

Understanding Health Services Delivery for Fibromyalgia (in England, Scotland & Wales)

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What is fibromyalgia?

Fibromyalgia is a condition characterised by persistent and widespread pain that is associated with intrusive fatigue, sleep disturbance, impaired cognitive and physical function and psychological distress. It is classified in the International Classification of Diseases ICD-11 as Chronic Primary Pain. (Royal College of Physicians, 2022)

Information Booklet

For people affected by Fibromyalgia

FIBROMYALGIA ACTION UK

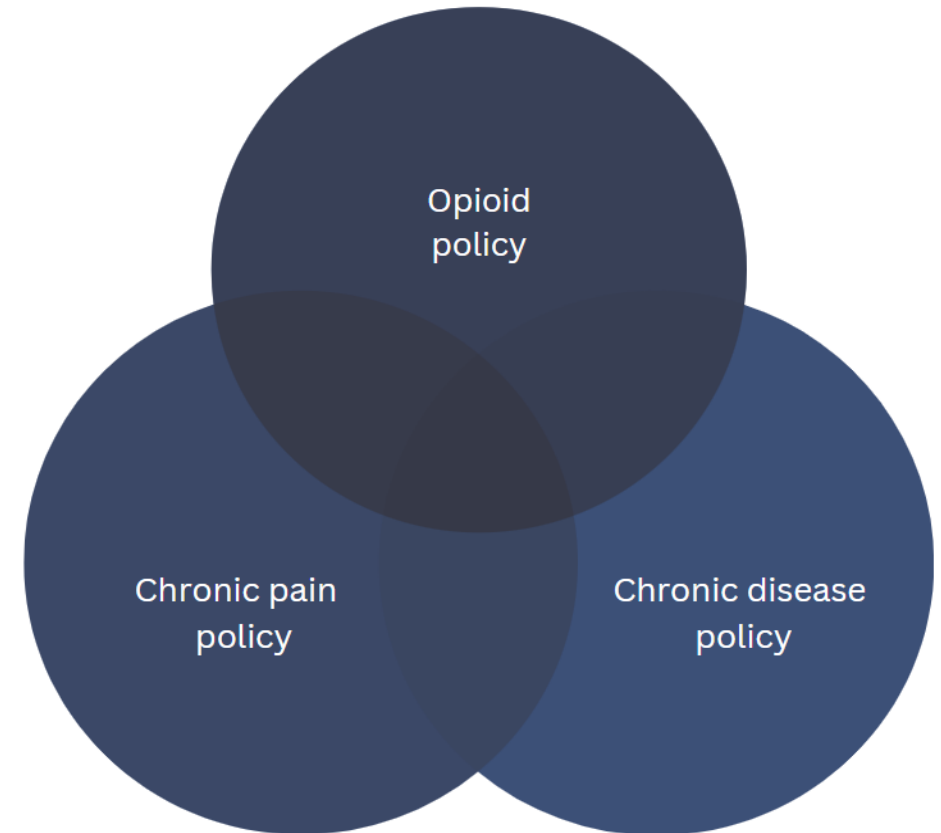
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Fibromyalgia Action UK

Background: Fibromyalgia policy and services (England, Scotland & Wales)

- Multiple policies and guidelines that relate to fibromyalgia
- Evidence based interventions e.g. patient education, exercise (e.g. EULAR, 2016)
 - Weaker evidence for e.g. psychological therapies, pharmacotherapy, & multimodal rehabilitation
- Little guidance about how services should be delivered as a whole
- Huge variation in service provision



Patient-centred Care for Fibromyalgia: New pathway Design (PACFiND)

Chief Investigator: Gary Macfarlane Co-Chief Investigator: Rosemary Hollick

Work Packages:

- A suite of mixed-methods studies on patient experience and service delivery (led by University of Aberdeen)
- Qualitative study of twelve ‘innovator’ sites (led by University of Oxford)
- Coproduction of recommendations with stakeholders (led by University of Aberdeen)



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“No-one wants to look after the fibro patient” (Doebel et al., 2020)

