Patient and Public Involvement in the evaluation of a new fibromyalgia service

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Research Aim

'Beyond pain: exploring tailored care for people with fibromyalgia' is a proposal for a long-term study of a new community-based fibromyalgia service. It is based on a pilot study carried out at St Helen's and Knowsley Musculoskeletal Physiotherapy Services following the launch of a new fibromyalgia pathway in 2022. The pilot measured mental wellbeing and MSK symptoms in 56 patients over 6 months, from baseline to discharge. The proposed study aims to build on the previous findings, evaluating the service, improving tailored care and ultimately improving the lives of those living with fibromyalgia.

Aims of Patient and Public Involvement

The new pathway was developed in coproduction with a patient steering group. With Patient and Public Involvement (PPI) we aimed to continue this engagement, exploring perceptions of the service not only from people with experience of fibromyalgia and/or the current service, but from other stakeholders including family, carers and the wider public. We aimed to receive feedback on the service and the proposed study, which would help to identify important issues for future research.

The group

N = 19 Females
N = 4 Males

Broad range of ages

Majority had a fibromyalgia diagnosis; carers and family members also participated

Diversity of participants including neurodiverse

Recruited through St Helen's and Knowsley Musculoskeletal Physiotherapy Services, and People in Research website (NIHR)

3 discussion groups including 6-9 people each, via MS Teams and face-to-face

Groups were audio-recorded and transcribed verbatim

"What is my pain level when it's normal for me?"

"How you see yourself is different to how others see you"

Impact of Patient and Public Involvement

Themes	Outcome of discussion
Experiences of fibromyalgia	Long, difficult, often isolating healthcare journeys were reported
	Participation and ability to perform meaningful activities were strong markers of success
	Symptoms fluctuate day-to-day and had predictable triggers for some, but not for all
	Acceptance of the condition is part of the 'fibromyalgia journey'
Perceptions of the service	Feedback was overwhelmingly positive, from those who had been part of the service and those who had not
	Designed specifically for this patient group, with professionals who understand the condition
	Strong support for peer support group
	Telehealth was welcomed by some, and others would not use. Most agreed the option should be given especially for an app with symptom tracker
Feedback on the proposed research study	Fibromyalgia is different for every individual: outcome measures need to reflect this
	Outcome measures should also take into account the variability of symptoms (daily, weekly, seasonal)
	Longer term evaluation preferred
	Family members could provide useful insights
Willingness to be part of the Project Advisory Group	Over half said they would be willing to contribute

Perspectives of Public Involvement

- The groups provided invaluable feedback both on the existing service model, and on the proposed research going forward
- The groups gave independent insight into improvements that could be made, and on what matters to them in terms of treating and studying fibromyalgia
- There was a sense of engagement and of wanting to be involved in fibromyalgia research, which was encouraging and positive
- The groups valued being able to talk with others with fibromyalgia
- Changes can be made to the proposed research in response to the outcomes of the PPI