the lead author after participants had been provided with a participant information sheet. Participants were made aware they could withdraw at any time.*

### Authors' contributions

*MP conceived and designed the study, conducted the focus groups, and led the drafting of the manuscript. FM, CD, and AM supported data transcription and contributed to the thematic analysis. All authors contributed to the interpretation of findings, manuscript composition, and critical revisions, and approved the final version for submission.*

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## **Appendix 1:**

### **Participant Information Sheet – Stakeholders**

#### ***Group-based Physical Activity for People with Widespread Persistent Pain***

We'd like to invite you to take part in our research study. Joining the study is entirely up to you, before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through this information sheet with you, to help you decide whether you would like to take part and answer any questions you may have.

This Participant Information Sheet tells you the purpose of the study and what will happen if you take part.

#### **Why are we doing this research?**

Widespread persistent pain is pain affecting 3 or more body areas that has lasted longer than 3 months. There is a lot of evidence that being active can help improve function and quality of life for people living with persistent widespread pain. Unfortunately, there are often challenges that make it difficult to take part in physical activity. This research is being undertaken to improve our understanding of the difficulties faced by people with persistent pain when it comes to physical activity, and to help us create better more accessible services to increase physical activity in the future.

#### **What will the research involve?**

We want to understand the challenges faced by people with long-term pain when it comes to being active. We also want to hear about currently available (or previously available) group activity services for people with persistent pain. The information we gather will help us to design a new group-based programme to help people with persistent pain become more active in the future. To do this, we want meet with 3 groups of people:

1. People living with long-term/persistent pain
2. Physiotherapists working with people with long-term pain and their managers
3. Members of 3<sup>rd</sup> sector organisations involved in delivering physical activity services

We will run a 1 hour focus group with each of these cohorts separately to explore their experiences and opinions of living with persistent pain and working with people with persistent pain respectively.

#### **Where will the research take place?**

Groups will be invited to Crosshouse Hospital at a date and time yet to be decided.

## **Appendix 2:**

### **Participant Information Sheet – Patients**

#### ***Group-based Physical Activity for People with Widespread Persistent Pain***

We'd like to invite you to take part in our research study. Joining the study is entirely up to you, before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through this information sheet with you, to help you decide whether or not you would like to take part and answer any questions you may have.

This Participant Information Sheet tells you the purpose of the study and what will happen if you take part.

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#### **What will the research involve?**

We want to understand the challenges faced by people with long-term pain when it comes to being active. We also want to hear about currently available (or previously available) group activity services for people with persistent pain. The information we gather will help us to design a new group-based programme to help people with persistent pain become more active in the future. To do this, we want meet with 3 groups of people:

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We will run a 1 hour focus group with each of these cohorts separately to explore their experiences and opinions of living with persistent pain and working with people with persistent pain respectively.

#### **Where will the research take place?**

Groups will be invited to Crosshouse Hospital at a date and time yet to be decided.



### Appendix 3: Focus Group Guide for People with Persistent Widespread Pain

#### Introduction

*This project is about your experience of pain and how it impacts your ability to be physically active. Our aim is to work together to understand what you would like to see in healthcare services that would make it easier for you to be physically active. I would like to ask you all a few questions today about the activities you like to do and the challenges you face in relation to physical activity, if that's ok? Are you happy to chat to me about this?*

*Great, so there are no right or wrong answers to these questions. I will not tell anyone what you have said, and we won't mention your name when we write a report about the project. If you aren't sure what to say or don't want to answer some of the questions, that's fine. If at any time you want to stop just let me know.*

*The idea of a focus group is to chat as normally as possible with each other- we want it to be like a group discussion. If we can, also be respectful to each other and avoid talking over each other. If it's OK with you, I would like to use a tape recorder. This is just so I don't have to write everything down as you speak, and I can listen properly to what you are saying. The tape will only be listened to by the person typing it up – no one else will hear what has been said. Your name won't be written anywhere. Can I ask if it is ok with you all for me to use a tape recorder? If not, I will just make notes. Before we begin, do you have any questions you want to ask?*

#### Experience of Physical Activity

1. Do you think that PA is important in managing your chronic pain? (If so, why? Did someone tell you it would be? Have you tried it?)
2. In a typical day, do you do any PA? (What? When? Give me examples?)
3. What motivates you to do PA?
4. What holds you back?
5. How does physical activity/exercise make you feel (physically and emotionally)?
6. Do you notice any good/positive things that happen to you when you do physical activity/sport (Do you sleep better? Do you feel stronger/more confident? Weight loss? Feel healthier?)
7. Do you notice any bad/negative things that happen to you when you do physical activity/sport? (More tired? Less time to do other things? Increased symptoms?)
8. Is there anything that gets in the way or prevents you from doing physical activity? (Fear? Flare up? Weather?)
9. In a typical day how many hours would you say you sit down for prolonged periods of time? (What makes you sit for long periods of time?)

10. Is there anything that makes it hard to cut down on your time spent sitting or lying down? (Flare up? Not feeling well? Side effects of medication?)

#### Pain and Physical Activity

11. In what ways do you feel your pain can make it harder to change your physical activity?
12. In what ways do you think your pain can make it harder change the time you spend sitting or lying down?

#### Group-based Exercise

13. What are your thoughts on attending group-based exercise classes? (Has anyone ever attended a group-based exercise class before? What was it like?)
14. What would make you more likely to attend a group-based exercise class? (Content? Structure? Staff? Location? Duration? Time? Travel?)
15. What would make you less likely to attend a group-based exercise class?
16. Would you attend a virtual group exercise? (Yes/No? Why?)

That's all the questions I have for you today. Is there anything else you want to say? Do you have any questions?