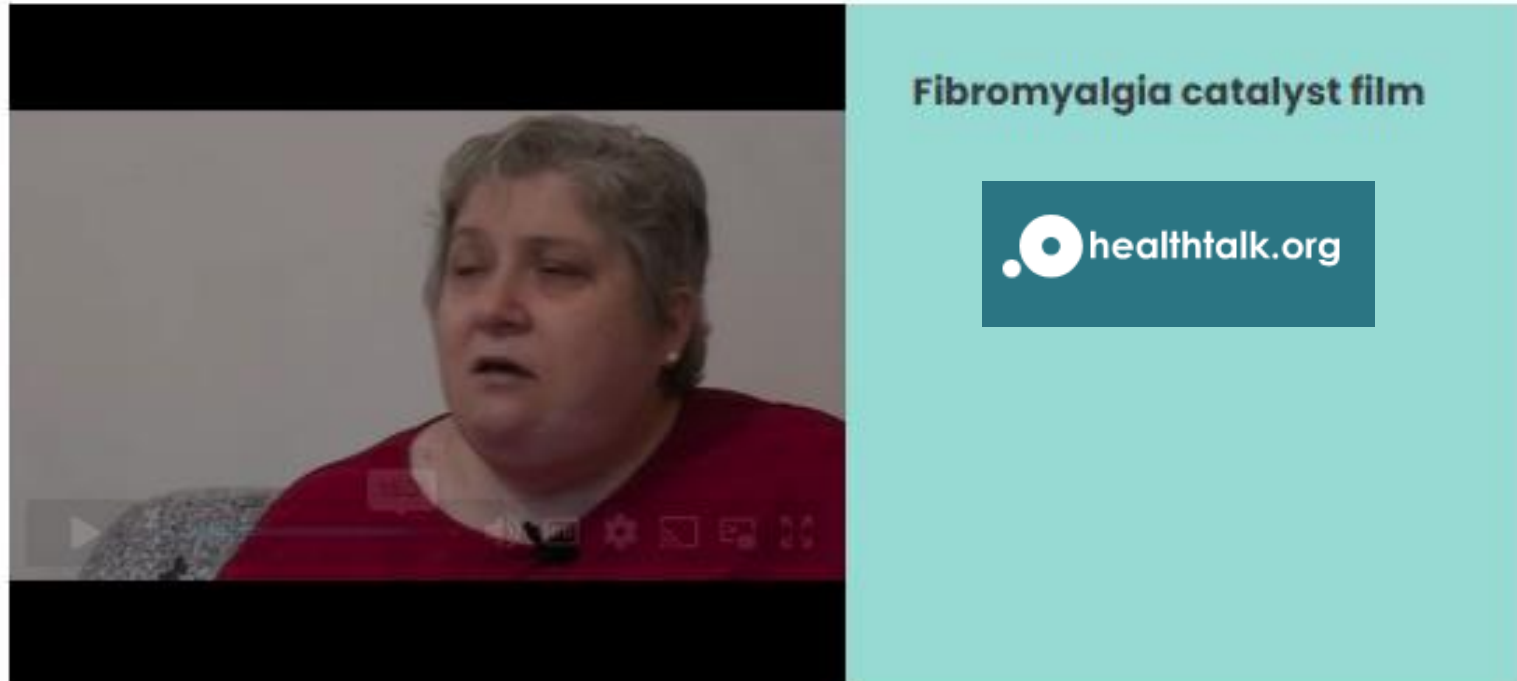
- Two narrative reviews
 - Models of care for people with fibromyalgia
 - Patients’ experiences, preferences, and unmet needs
- Care for fibromyalgia was inconsistent and poorly coordinated
- Patients reported difficult interactions with the healthcare system
 - Fibromyalgia was often not viewed as a real condition
 - People felt that they were not listened to or believed



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Patient experiences of fibromyalgia & services (based on 31 interviews)



This film was made as part of PACFIND (PATient-centred Care for Fibromyalgia: New pathway Design) study, funded by Versus Arthritis.

Comparing the Impact of Symptoms and Health Care Experiences of People Who Have and Have Not Received a Diagnosis of Fibromyalgia (Doebel et al., 2022)

- Fibromyalgia diagnosis took an average of three years following presentation of symptoms
- People with a fibromyalgia diagnosis were more likely to be out of employment compared to others with chronic pain symptoms



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UK Healthcare services for people with fibromyalgia: two web-based national surveys (health professionals & patients)

(Wilson et al., 2022)

- Diagnosis and treatment of fibromyalgia very variable
- Most treatment focused on education and pharmacotherapy
- Patients reported a lack of available services



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Large-scale, data linkage study in Wales

- Secured Anonymised Information Linkage (SAIL) Databank
- 22,566 fibromyalgia cases identified 2004-2018
- High use of anti-depressants, gabapentinoids, opiates



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Aim

- To understand how innovative models of care for fibromyalgia are being organised and delivered, as the basis for co-designing new care pathways



