Patterns of Healthcare Use, Comorbidities, and Treatment of Fibromyalgia:

Insights from Survey and Administrative Healthcare Data in Scotland and Wales

PACFiND Report

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Executive summary

The Patient-centred Care for Fibromyalgia: New pathway Design (PACFiND) project was led by the University of Aberdeen with partners across the UK and funded by Versus Arthritis (now Arthritis UK). Its goal was to understand the experiences of people living with fibromyalgia and design more effective, person-centred care pathways.

This report presents findings from a key area of the PACFiND project, which examined patterns of healthcare use, and clinical characteristics and treatments prescribed to people living with fibromyalgia across Scotland and Wales. Using survey and linked, administrative healthcare data, these analyses provide new insights into how people with fibromyalgia interact with the health system before and after diagnosis and highlight the implications of current care patterns for patient experience, safety, and service design.

Across both nations, people with fibromyalgia experienced complex and prolonged healthcare journeys, marked by multiple specialist referrals, frequent investigations, and a predominant reliance on pharmacological management. Despite differences in data sources and health system organisation, similar trends emerged: diagnostic uncertainty, fragmented and poorly coordinated care, limited access to holistic support, and a high potential for avoidable harm.

Healthcare utilisation was high both before and after diagnosis. Individuals who met the 2011 American College of Rheumatology criteria for fibromyalgia but had not received a diagnosis had the greatest levels of healthcare use—often two to three times higher than those with chronic pain or a confirmed fibromyalgia diagnosis. These findings suggest diagnostic uncertainty and a lack of confidence among clinicians, with a high number of referrals to surgical and other medical specialties, often culminating in Rheumatology outpatient attendances immediately prior to diagnosis.

Fibromyalgia frequently co-existed with other long-term conditions, adding to diagnostic complexity and increasing the risk of over- or under-investigation. While some procedures may be appropriate, unnecessary or repeated investigations are potentially harmful and costly to the healthcare system. After diagnosis, healthcare use remains high, reflecting persistent unmet needs and limited access to appropriate services.

Qualitative and survey findings from across the PACFiND project reinforce these results. Healthcare professionals described uncertainty in making the diagnosis and some question the diagnostic label, with often few referral options, and structural barriers to delivering holistic care. Patients reported long diagnostic journeys, stigma, exclusion from services, and feeling “cut loose” after diagnosis. Where care was viewed positively, it was characterised by trusted relationships, continuity, and whole-person approaches, features not well supported in existing systems.

The consistency of findings across two distinct national health systems highlights that these are system-level challenges rather than local variations. Lack of clear service ownership, weak integration between primary and secondary care, and limited multidisciplinary capacity contribute to both inequity and inefficiency in fibromyalgia care.

These results point to clear opportunities for care improvement: strengthening the role of primary care in diagnosis and management, clarifying care pathways, promoting non-pharmacological approaches, and ensuring continuity through coordinated, multidisciplinary support. Addressing these issues could improve outcomes for patients while reducing costs and harm across the health system.

Further information on the PACFIND project and our findings can be found at: https://www.abdn.ac.uk/iahs/academic/epidemiology/our-research/studies-list/pacfind/

The key outputs from the PACFiND study are grouped into three areas:

- **Understanding Existing Services**
- **Understanding Experience, Need and Preferences**
- **Shaping Supportive Health and Work Systems**

Summaries of the outputs are provided in Supplementary 2. Together, these show how each component has enhanced our understanding of fibromyalgia care and is informing the development of evidence-based, person-centred solutions.

1. Introduction

Fibromyalgia is a chronic, complex condition characterised by widespread pain, fatigue, and multiple somatic and psychological symptoms. Although a large body of evidence has informed management recommendations, few studies have examined how best to design and deliver services that provide effective, equitable care within resource-constrained health systems. Much of the available evidence characterising the health and use of health services for people with fibromyalgia is based on small or highly selected samples, limiting generalisability. Routinely collected healthcare data offers an opportunity to study large, unselected populations, enabling better quantification of fibromyalgia characteristics, comorbidities, healthcare use, and patient journeys.

2. Methods

Using routinely collected healthcare data from Scotland and Wales, we explored patterns of healthcare utilisation, comorbidities, and treatment of people with fibromyalgia. Analyses were conducted separately within each nation using linked datasets with harmonised approaches to allow cross-country comparison.

2.1 Scotland

We approached participants from the MAintaining MusculOskeleTal Health (MAmMOTH) study. This study involved a population survey of people from sixteen selected primary care practices in Grampian, Highland and Greater Glasgow & Clyde NHS health boards (Macfarlane et al, 2021). Participants were initially surveyed in 2016, and respondents were re-surveyed in 2019 as part of the current study. They were categorised into three fibromyalgia-related groups: patients reporting a diagnosis of fibromyalgia from a healthcare professional, patients without a fibromyalgia diagnosis but meeting 2011 ACR fibromyalgia research criteria, and patients with chronic pain.

The survey included specific tick-box questions on whether they had received a diagnosis from a healthcare professional of one of the following conditions: Rheumatoid Arthritis, Psoriatic Arthritis, Axial Spondylitis and Osteoporosis.

The survey data were then linked to the national community and emergency care (including GP out-of-hours, and Emergency Department attendances), hospital admissions, hospital outpatient attendances and records of all medications dispensed in community care. Data linkage was conducted by the NHS Scotland electronic Data Research and Innovation Service (eDRIS) via deterministic linkage methods using unique personal identification numbers in a process shown to produce highly accurate and complete data (Evans and Macdonald, 1999).

Analysis

Data were analysed to compare healthcare use between groups. For individuals with a fibromyalgia diagnosis, healthcare use was also examined before and after diagnosis. The year of diagnosis was self-reported in the survey, and diagnosis date defined as the midpoint of that year (1 July).

Healthcare use was expressed as the number of events per 100 person-years to account for differences in the duration of follow-up across groups. Person-years were calculated for each individual from the start to the end of their contribution to the dataset, defined as the period between either their Community Health Index (CHI) registration date or the start of data collection (whichever occurred later), and either their CHI deregistration date or the end of data collection (whichever occurred earlier).

Data collection covered the period from the first day of the month in which data were first recorded for each dataset: 2006 for outpatient and hospital admissions, 2007 for emergency department attendances, and 2014 for GP Out-of-Hours, through to 1 January 2020.

Person years was calculated for each individual and then summed across all individuals within the same group. Total healthcare usage in each group was then divided by the total sum of person years for that group and multiplied by 100. Person years were also calculated before and after a fibromyalgia diagnosis, with before person years calculated from registration date/start of dataset to fibromyalgia diagnosis date, and after person years calculated from fibromyalgia diagnosis date to deregistration date/end of dataset.

2.2 Wales

We conducted a case-control study of individuals with fibromyalgia using deidentified data held in the Secured Anonymised Information Linkage (SAIL) databank representing around 85% of the population of Wales. The datasets encompass national longitudinal primary and secondary care information, anonymously linked using an encryption system with a trusted third party (NHS Wales Informatics Service) (Lyons et al, 2009; Ford et al, 2009).

Individuals aged 18 years and over, registered with a primary care provider in Wales, and with a Read code present for fibromyalgia (N239. or N248.) in their records between 2000 and 2017 (cases). The index date for a case was the first time such a code appeared in their record during this period. Cases were matched with up to four controls by age, sex, deprivation quintile using the Welsh Index of Multiple Deprivation (WIMD, 2019).

Primary and secondary care data were linked longitudinally, enabling analysis of healthcare events, comorbidities, and prescribing patterns before and after diagnosis. Primary and secondary care data was linked at the person level and used to follow up individuals through the health system, including one year pre- index date. Comorbidities and medications recorded in primary care records

were defined by previously used Read Codes in published SAIL studies (Cooksey et al, 2022). For chronic widespread pain, and stress/bereavement and adverse life events, we used code lists previously published by Mansfield et al. (2016), and Somayajula et al. (2022), respectively. Codelists for diagnostic procedures can be found in Supplementary 1 (Tables 1-4).

