



Key finding

A framework for redesigning services for fibromyalgia which supports patient autonomy and multidisciplinary care across diverse healthcare systems

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PACFiND: Co-designing principles to inform reconfiguration of fibromyalgia care across health systems

Background

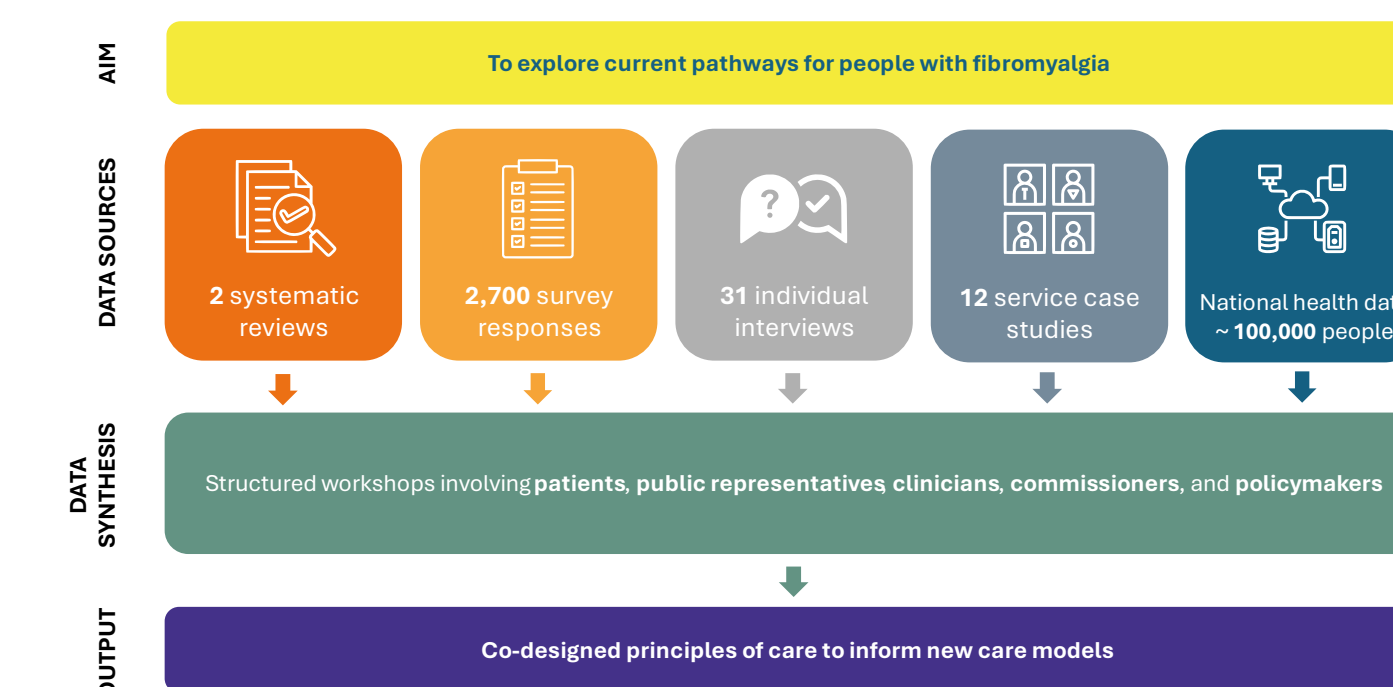
Fibromyalgia is a **contested and poorly supported condition**, characterised by widespread pain, fatigue, and cognitive symptoms, often compounded by **stigma and delayed diagnosis**. Existing **services are fragmented and inconsistent**, with high patient and system burden.

The **PACFiND study** (PAtient-centred Care for Fibromyalgia: New pathway Design) aimed to inform new models of care for fibromyalgia.

Methods

A **mixed method design** integrated systematic literature reviews, surveys of, and interviews with, people with fibromyalgia symptoms/diagnosis and healthcare professionals, analysis of routine healthcare data and service case studies, to explore care pathways for fibromyalgia in the UK, see Figure 1.

Figure 1. Mixed-method study design.



Data collection included over 2,700 survey responses from patients and professionals, 31 in-depth interviews, 12 UK-wide service case studies, and national healthcare data on nearly 100,000 individuals.

Findings were synthesised through investigator meetings and structured workshops, involving patients, public representatives, clinicians, commissioners, and policymakers to co-design principles of care to inform new care models.