Methods

- 12 Case Study sites (England, Scotland & Wales)
- Interviews with practitioners & service coordinators (53 interviews)
- Observations of practice, with document review (200 hours+)
- Qualitative data analysis, informed by sociological theory
 - Case study overview
 - What services are being delivered in each case?
 - What seems to be working well?
 - Commonalities and differences across sites



12 Sites (Welsh sites identified, with permission)

WALES Persistent Pain Management Services Betsi Cadwaladr UHB	WALES Chronic Pain Service Hywel Dda UHB	WALES Cynon South Pain Service Cwm Taf Morgannwg UHB	WALES St Joseph's Hospital (private) Aneurin Bevan UHB area
ENGLAND	ENGLAND	ENGLAND	ENGLAND
ENGLAND	SCOTLAND	SCOTLAND	SCOTLAND

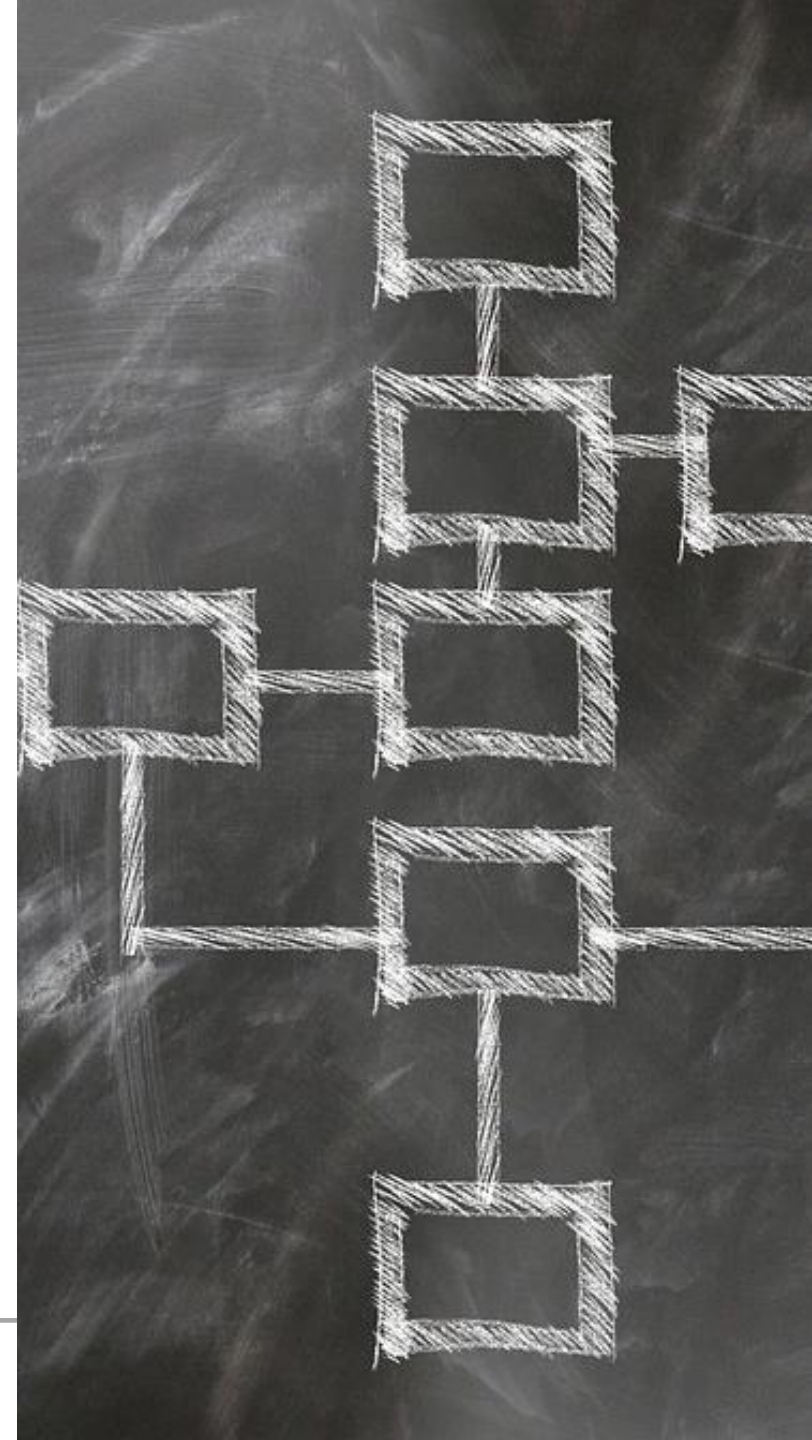
Variation across the case studies

- Size/scope/formulation of service or intervention
 - From large MDTs to single-practitioner interventions
 - Delivered in community, acute, and private sector settings
- Workforce
 - Medically vs non-medically (e.g. AHP) led
 - Various practitioners (e.g. Physiotherapy, Occupational Therapy, Psychology, Pharmacy... other)
 - Complementary & Alternative Therapies / non-clinicians in a few sites
- Some fibromyalgia-specific but most multi-condition
 - E.g. with other chronic pain / fatigue conditions