Primary healthcare encounters were calculated as counts of 'events' (i.e. Read codes) present in the primary healthcare records which may relate to visits or contact with primary care or can relate also to procedural codes e.g., blood tests. Mortality data was obtained by linking to the Annual District Death Daily dataset from the Office of National Statistics.

Analysis

Descriptive statistics were used to examine socio-demographic characteristics, comorbidities and medications and healthcare use (primary care encounters, secondary care attendance, referrals to specialty outpatient facilities, surgical procedures and diagnostic investigations). Only people who did not have a health event recorded in the period prior to the index date were included in the population for measuring prevalence of the specific health event in the post-index date period. These are indicated in the tables as "new events". In contrast for events such as health services use, everyone was examined in the post-index date period irrespective of whether the event occurred prior to the index date. These are indicated in the tables as "all events". All data analysis was conducted using STATA Version 17.

Ethical approvals

Wales: The study was approved by the SAIL Information Governance Review Panel (approval number: 0419).

Scotland: Approvals for data linkage were obtained from the Public Benefit and Privacy Panel for Health and Social Care, Scotland (1920-0001).

3. Findings

Findings are presented separately for Scotland and Wales, followed by interpretation in the context of wider PACFiND evidence from patients, healthcare professionals, and fibromyalgia service case studies.

3.1 Sociodemographic characteristics

Scotland

A total of 275 participants from the MAmMOTH study who responded to the 2019 survey consented to data linkage. This cohort comprised 71 participants with a self-reported fibromyalgia diagnosis, 99 who met the 2011 ACR fibromyalgia research criteria but did not report a diagnosis (fibromyalgia criteria group), and 105 with chronic pain. Routine healthcare data linkage was successfully achieved for 196 individuals.

The mean age was comparable across groups: 57.1 years (SD 11.2) for the fibromyalgia diagnosis group, 59.2 years (SD 10.4) for the fibromyalgia criteria group, and 59.4 years (SD 13.5) for the chronic pain group. The fibromyalgia diagnosis group was predominantly female (84.5%), compared with 61.6% in the fibromyalgia criteria and 65.7% in the chronic pain groups. Participants in the fibromyalgia criteria (33.3%) and fibromyalgia diagnosis (29.6%) groups were substantially more likely to be out of paid employment due to illness than those in the chronic pain group (12.4%).

Wales

19,742 fibromyalgia cases and 76,746 matched controls were analysed. Fibromyalgia patients were predominantly female (89%), median age 48 years. Compared to controls, a greater proportion of fibromyalgia patients had higher BMI (30.3 v 28.8 kg/m2), were a current/ex-smoker (73 v. 68%) and had codes for stress and/or bereavement (27.2 v. 17.6%) and adverse life events (10.7 v. 8.8%) in their electronic health records.

3.2 Healthcare use and complex healthcare journeys

Healthcare use

We found that people with fibromyalgia experience complex and prolonged interactions with the health system before and after diagnosis.

Scotland

In Scotland, 196 individuals were included in the analysis: 46 with a fibromyalgia diagnosis, 75 meeting fibromyalgia criteria but without diagnosis, and 75 with chronic pain. Overall healthcare use in individuals reporting a diagnosis of fibromyalgia and the chronic pain groups was similar.

However, those meeting fibromyalgia criteria without diagnosis had two to three times higher healthcare use across outpatient, hospital, GP out-of-hours, and A&E services (Table 1). The greatest difference is seen emergency hospital admissions, where the fibromyalgia criteria group are 2.5 times more likely to have an emergency hospital admission compared to individuals with chronic pain or a fibromyalgia diagnosis, and 1.4 times more likely to have an outpatient attendance than individuals reporting a fibromyalgia diagnosis.

Individuals with a diagnosis of fibromyalgia were more likely to have an outpatient attendance or an elective hospital emission than those with chronic pain, but were less likely to attend the emergency department, with no difference found in GP out of hours and emergency hospital admissions.

Table 1. Number of healthcare episodes by group per 100-person years

Dataset	Fibromyalgia Diagnosis	Meeting ACR 2011 Fibromyalgia Criteria	Chronic Pain
Outpatient Attendances	194.7	265.0	151.5
Hospital Admissions	-	-	-
Emergency	7.4	18.5	7.3
Elective	31.4	50.9	22.7
GP Out of Hours	13.6	22.3	11.3
Emergency Department	16.9	32.3	21.3

Among those with a confirmed diagnosis of fibromyalgia, there were clear differences in patterns of healthcare use before and after diagnosis (Table 2). Prior to diagnosis, individuals were more likely to attend GP out-of-hours services. Following diagnosis, they had a higher number of emergency and elective hospital admissions, as well as more accident and emergency attendances. The overall number of outpatient appointments remained similar before and after diagnosis.

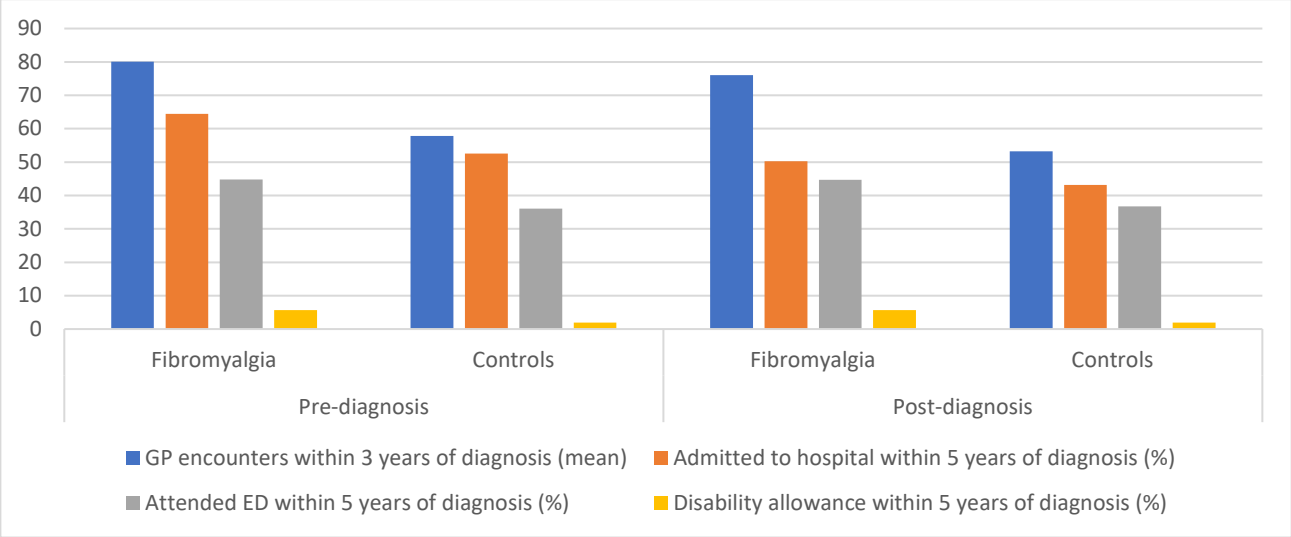
Table 2. Number of healthcare episodes per 100-person years before and after diagnosis of fibromyalgia

Dataset	Before fibromyalgia diagnosis	After fibromyalgia diagnosis
Outpatient Attendances	203.3	195.2
Hospital Admissions	-	-
Emergency	4.5	8.9
Elective	20.8	33.9
GP Out of Hours	32.6	10.9
Emergency Department	7.7	20.7

Wales

In Wales, compared to matched controls, people with a diagnosis of fibromyalgia had more GP encounters, admissions to hospital and emergency department attendances before and after diagnosis, see Figure 1. A greater proportion of those with fibromyalgia were in receipt of Disability Living Allowance.

