Fibromyalgia Sandpit

30th September 2025

Summary of Outputs

Introduction

The Fibromyalgia Sandpit brought together a multidisciplinary group of professionals (see appendix for list of attendees) to discuss a wide range of issues relating to this misunderstood and under researched condition. The discussions discovered education, research priorities, potential improvements to patient pathways) and policy initiatives. The patient voice was represented by Fibromyalgia Action UK, who also presented a patient vox pop video (view here).

Conclusions

- **Culture change** - There is a need for not only improved education of healthcare professionals but also a wider cultural change across our healthcare system to validate Fibromyalgia as a genuine health condition[1].

- **Patient education** – There is no shortage of information for patients on how to manage their condition (if they know where to look) but no single, consistent resource to which they can be directed by healthcare professionals.

- **Pathway issues** - The linear care pathway for diagnosis and disease management is ill-suited to a multi-factorial condition. Community based care could improve disease management and reduce burden on secondary care services.

- **Registry** - researchers would benefit from the creation of a Fibromyalgia Disease Registry to enable study of disease mechanisms and mechanism/symptom-based stratification of patients.

- **Economic case** – The availability of economic impact data (linked to employment) would help make the case for additional financial support and provide a measurable reference point to indicate changes in disease outcomes over time.

Discussion Points

Education

- There is a **lack of knowledge** of Fibromyalgia among most healthcare professionals and a lack of consistent advice.
- Good example of clinician-to-clinician **education programme** that could be replicated for Fibromyalgia - Physical Activity Clinical Champions (PACC)

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[1] 'Condition' & 'syndrome were used interchangeably. Another term was 'chronic amplified pain syndrome'. FYI, the NHS definition says 'Fibromyalgia, also called fibromyalgia syndrome (FMS), is a long-term condition that causes pain all over the body.' The patient view expressed in the meeting was to use 'condition' as 'syndrome' was perceived to have negative connotations.

- Many in the healthcare profession continue to **question the validity** of the condition. Understandably, this is highly frustrating for patients who feel they need to battle with healthcare professionals and the healthcare system to be taken seriously. Addressing negative stereotypes within the NHS will require senior management involvement to drive **cultural change**.
- Patients want to feel they are **being listened to** and to be given **hope** that (even if not cured) they can be supported to live productive lives.
- Patients (and their families) need to be helped with **expectation management** and coping strategies.
- HCP education needs to include guidance on **how to talk to patients** about diagnosis and support – 'understanding how to talk to patients is as important as understanding the science'. The Physiotherapy Pain Association's *Psychologically Informed Conversations* was suggested as a good example of how this should be done.
- There is **plenty of information available** if clinicians/patients know where to look – for example, NICE Guidelines + HealthTalk. Professor Gary McFarland also referenced his work on the EULAR revised recommendations for the management of fibromyalgia - source & explained that working on new set of guidelines for 2026, including patient videos.
- Importance of **cultural context** when it comes to understanding and accepting pain - Rethinking Pain provides good example of improving patient health literacy by accommodating different cultural, faith and socio-economic factors. Research study on cultural competence in health care translation.
- Possible **imbalance** in education and training that prioritises pharmacological interventions over psychosocial support.
- **Digital tools/channels** (enhanced by use of AI) becoming increasingly important – plenty of good examples in other disease areas.

Clinical Pathway

- Existing patient experience for diagnosis and disease management is **not working**.
- Fibromyalgia is a complex adaptive problem, often accompanied by related conditions (IBS, hypothyroidism, hypersensitivity, sleeping disorders) which necessitates a **more holistic/multi-disciplinary response** than currently provided (by a linear approach).
- Support best provided at **primary care/community level**, which might also avoid negative patient experience of being passed around multiple experts/clinics.
- Need for **pathway research** comparing outcomes/experiences of early referral to multi-disciplinary centres compared to specialists. Secondary or specialist services like pain clinics might not be needed for every patient where primary care/community care could suffice
- **Economics of provision** is an issue (requires more specialist staff for multiple interventions) … need to make ROI case (cost to society) to justify additional resources.
- Are there **lessons that can be learned** from provision of other MSK services?
- Lack of funding for **adolescent pain services**.
- How do we align with focus on **Neighbourhood Health Service** in 10 Year Plan?
- Given scale of (chronic pain and fatigue) problem, we are never going to train enough people to meet needs, which is why **digital solutions** are essential.
- Need to review what is **best practice internationally**.