Developing ‘Guiding Principles’ for Fibromyalgia Services

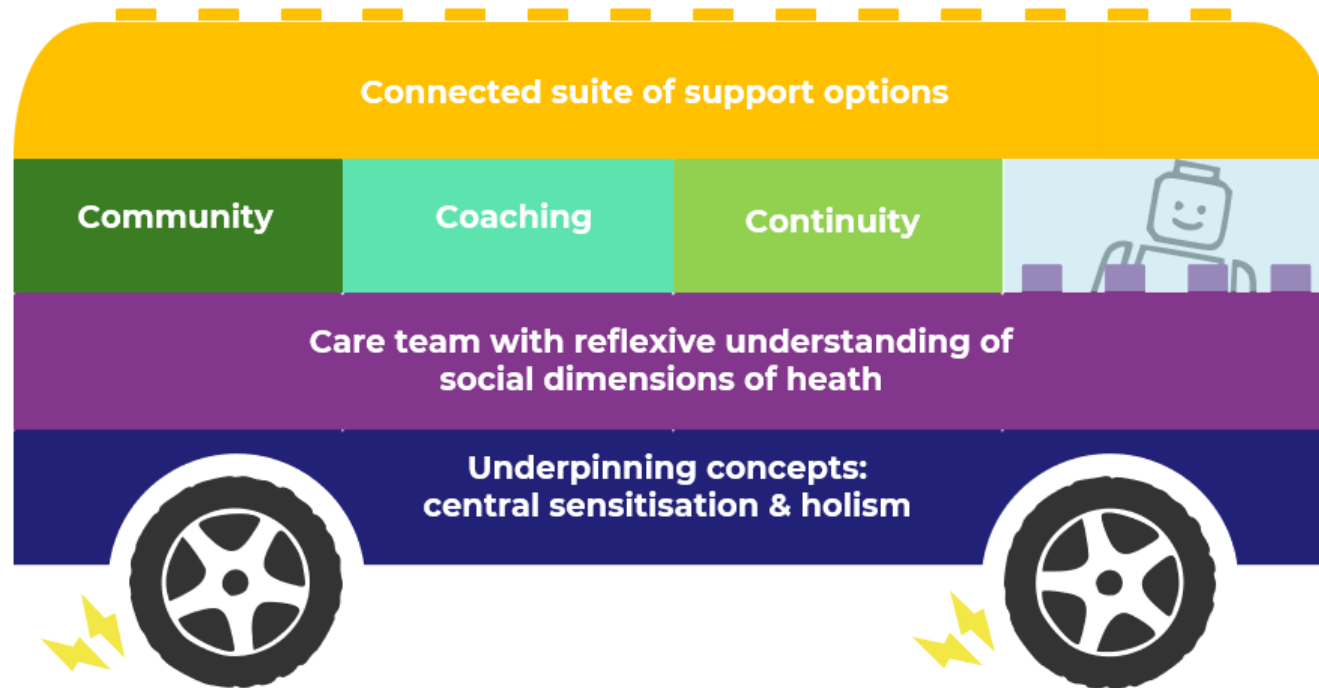
- Learning based on commonalities across sites – what seemed to be working well in real-world practice
 - Principles and key domains
 - NOT A GUIDELINE or ‘recipe’ for what to do
- Co-designed with stakeholders
 - Stakeholder Workshop Sept 2023 for case study site reps
 - Policymakers Summit Dec 2023 & Feb 2024
 - Ongoing Patient and Public Engagement & Involvement
- For policymakers, service developers & commissioners



The Bus Infographic (Guiding Principles for Fibromyalgia Services)



Guiding Principles
for Fibromyalgia
Services



BUMPY RIDE: REALISTIC STEP-BY-STEP GOALS towards IMPROVEMENT / RECOVERY

Guiding Principles: the 'bricks'

