Hollick RJ[1], Anderson S[1], Black C[2], Choy E[3], Cooksey R[3], Doebl S[1], James WRG[1], Jones GT[1], Lam K[1], Macdonald R[1], Macfarlane GJ[1] on behalf of The PACFIND study team

[1] Aberdeen Centre for Research Excellence in Musculoskeletal Health (Epidemiology Group), University of Aberdeen, Aberdeen, UK
[2] NHS Grampian, Aberdeen, UK
[3] Cardiff University, School of Medicine, Cardiff, UK

Key finding

Undiagnosed fibromyalgia drives high, potentially avoidable healthcare use.

Earlier recognition and coordinated community care could reduce unnecessary investigations, prescribing and harm.

UNIVERSITY OF ABERDEEN
EPIDEMIOLOGY
CELEBRATING 20 YEARS
2005 - 2025

PACFIND
Designing new services with patients

Over-investigated yet Underdiagnosed: Reframing Fibromyalgia Care Pathways

Background and Aim

Fibromyalgia often co-occurs with rheumatic and immune-mediated inflammatory diseases, complicating diagnosis, disease activity assessment, and treatment decisions.

However, population-level evidence on healthcare use before and after diagnosis, and how current pathways contribute to unmet need, remains limited.

We examined healthcare use, prescribing, referrals and investigations across two UK healthcare systems to inform more effective, person-centred models of care.

Methods

We analysed linked health data from **Scotland and Wales** using harmonised approaches.

WALES	SCOTLAND
19,742 people with fibromyalgia and **76,746 matched controls**	**275 survey respondents:** → **71** with a **diagnosis of fibromyalgia** → **99** meeting **2011 ACR criteria** but with **no diagnosis** → **105** with **chronic pain**
People with codes for fibromyalgia identified from **primary healthcare records** in the **SAIL databank**	**Survey data linked to national health records** (outpatient, hospital, emergency care, GP out-of-hours and prescribing data)
Healthcare use in primary and secondary care, investigations and procedures before and after diagnosis between cases and control group	**Healthcare use (outpatient, hospital, emergency, GP out-of-hours)** before and after diagnosis across people with a diagnosis of fibromyalgia, meeting criteria but no diagnosis, and chronic pain

Results

1. Healthcare use was high, especially in undiagnosed fibromyalgia

In Wales, people with fibromyalgia had more GP encounters, hospital admissions and emergency department attendances than matched controls, both before and after diagnosis.

In Scotland, people meeting fibromyalgia criteria but without a diagnosis had the highest healthcare use.

1.4 ↑ outpatient episodes*

2.5 x ↑ emergency admissions*

2-3 x ↑ healthcare use**

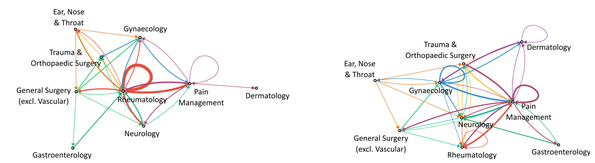
** compared to people with a fibromyalgia diagnosis*

*** outpatient, hospital, emergency department and GP out-of-hours services compared to those with chronic pain or fibromyalgia diagnosis*

2. Care journeys were fragmented

Before diagnosis, Welsh cases had significantly more outpatient referrals to 17/20 specialties, especially **gastroenterology, neurology, pain, orthopaedics,** and **surgery**.

In Scotland, mapping outpatient activity showed more rheumatology attendances before diagnosis and greater pain management attendances afterwards (Figure 1).



(a) 1 year pre-diagnosis ***(b) 5 years post-diagnosis***

Figure1. Transitions between outpatient specialty visits in (a) the 1 year leading up to a diagnosis of fibromyalgia and (b) 5 years post diagnosis of fibromyalgia. Thicker lines represent a greater number of transitions, and the arrows indicate the direction of movement between specialties (e.g., an Orthopaedics appointment followed by a Rheumatology appointment).

3. Medication use, imaging and procedures were common

Amongst Welsh fibromyalgia cases, medication use was high compared to controls and often initiated before diagnosis:

87% Antidepressants (vs 52%)

24% Gabapentin (vs 6%)

69% Opioids (vs 48%)

29% Steroids (vs 18%)

People with fibromyalgia were also more likely than controls to undergo diagnostic imaging and surgical procedures before and after diagnosis (Figure 2).

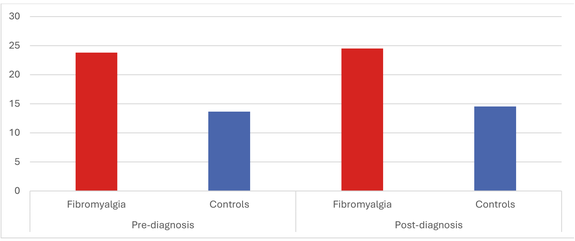


Figure 2. Proportion of surgical or imaging diagnostic investigation codes in electronic health records of fibromyalgia cases and controls

Summary

People with fibromyalgia experience high, complex and potentially avoidable healthcare use, particularly when symptoms remain unrecognised or undiagnosed.

Patterns of referral, investigation and prescribing suggest diagnostic uncertainty, fragmented pathways and limited access to evidence-based care, while high healthcare use post-diagnosis highlights ongoing unmet need.

Key implications

- **Support earlier recognition within primary care**
- **↑ awareness in specialties seeing undiagnosed patients**
- **↓ unnecessary investigations & prescribing, particularly opioids**
- **Shift resources to coordinated, community-based multidisciplinary pathways**

Addressing these offers opportunities to improve outcomes, reduce harm, and deliver person-centred cost-effective care.