Figure 1. Healthcare use pre and post diagnosis of fibromyalgia in Wales



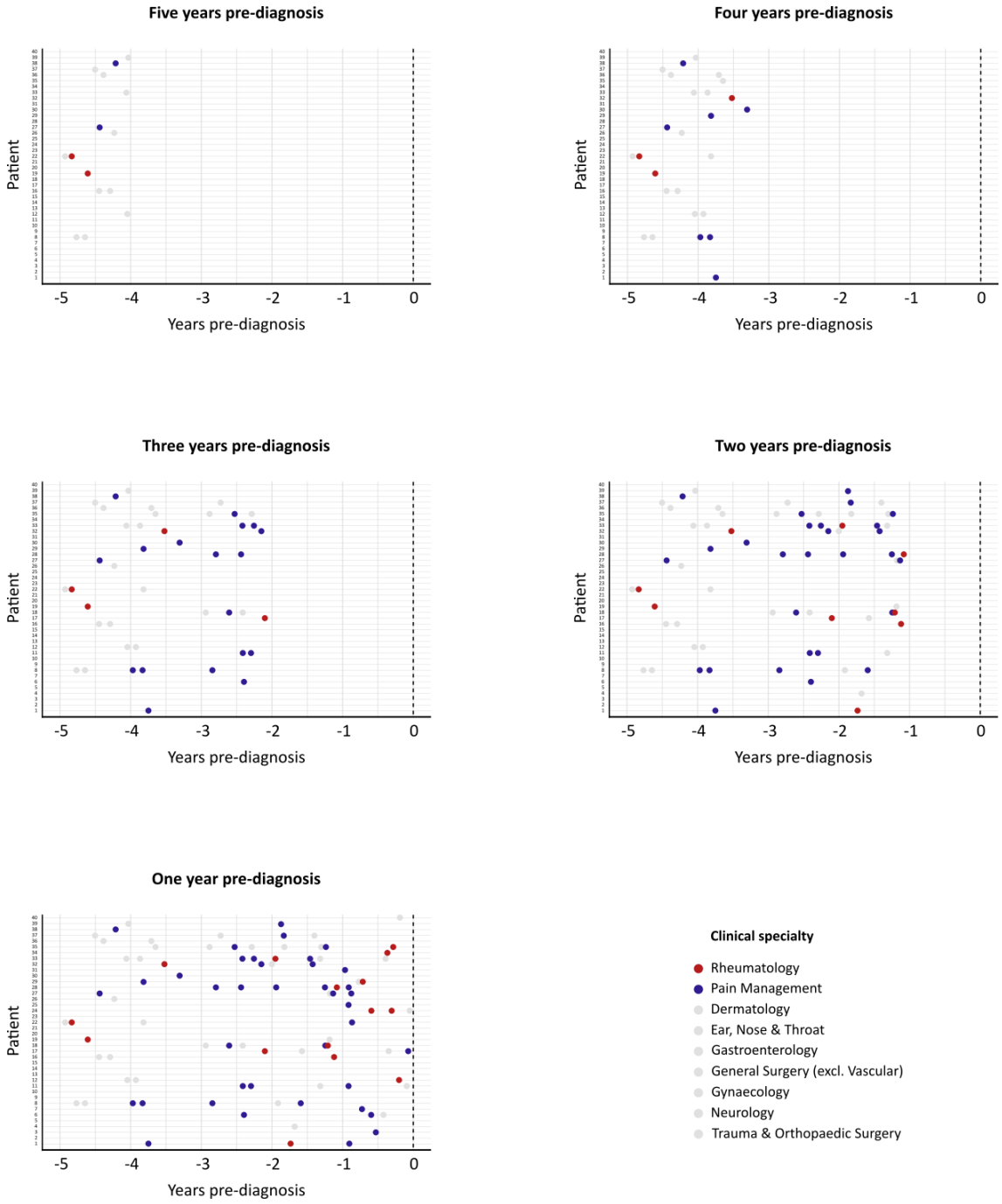
Complex healthcare journeys

Visualising individual healthcare pathways (sequences of secondary care health care episodes pre and post diagnosis of fibromyalgia) illustrates the complex care pathways experienced by people living with fibromyalgia and can help identify key touch points within the patient journey to help improve services.

Scotland

In Scotland, we observed complex, multi-specialty referral patterns both before and after diagnosis, with frequent outpatient appointments in specialties such as Rheumatology, Neurology, Gastroenterology, and Orthopaedics. Figures 2 and 3 show how patients moved between specialties in the period leading up to a fibromyalgia diagnosis. In Figure 3, the thicker lines represent a greater number of transitions, and the arrows indicate the direction of movement between specialties (for example, an Orthopaedics appointment followed by a Rheumatology appointment). In the five years preceding diagnosis, there was a steady increase in outpatient activity, and most notably a rise in Rheumatology attendances during the year immediately before diagnosis.

Figure 2. Pre-diagnosis - individual outpatient visit sequences in the lead up to diagnosis of fibromyalgia (Scotland)



An animated version of this figure is available at:
https://www.abdn.ac.uk/iahs/academic/epidemiology/our-research/studies-list/pacfind/figure-2/

Figure 3. Transitions between specialties in the 5 years leading up to a diagnosis of fibromyalgia.