Research

- Broad support for creation of a UK-wide FMS **registry** (including adolescents) that will elevate status of Fibromyalgia and facilitate longer term analysis. Should include core outcome measures (to be decided) to help manage patient expectations. Lack of ownership (unlike other major conditions) may be an issue. Important to find balance between high quality data and (input) workload for primary care physicians and radiologists. Important not to be too purist/narrow in data capture – lots of overlaps with other conditions (hypermobility, fatigue, psychological issues) and inclusion of co-morbidities will facilitate valuable cross analysis.

- **Measuring outcomes** is challenging … largely based on personal (heterogenous) experience and expectations – pain reduction, lower levels of fatigue, increased mobility, sense of wellbeing. One quantifiable measure is getting people **back to work** – aligns with focus on much health research funding on productivity.
- Challenge facing researchers is dealing with **different symptomatic profiles**. Unlike other diseases, Fibromyalgia does not have clearly defined aetiology, causality and pathogenesis and characterisation. Importance of open mindset when researching mechanisms, rather than predetermining factors.
- Need to address **gender imbalance** - disproportionate representation as a condition mainly affecting women may mean that men are excluded from research. Also likely that the ways women and men present in the clinic will be different, thereby impacting diagnosis.
- **Phenotyping** has been effective in other rheumatological disorders. Might be able to find clinical phenotype clusters (age, BMI, gender, fatigue + pain). Could explore whether clinical phenotypes agree with molecular endotypes.
- Research on **Self-management of nervous system** has shown promising signs**.**
- More work required on **optimal prescribing** – most pharmacological therapy is ineffective.
- **Adolescent Fibromyalgia** under researched outside US and other European countries, which means we are underestimating prevalence and delaying intervention until problems are picked up in adulthood. Anecdotal evidence that clinicians are seeing more patients under 25 (aligned with similar increase in mental health problems among younger people). ‘Doctors are reluctant to prescribe a lifelong condition to someone under the age of 18’. View of many rheumatologists that even allowing them to have treatment is dangerous as it feeds their catastrophising. Would be useful to capture data from adolescence into adulthood to provide longitudinal understanding of how condition unfolds.
- Research into immune mediated and neuropathy related bases of pain in FMS required at larger scale … we know there is higher propensity for binding to certain glial cells and mast cells.
- Research underlying other symptoms besides pain also needed, including fatigue and cognition that may also still be linked to pain
- James Lind Alliance – Fibromyalgia priorities.
- **Versus Arthritis**, which has traditional invested in fibromyalgia research will in the future only fund research in the context of arthritis, which leaves a significant funding gap.

Other discussion points

- ORUK has been reviewing **innovation** within MSK health including pain management – commissioned NIHR’s Innovation Observatory global horizon scan.
- Need for review of **political, social, economic and regulatory environment**

Appendix – Sandpit Attendees

Sibtain Anwar, Head of Pain Medicine Section, Royal Society of Medicine
Tonia Vincent, Rheumatologist and researcher, University of Oxford
Roger Knaggs, President, British Pain Society
David Andersson, Researcher, Kings College London
Gary McFarlane, Researcher, University of Aberdeen
Ian Curran, Deam for Education, Barts and the London
Des Quinn, Chair, Fibromyalgia Action UK
Ana Luiz Paula, Patient representative
Seema Gudivada, Clinical Programme Director, Royal Society for Public Health
Andrew Segerdahl, Senior Postdoctoral Researcher, Nuffield Department of Clinical Neurosciences
Shafaq Sikandar, professor of Sensory Neurophysiology, Queen Mary University of London
Kirsty Bannister, Researcher (CNS), Imperial College London
Leila Heelas, Physiotherapist, Oxford University Hospitals
Christopher Eccleston, professor of Pain Psychology, University of Bath
Faisal Shaikh, GP and MSK Clinical Lead Surrey, Oxford University Hospitals
Rebecca Pardow, APPP and Joint Clinical Lead, Sandwell and West Birmingham NHS Trust
Helen Makins, Consultant in Pain Medicine (Anaesthesia), Gloucestershire Hospitals NHS Foundation Trust
Tom Shelton, Advanced Physiotherapy Practitioner, Mid Yorkshire Teaching NHS Trust
Karen Dawson, Clinical Nurse Specialist, MPFT Bank
Arash Angadji, Chief Executive, Orthopaedic Research UK
Martin Thomas, Head of Policy, Orthopaedic Research UK