**Underpinning concepts:
central sensitisation &
holism**

Coaching

**Connected suite of
support options**

**Care team with reflexive
understanding of social
dimensions of health**

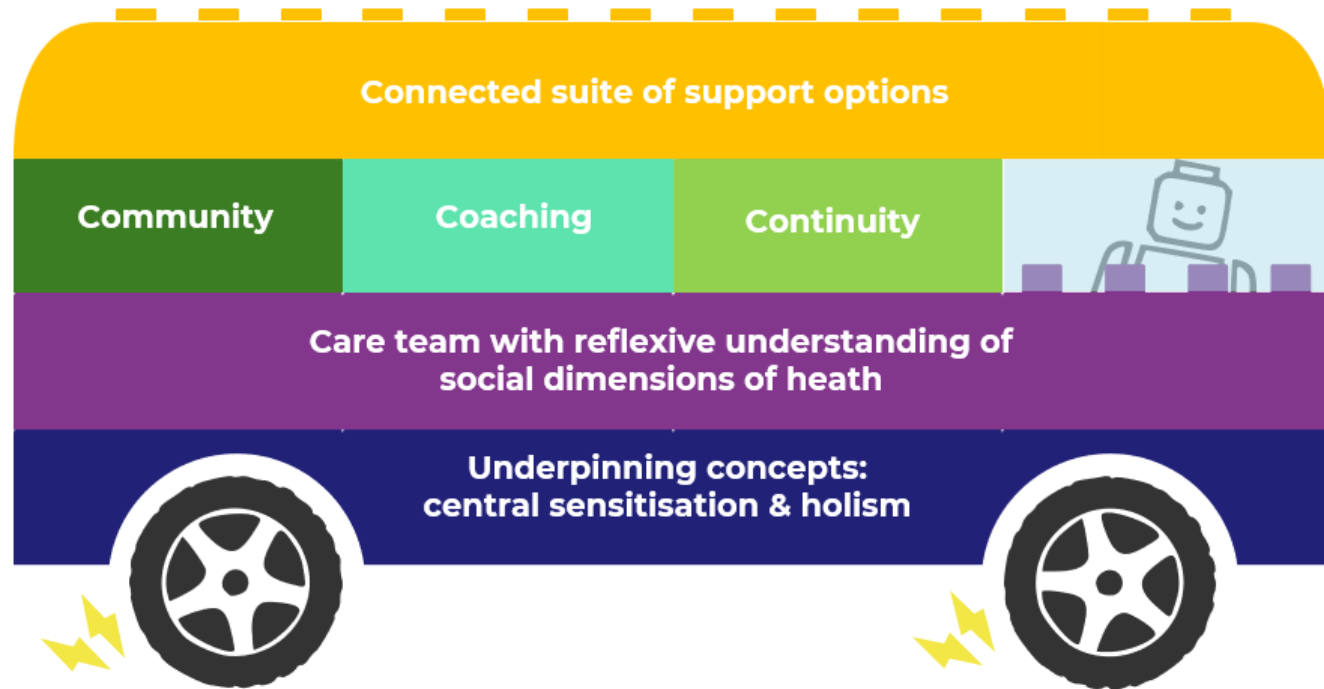
Continuity

Community

The Bus Infographic (Guiding Principles for Fibromyalgia Services)



Guiding Principles
for Fibromyalgia
Services



BUMPY RIDE: REALISTIC STEP-BY-STEP GOALS towards IMPROVEMENT / RECOVERY

Barriers to developing biopsychosocial services

- Narrow understandings of ‘evidence’ (e.g. from randomised controlled trials)
 - Complex conditions and complex interventions require a range of evidence
- Welfare Benefits System
 - Proving illness and punitive systems work against improvement and recovery



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Opportunities for cost-effective care

- Biopsychosocial services should reduce expensive medical consultations
- Shorter waits, fewer battles against the system, & fewer futile interventions promotes greater wellbeing (less stress) leading to greater self-care & ability to manage and/or recover
 - Reduced need for, and harms of, pharmaceuticals*
 - Reduced sickness and need for welfare benefits*

***But quality, non-pressurising support is required. Threats (e.g. of removal of medications or benefits) are likely to have the opposite effect.**



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Summary

- We have developed some Guiding Principles for Fibromyalgia Services
 - Co-designed with patients and ‘innovator’ services
 - Illustrative Bus Infographic
- Guiding principles provide a framework for service developers & commissioners



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Thank you ...



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For more information

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- Qualitative case studies (Oxford): Caroline Cupit; Teresa Finlay; Catherine Pope

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References

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FORTCOMING (Submitted 2024):

Three papers from the qualitative study – details TBC.