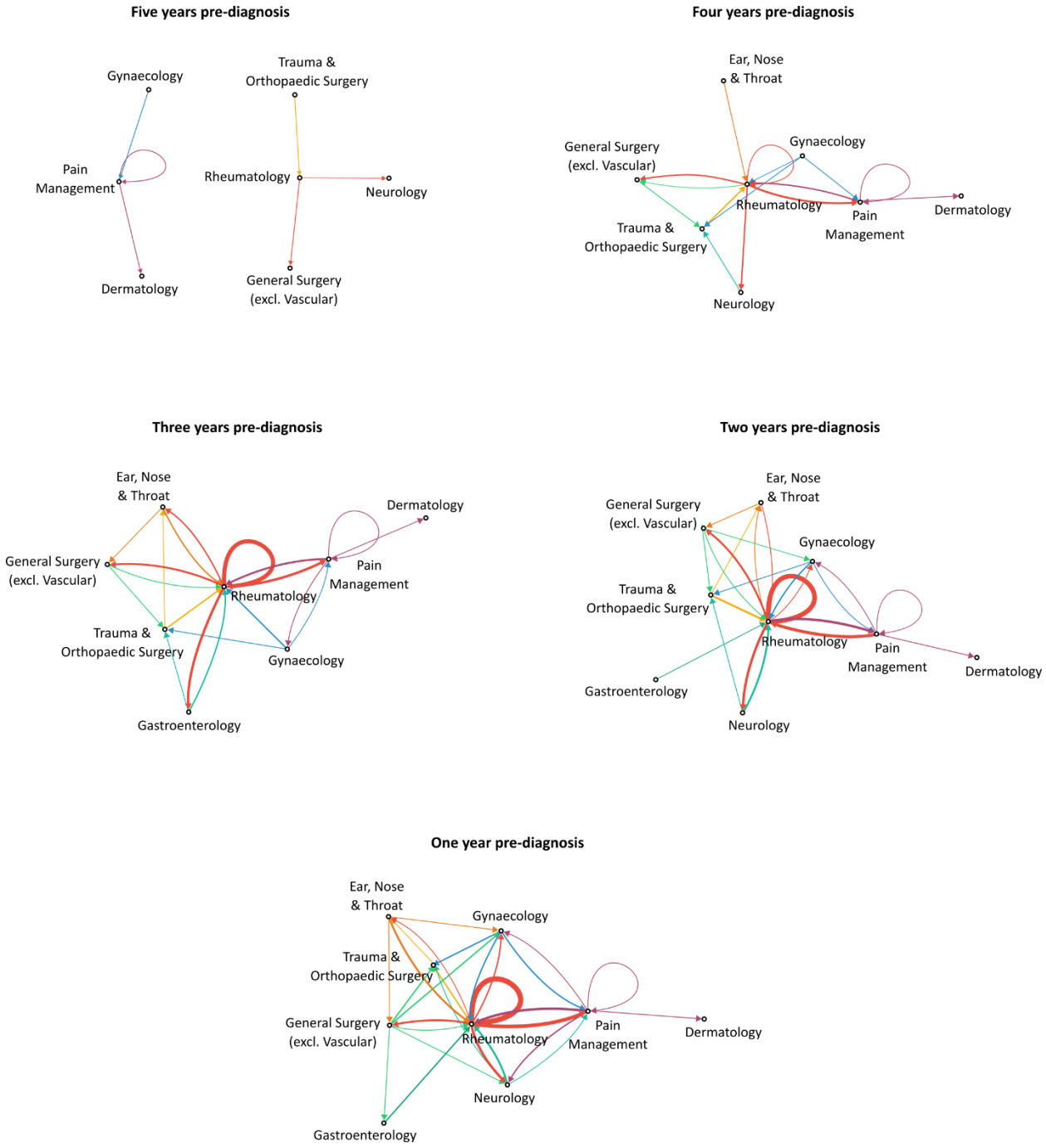
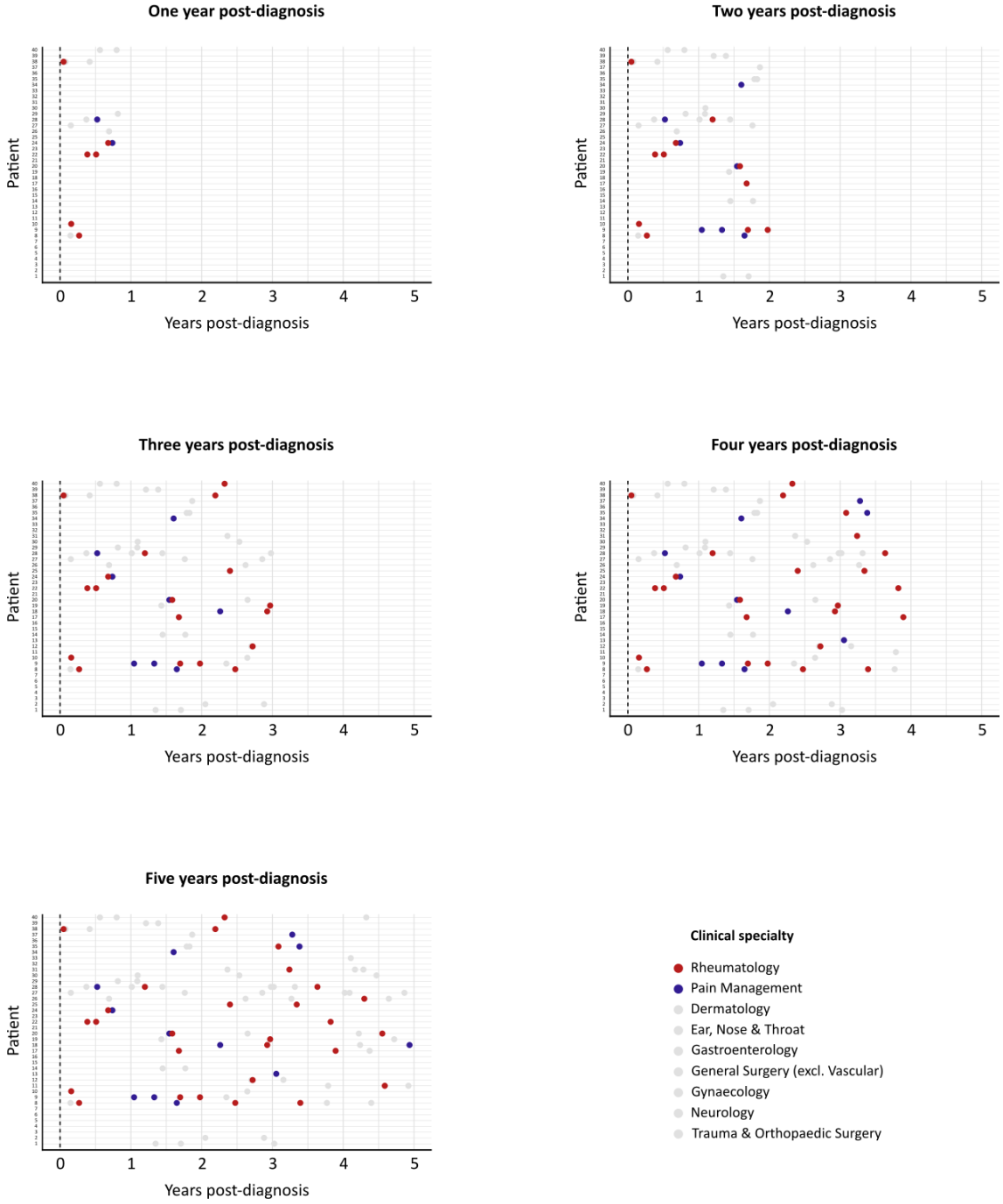


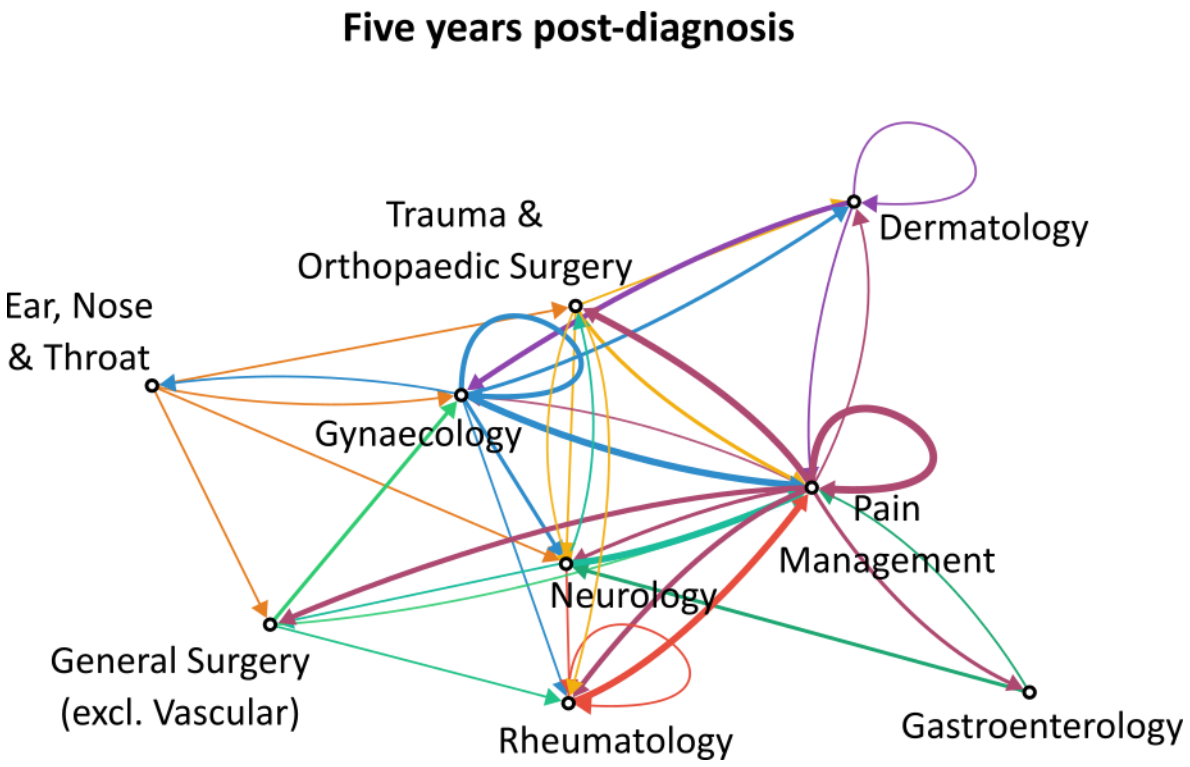
Figure 4 illustrates how patients moved between specialties in the period following a diagnosis of fibromyalgia in Scotland. In contrast to the pre-diagnosis patterns, there are fewer Rheumatology outpatient visits (and those that are present may reflect individuals with fibromyalgia alongside an autoimmune rheumatic condition), and more pain management visits.