Results

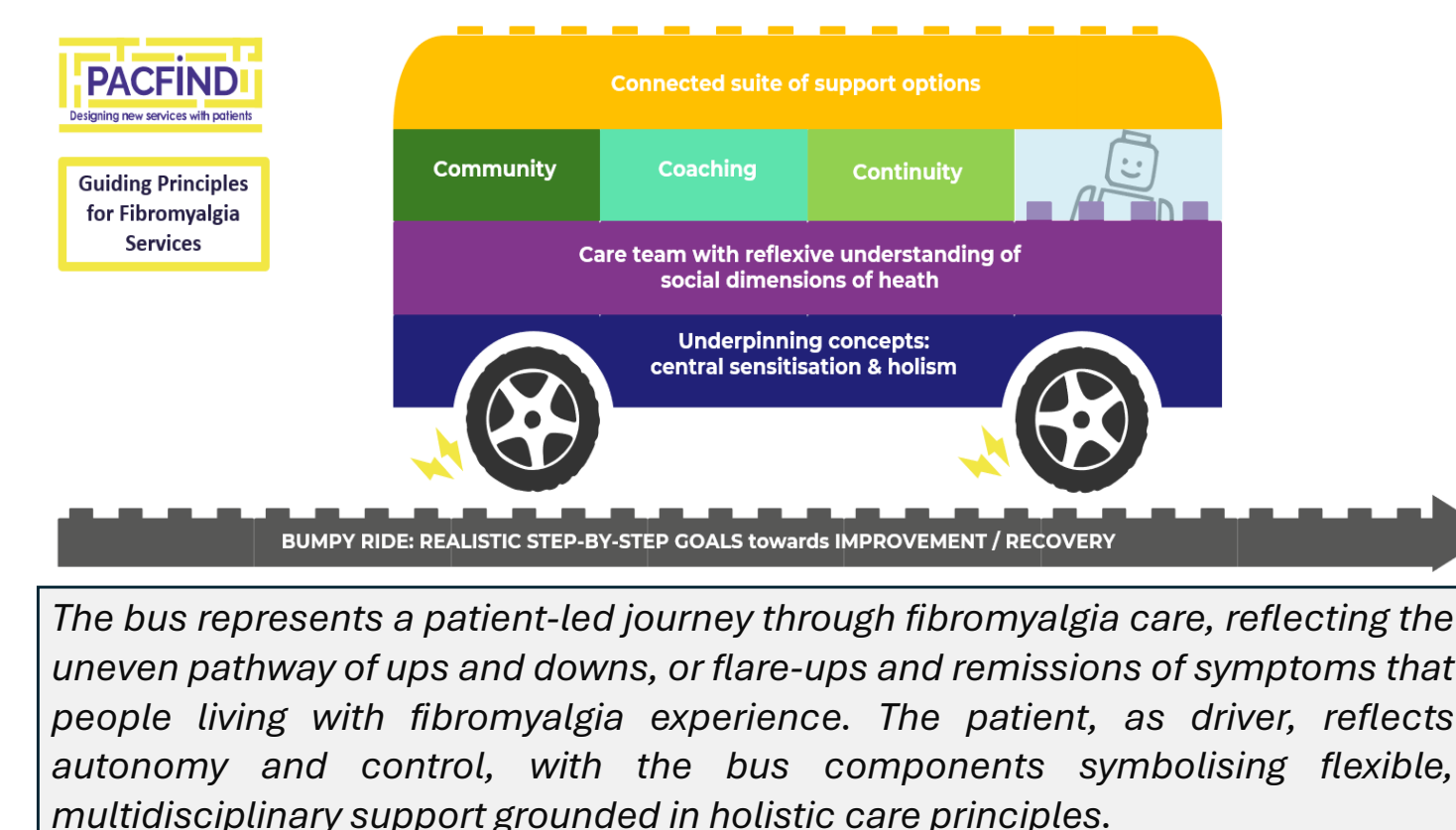
- Findings highlighted **delayed and inconsistent approaches to diagnosis**, especially in **men**, and limited post-diagnosis support.
- Many health professionals questioned the **validity of fibromyalgia diagnosis**.
- Patients faced a **revolving door of referrals** across specialties, particularly pain management, gastroenterology, and general surgery.
- Patients reported substantial **out-of-pocket costs, difficulty navigating services, and poor work outcomes**.
- Healthcare professionals expressed **uncertainty in making a diagnosis** and management, with variable understanding of fibromyalgia as a **central sensitisation condition**.
- Patients voiced strong **preferences for personalised, holistic, and non-pharmacological interventions**, delivered with empathy and continuity.

- Community resources, such as **support groups**, play a key role but lack formal recognition.

Insights informed evidence-based care principles and potential delivery across different settings:

- (1) **Primary care settings** e.g., family physicians for early recognition, supported by training;
- (2) **Specialist input for complex diagnosis** and management; and
- (3) **Wraparound support**, integrating physical, psychological, and peer-led services. These aim to reduce inappropriate referrals, improve experience and outcomes, and enable tailored, appropriate place-based care (Figure 2).

Figure 2. Evidence-based principles of care to guide fibromyalgia service redesign.



Discussion

The PACFiND study has **co-designed multilevel principles for fibromyalgia care** aligned with patient needs and system priorities.

We identified **common challenges common across healthcare systems** - delayed diagnosis, fragmented care, and unmet patient needs.

Although the **logistics of implementation may differ**, the core principles of integrated, person-centred, and evidence-informed care are widely applicable.

This model offers a **flexible framework to guide service redesign internationally**. We are using findings to create a **toolkit to inform health policy and support service redesign** in fibromyalgia and other complex chronic pain conditions.

Further information