Figure 4. Post-diagnosis – individual outpatient visit sequences following diagnosis of fibromyalgia (Scotland)



An animated version of this figure is available at:
https://www.abdn.ac.uk/iahs/academic/epidemiology/our-research/studies-list/pacfind/figure-4/

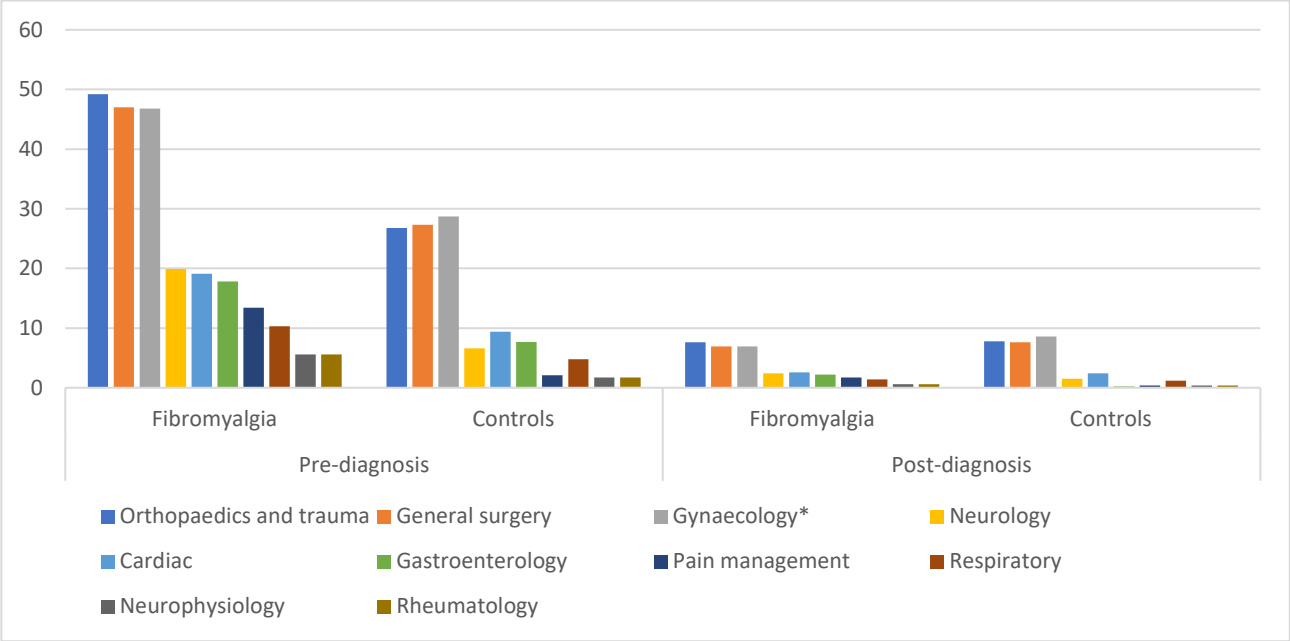
Figure 5. Transitions between specialties in the 5th year after diagnosis of fibromyalgia.



Wales

In Wales, people with a diagnosis of fibromyalgia had significantly more outpatient referrals across most specialties examined (17/20) in the year before diagnosis, particularly to Gastroenterology, Neurology, Pain Management, General Surgery, and Orthopaedics, see Figure 6. Nearly half of fibromyalgia cases were referred to each of General Surgery, Orthopaedics, or Gynaecology, reflecting widespread healthcare use and potential diagnostic uncertainty. Following diagnosis there was little difference in amount of outpatient attendances between fibromyalgia cases and controls, consistent with what we found in Scotland.

Figure 6. Referrals to specialist outpatient clinics one-year pre and post diagnosis of fibromyalgia in Wales.



3.2 Comorbidities

Scotland

In Scotland, data on self-reported comorbidities were available for the cohort consenting to data linkage (n=275). Participants in the Fibromyalgia criteria group reported the highest prevalence of rheumatoid arthritis (19.2%) and osteoporosis (19.2%) (Table 3). The prevalence of axial spondylitis (7.0%) and psoriatic arthritis (4.2%) was highest in those reporting a diagnosis of fibromyalgia.

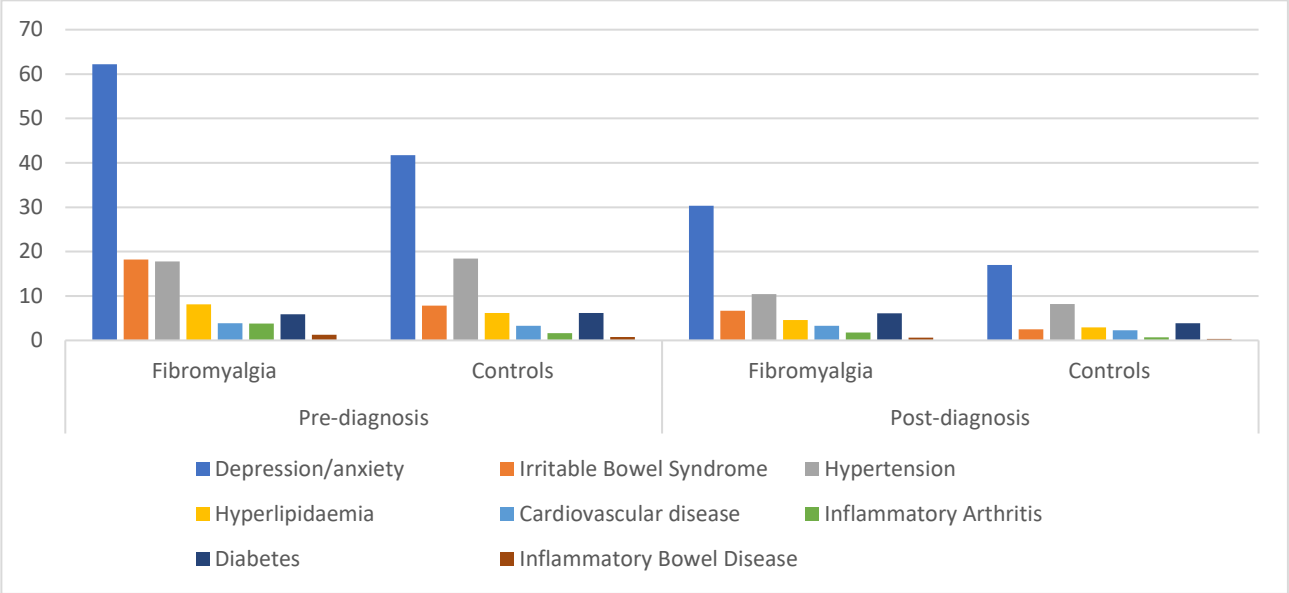
Table 3: Self-reported prevalence of specific comorbidities in the Scottish cohort (n=275)

Comorbidity	Chronic Pain (n=105)	Meeting Fibromyalgia criteria (n=99)	Fibromyalgia diagnosis (n=71)
Rheumatoid Arthritis	11 (10.5%)	19 (19.2%)	9 (12.7%)
Psoriatic Arthritis	4 (3.8%)	1 (1.0%)	3 (4.2%)
Axial Spondylitis	3 (2.9%)	5 (5.1%)	5 (7.0%)
Osteoporosis	7 (6.7%)	19 (19.2%)	9 (12.7%)

Wales

In Wales, several co-morbidities (recorded in general practice) were more common in people with a code for fibromyalgia compared to controls, see Figure 7. Depression and/or anxiety was recorded in almost three-quarters of cases (73.6 v. 52.3%), while irritable bowel syndrome (6.7 vs 2.5%) and sleep disorders were also more common (24.8 v. 13.6%). Inflammatory conditions were also more commonly recorded, specifically Inflammatory Arthritis (5.4 v. 2.2%) and Inflammatory Bowel Disease (1.9 v. 1.1%).

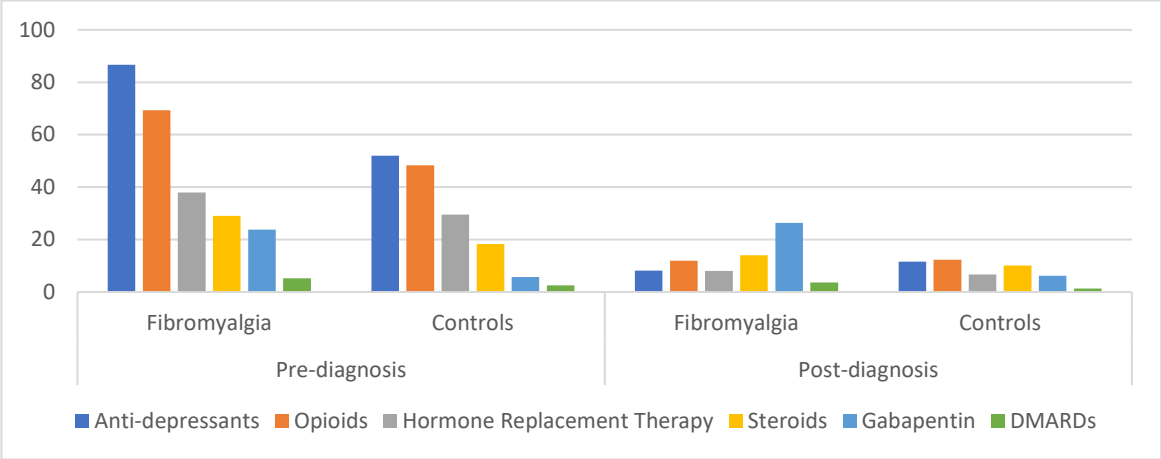
Figure 7. Co-morbidities in fibromyalgia cases and controls, one-year pre and post diagnosis (Wales).



3.3 Management Approaches and Implications for Safe Care

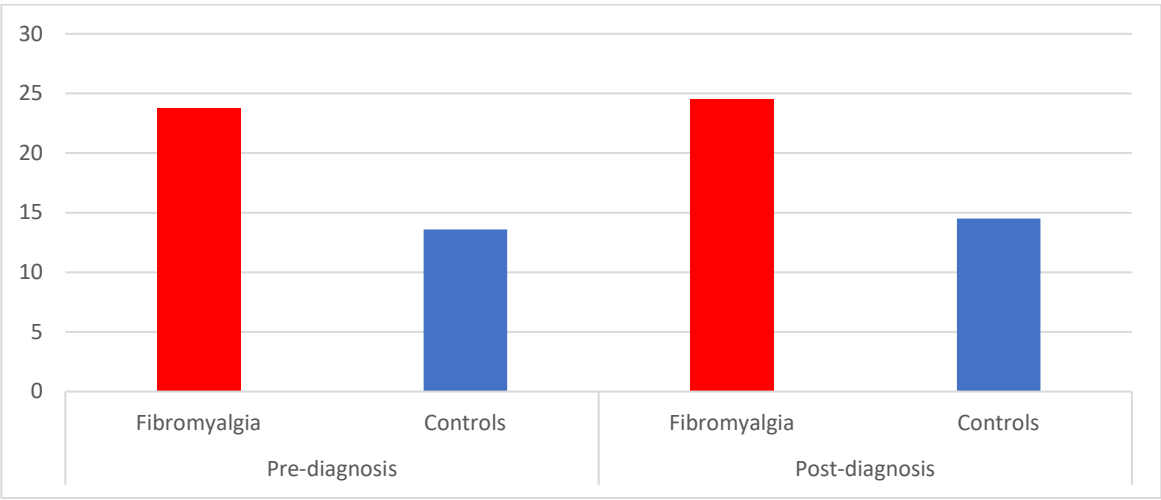
A detailed assessment of management approaches was possible within the Wales dataset only. Prescribing patterns demonstrate a dominant pharmacological approach to managing fibromyalgia. The use of anti-depressants was near universal in people with fibromyalgia (95%), gabapentin was used by half of cases (51%), and 82% had been prescribed opiates, despite recommendations to prioritise non-pharmacological treatments. Steroid use was also common in cases (44%), see Figure 8.

Figure 8. Prescribed medications in fibromyalgia cases and controls, one-year pre and post diagnosis (Wales).



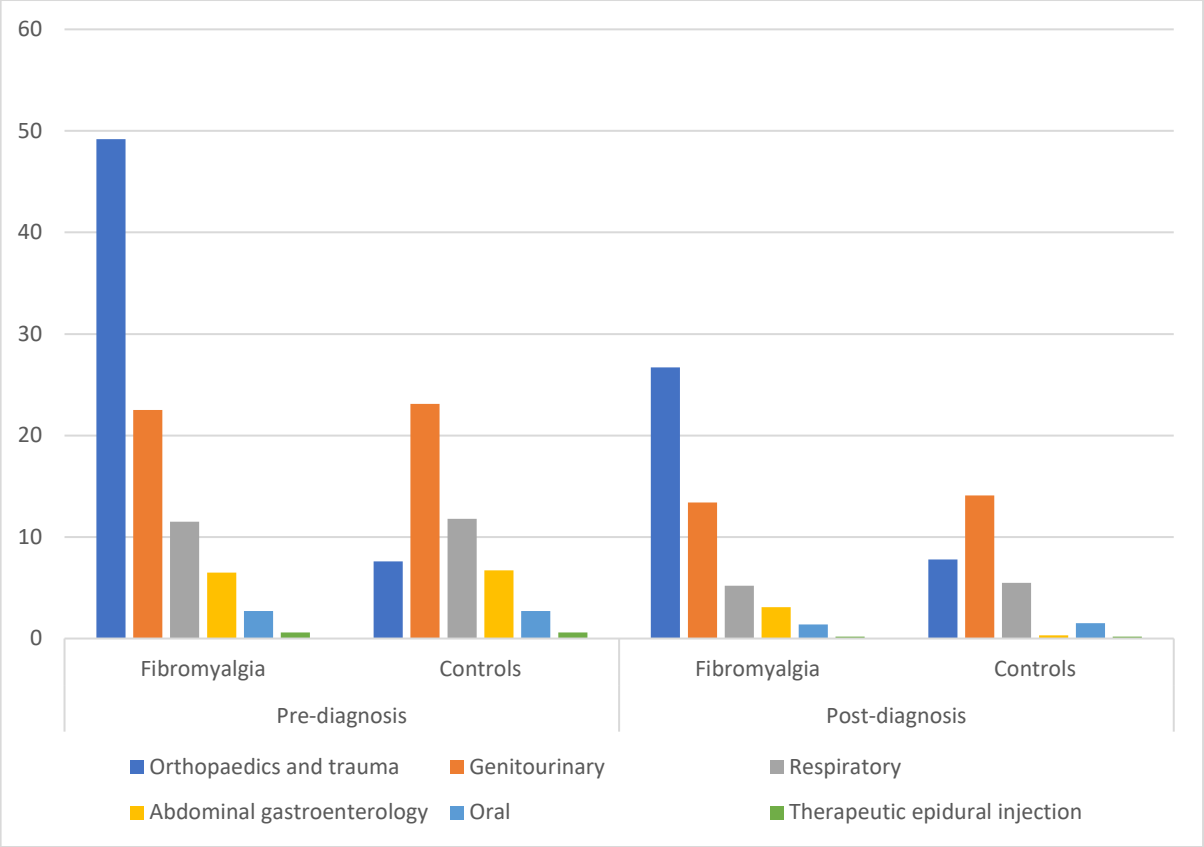
People with fibromyalgia were also more likely to have a surgical or imaging diagnostic investigation code in their electronic healthcare records before and after diagnosis, see Figure 9.

Figure 9. Proportion of surgical or imaging diagnostic investigation codes in electronic health records of people with fibromyalgia and controls.



Similarly, people with fibromyalgia had more orthopaedic and trauma surgical procedures in their health records pre and post diagnosis of fibromyalgia, compared to controls. Those with fibromyalgia were also more likely to have gastrointestinal surgical procedures in their records following diagnosis, see Figure 10.

Figure 10. Proportion of surgical procedure codes in electronic health records of people with fibromyalgia and controls.



4. Discussion and key learning points

Analyses of administrative healthcare data from Scotland and Wales reveal consistent patterns of fragmented care, diagnostic uncertainty, and a predominant reliance on pharmacological management for people with fibromyalgia. High levels of healthcare utilisation among individuals who meet criteria for fibromyalgia but remain undiagnosed, together with frequent surgical and diagnostic imaging investigations prior to diagnosis, suggest limited confidence among clinicians and ongoing uncertainty in recognising the condition.

Fibromyalgia frequently co-exists with other conditions, further compounding diagnostic complexity. While some invasive investigations may be clinically appropriate, others may be unnecessary or unrelated to fibromyalgia symptoms. Conversely, diagnostic overshadowing can result in under-investigation of other important health issues. Together, these patterns expose patients to potential harm from both over- and under-investigation. Notably, high levels of healthcare utilisation persist even after diagnosis, indicating that many patients still lack access to appropriate, effective, and coordinated services.

When interpreting these data, several factors should be considered. In Wales, analyses included only individuals who had received a diagnosis; those still undiagnosed who are likely to have the longest and most complex diagnostic journeys were not captured, potentially underestimating time to diagnosis and associated challenges. Nevertheless, the use of population-level data provides excellent coverage, reducing participation bias and allowing inclusion of large patient numbers. This represents, to our knowledge, the largest study to examine health service use among people diagnosed with fibromyalgia.

Identifying a suitable comparison group in the SAIL databank also posed methodological challenges. Some individuals, though registered with general practice, may have moved away. We therefore selected people without a record of fibromyalgia but with a healthcare encounter around the same time as their matched case received a diagnosis, providing a pragmatic and robust comparator. Finally, as reasons for referrals are not captured, some may relate to other conditions, particularly common comorbidities such as osteoarthritis.

Nevertheless, the consistency of findings across two distinct health systems within the UK highlights the systemic nature of the challenges in fibromyalgia care. A lack of clear service ownership, limited integration between primary and secondary care, and absence of multidisciplinary support contribute to inefficiency and inequity and potential for harm.

Qualitative findings from across the PACFiND programme reinforce this picture. Healthcare professionals describe diagnostic uncertainty, concerns about the value of the fibromyalgia label, limited referral options, and system-level barriers to holistic care. Patients report lengthy diagnostic journeys, stigma, a lack of validation, exclusion from services, and a sense of being “cut loose” following diagnosis. In contrast, positive experiences emphasise the importance of trusted

relationships, continuity, and whole-person care which are elements not well supported by current service structures.

Our findings underscore the need for earlier recognition of fibromyalgia and better-coordinated care pathways to reduce avoidable investigation and inappropriate prescribing. Addressing these gaps through pathway redesign, role clarification, and sustained continuity of care offers clear potential to improve outcomes and reduce costs.

Key learning points for practice and policy include:

- Increasing knowledge and understanding of fibromyalgia
  - Empower primary care to diagnose and manage fibromyalgia confidently, supported by clear referral pathways.
  - Raise awareness among healthcare professionals, especially in surgical and gynaecological specialties.
- Avoiding harm
  - Balance diagnostic certainty with avoidance of harm from unnecessary investigation and prescribing.
- Providing good care
  - Promote continuity, trust, and holistic support across the life course.
- Resources
  - Reallocation of resources towards coordinated multidisciplinary models of care.
  - Reducing inappropriate referrals and investigations, and harm from under investigation and inappropriate prescribing e.g., opiates and its consequences (addiction, accidental overdose, side effects)

6. The PACFIND programme

Further information on the PACFIND project and our findings can be found at: https://www.abdn.ac.uk/iahs/academic/epidemiology/our-research/studies-list/pacfind/

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7. Future Work

Future analyses will identify subgroups of patients with distinct healthcare use and medication patterns, such as those experiencing frequent emergency admissions, invasive procedures, or long-term opiate use, and explore associated demographic and clinical features. These insights will inform targeted interventions to reduce harm and improve equity.

We are also engaging clinicians, commissioners, and patients to co-develop practical resources and guidance to support earlier diagnosis, safer prescribing, and integrated service design aligned with NHS sustainability and equity priorities.

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Supplementary Materials

Supplementary 1: Read codes (Wales)

The following read codes were used during data linkage for this research. Click on the below links to download a full PDF reference.

- Supplementary Table 1: Definitions
- Supplementary Table 2: Medications
- Supplementary Table 3: Specialties
- Supplementary Table 4: Surgical procedures

Supplementary 2: Full details of PACFiND programme outputs

Understanding Existing Services

"No one wants to look after the fibro patient."

Two narrative systematic reviews examined existing models of care and patients' experiences. **No evidence-based, whole-system model** was found. Limited benefits were seen from ongoing secondary care follow-up. Patients described **delayed diagnosis, inconsistent care**, and **not being believed**. Positive experiences such as being listened to and involved in decisions, improved satisfaction and confidence.

The paper is available at:

Doebl et al. No one wants to look after the fibro patient". Understanding models, and patient perspectives, of care for fibromyalgia: reviews of current evidence , PAIN: August 2020, 161 (8) p 1716-1725. https://doi.org/10.1097/j.pain.0000000000001870

UK surveys of healthcare services for fibromyalgia

Two UK-wide online surveys gathered responses from **1,701 healthcare professionals** and **549 people with fibromyalgia**. Services were **highly variable**, with few clear pathways. About **one-third of GPs said they did not diagnose fibromyalgia**, citing lack of confidence or uncertainty about its validity. Non-drug therapies were limited, leaving education and medication as mainstays. Many GPs felt that **there was a lack of support** from secondary care when they did need help or advice, such as around **diagnostic uncertainty**.

Patients identified **lack of available services** as their greatest unmet need and frequently turned to private or community-based support. Three themes summarised experiences: **"a troublesome label," "a heavy burden,"** and **"a low priority."**

You can watch a summary video of the results of these surveys by holding the CTRL key and clicking on the below image:

Read the research paper at:

Wilson, Beasley et al. UK healthcare services for people with fibromyalgia: results from two web-based national surveys (the PACFiND study). BMC Health Services Research, 22, 989 (2022). https://doi.org/10.1186/s12913-022-08324-4

A Plain Language Summary for this paper is also available here .

Understanding experiences, needs and preferences for care

Comparing the impact of symptoms and health care experiences of people who have and have not received a diagnosis of fibromyalgia: A cross-sectional survey within the PACFiND study

We compared people with fibromyalgia, those with similar symptoms but no diagnosis, and those with chronic pain. People with fibromyalgia were more likely to be women, took an average **of three years to be diagnosed**, most **often in hospital,** and reported **poorer GP experiences** than those

with chronic pain. The **impact on daily life and work** was substantial and greater than for comparison groups.

Read the full paper at:

Doebl et al. Comparing the Impact of Symptoms and Health Care Experiences of People Who Have and Have Not Received a Diagnosis of Fibromyalgia: A Cross-Sectional Survey Within the PACFiND Study . Arthritis Care & Research (2021),74: 1894-1902. https://doi.org/10.1002/acr.24723

A Plain Language Summary for this paper is also available here .

Link to Health Experiences Insight (HEXI) Interviews

Thirty-one people from across the UK shared their experiences through interviews, now available on the Health Experiences Insight (HEXI) website. Videos and audio clips explore early symptoms, healthcare encounters, and therapies. These have been viewed **over 40,000 times**, helping raise awareness of patient experience.

You can visit the HEXI section on fibromyalgia at: https://hexi.ox.ac.uk/Fibromyalgia/overview

Patient preferences for models of care for fibromyalgia: A discrete choice experiment

A Discrete Choice Experiment with **518 people** explored preferences for service design. The most valued model included **early diagnosis** and **ongoing management by a Rheumatologist**, delivered face-to-face or virtually. Shorter waiting times and access to physical therapy were highly valued. Participants were willing to receive ongoing support from **nurses or GPs if care remained timely and continuous**, indicating scope for flexible, team-based models.

Read the full research paper at the following link:

Norwood P, Beasley M, Stevens M, Hollick R, Macfarlane G, McNamee P, Investigators PAS. Patient preferences for models of care for fibromyalgia: A discrete choice experiment. PLoS ONE. 2024;19(6):e0305030. https://doi.org/10.1371/journal.pone.0305030

Shaping Supportive Health and Work Systems

Chronicity rhetoric in health and welfare systems inhibits patient recovery: a qualitative, ethnographic study of fibromyalgia care

Using *Sociology for People* (Dorothy E. Smith), researchers examined how **healthcare structures, not just individual behaviours, shape neglect in fibromyalgia care**. When biomedical explanations are lacking, systems often shift from "nothing found" to "nothing can be done," reframing the issue as psychological and **withdrawing support**.

This analysis highlights how institutional logic perpetuates stigma and blame, and why improving care requires **system-level change** in biomedical ideology and organisation, not just better communication.

Read the full paper here:

Cupit C, Finlay T, Pope C on behalf of the PACFiND investigators. Chronicity rhetoric in health and welfare systems inhibits patient recovery: a qualitative, ethnographic study of fibromyalgia care. Social Science & Medicine, Volume 382, Oct 2025, 118313. https://doi.org/10.1016/j.socscimed.2025.118313

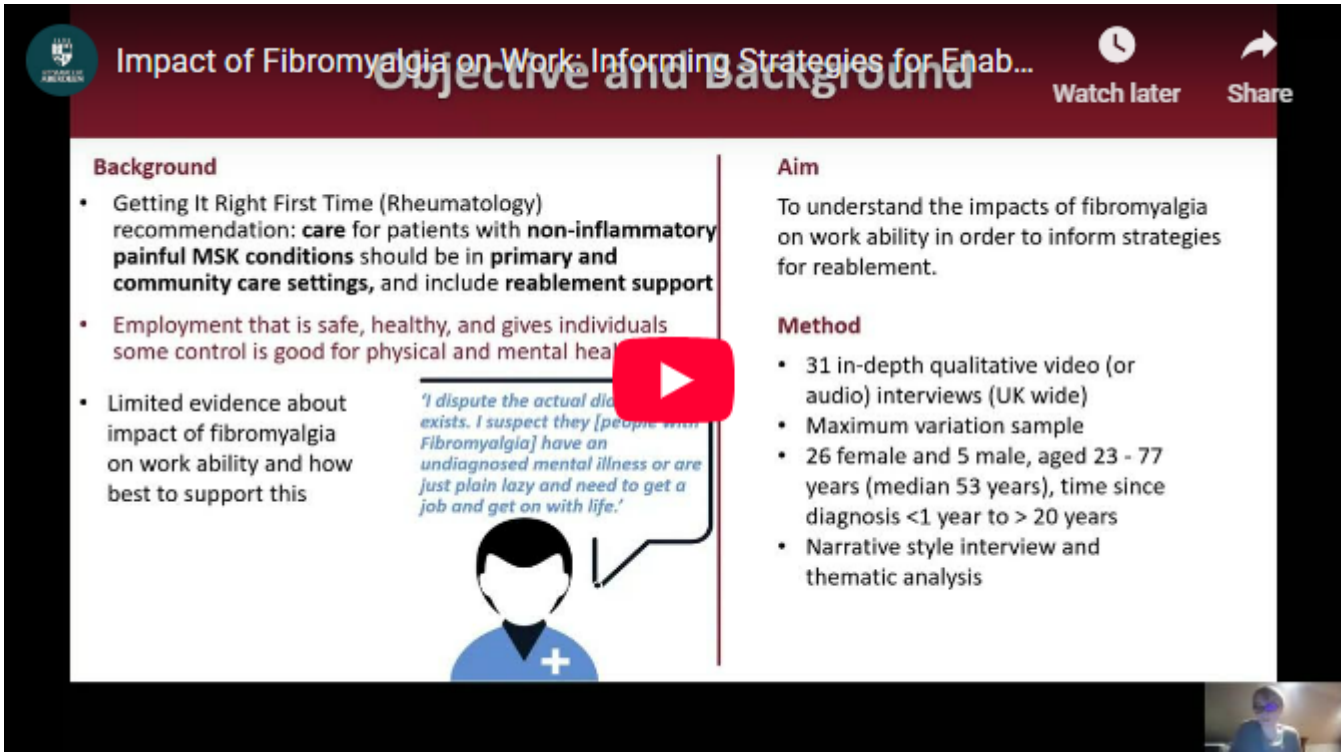
A Plain Language Summary for this paper is also available here.

Impact of Fibromyalgia on Work: Informing Strategies for Enablement

Interviews across the UK explored how fibromyalgia affects work. Many valued employment, but struggled with **fatigue, pain, poor concentration**, and **unpredictable symptoms**. Supportive employers and flexible arrangements, such as **adjusted hours, rest breaks, and home working**, were highly valued but not universal. Understanding among colleagues and employers was often limited, particularly for those without a formal diagnosis. Fibromyalgia disrupted education and career development, especially for younger people, leading to **grief for lost aspirations** and limited advice on sustaining work. Some changed careers or became self-employed to maintain flexibility.

Viewed through the lens of **biographical disruption**, fibromyalgia often undermines self-esteem and identity. The impact typically begins **before diagnosis** and is worsened by workplace systems that fail to accommodate fluctuating symptoms. **Early, tailored work support and flexible adjustments** are essential to help people **remain in or return to employment**. Employers should recognise fibromyalgia's **invisible, variable nature** and adapt systems to support continued participation.

You can watch a video presentation of this work by holding the CTRL key and clicking on the image below:

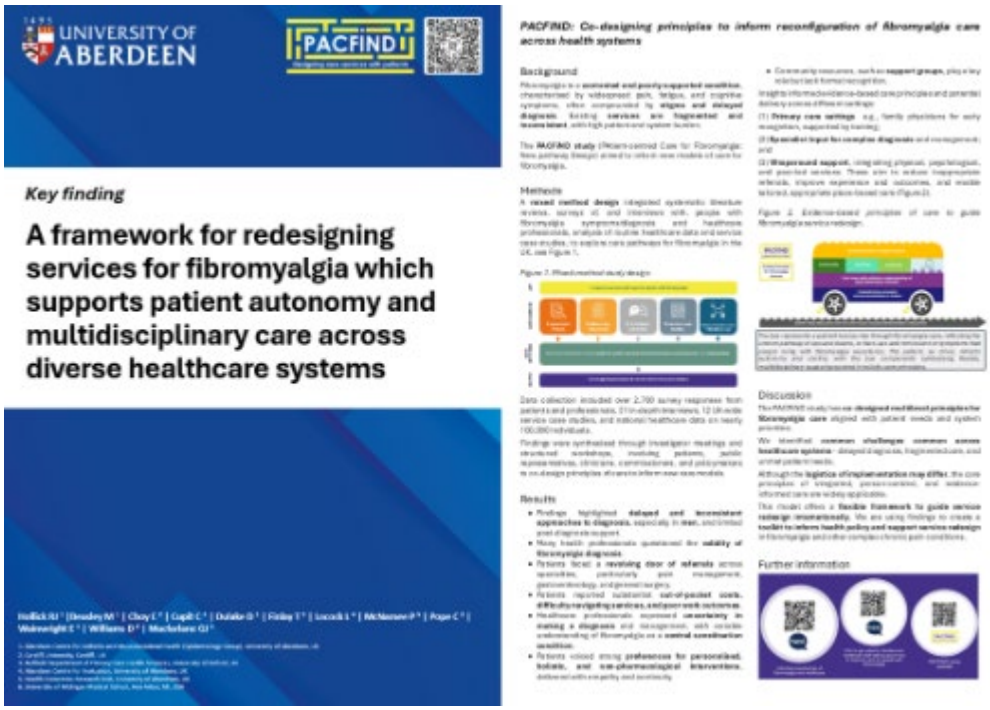


Co-designing principles for better care

By combining data from literature reviews, surveys, interviews, and case studies, and working with patients, clinicians, commissioners, and policymakers, PACFiND co-designed **multilevel principles for care** aligned with patient needs and system priorities.

We used this to create a **bus infographic** that symbolises a patient-led journey through care: the patient as driver (autonomy), supported by a multidisciplinary "bus" team. This model promotes **holistic, flexible, place-based care**, reduces inappropriate referrals, and improves experience and outcomes.

You can view a full version of the poster here.



Supporting conversations about healthcare improvement – a catalyst film for fibromyalgia

Insights from people living with fibromyalgia were brought together in a short film to spark discussion about service improvement. It illustrates the importance of being **believed, listened to, and taken seriously**. The film is intended as a **catalyst** for local patients, families, and NHS staff to collaborate on improving care experiences.

Watch the film by holding the CTRL key and clicking on the image below: