

**HOSPITALISATION IN FIBROMYALGIA: A COHORT-LEVEL OBSERVATIONAL STUDY OF IN-PATIENT PROCEDURES, COSTS AND GEOGRAPHICAL VARIATION IN ENGLAND.**

**Running head: In-patient care for patients with a diagnosis of fibromyalgia**

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## **Abstract**

**Objectives.** Fibromyalgia is a complex, debilitating, multifactorial condition that can be difficult to manage. Recommended treatments are usually delivered in outpatient settings; evidence suggests significant inpatient care occurs. We describe the scale and cost of inpatient care with a primary diagnostic code of fibromyalgia within the English National Health Service (NHS).

**Methods.** We conducted a cohort-level observational study of all patients admitted to hospital due to a diagnosis of fibromyalgia, between 1 April 2014 and 31 March 2018 inclusive, in the NHS in England. We used data from Hospital Episode Statistics Admitted Patient Care to study: age and sex of patients admitted, number and costs of admissions, length of stay, procedures undertaken, class and type of admission, and distribution of admissions across clinical commissioning groups (CCGs).

**Results.** 24,295 inpatient admissions, costing £20,220,576, occurred during the four-year study period. Most patients were women (89%) with peak age of admission of between 45 and 55 years. Most admissions were elective (92%). A number of invasive therapeutic procedures took place, including a continuous intravenous infusion (35%). There was marked geographical variation in the prevalence and cost of inpatient fibromyalgia care delivered across the country, even after accounting for CCG size.

**Conclusions.** Many patients are admitted for treatment of their fibromyalgia and given invasive procedures for which there is weak evidence, with significant variation in practice and cost across the country. This highlights the need to identify areas of resource use that can be rationalised and diverted to provide more effective, evidence-based treatment.

**Keywords:** fibromyalgia, epidemiology, pain assessment and management, health economics, quality of healthcare.

## **Key messages**

- An estimated 24,295 admissions, costing £20,220,576, were recorded over the four-year study period.
- Many invasive therapeutic procedures were undertaken, with 35% of admissions including a continuous intravenous infusion.

- The number of inpatient admissions and cost associated with fibromyalgia diagnoses care varies across the country.

## **Introduction**

Chronic pain is known to be a global problem, with estimates suggesting that it affects between a third and half of adults in the UK alone (1). These estimates are likely to be conservative as pain is not clearly defined and has only recently been recognised as a symptom as well as a disease entity in its own right (2). Fibromyalgia is a common clinical syndrome characterised by chronic widespread musculoskeletal pain often associated with sleep disturbance and fatigue, for which no other cause can be identified (3, 4). It has an estimated prevalence of between 1.2 and 5.4% of the population depending on the diagnostic criteria used (4). It is also associated with chronic overlapping pain conditions, such as irritable bowel syndrome, interstitial cystitis, vulvodynia, and temporomandibular joint syndrome, broadening its clinical impact (5, 6).

A broad range of pharmacological and non-pharmacological treatments have been investigated for treating fibromyalgia. The latest revision to the European League Against Rheumatism (EULAR) recommendations for managing fibromyalgia were much more firmly evidence-based than previous recommendations (7). The EULAR guidance supported the move towards timely diagnosis and early selection of appropriate treatment options, with a focus on education and non-pharmacological therapies such as exercise (7). All of the recommended treatments can be delivered in an outpatient setting, but the difficulty in ensuring widespread implementation in clinical practice has also been highlighted (8, 9).

Fibromyalgia is a significant health-related burden for patients. It also has high societal and healthcare costs, both indirectly through disability and loss of work productivity and directly through the costs of healthcare provision (10). This is similar to the broader picture of chronic pain and its burden to patients and society – perhaps starkly reflected by the opioid crisis in the USA (11). As fibromyalgia is primarily treated in outpatient settings, health economics research has focused on the cost of outpatient care (10). However, a small number of studies conducted predominantly over a decade ago suggested that healthcare use is not restricted to primary care and that a large portion of direct medical costs arise from hospitalisation in this patient group (10, 12, 13). This aspect of the economic burden may reflect the inadequacy

of current outpatient-based management or a failure to follow treatment recommendations. To our knowledge, inpatient management of fibromyalgia has not been investigated in the English healthcare setting.

We aimed to describe inpatient care directly attributable to fibromyalgia within the English National Health Service (NHS), including the estimated economic burden of these admissions, whether the procedures used in these admissions follow recommendations, and the geographical distribution of healthcare use across the country.

## **Methods**

### *Study design and setting*

This observational study was conducted using data from Hospital Episode Statistics (HES) Admitted Patient Care (APC), which is produced by the Health and Social Care Information Centre, NHS Digital (14) and provides data for all hospital inpatient admissions across all clinical commissioning groups (CCGs) in the NHS in England (15). These data have been regularly used for research on population-based admissions by disease (15). We used data for the last four financial years, from 1 April 2014 to 31 March 2018 inclusive. Data were sourced from Vantage by Health iQ (16). All data were available only in aggregate form. Specific ethical approval for this study was not required.

### *Study population*

Aggregate data was extracted for admissions identified with an International Classification of Diseases-10 (ICD-10) code for M79.7, the code for fibromyalgia introduced in the 2006 version, as the primary diagnosis. We also formed a comparison group, including individuals admitted due to irritable bowel syndrome (ICD-10 code K58), which is another chronic pain overlapping condition. After a patient has been discharged, accredited clinical coders at each hospital follow standardised rules to enter diagnosis and procedure details reported in the clinical discharge summary into their electronic patient information database. These are then extracted by NHS Digital for reporting and reimbursement purposes. The [primary diagnosis accounts for the majority of the length of stay of the admission \(15\)](#). To protect the privacy and confidentiality of individuals, small-number suppression has been applied to all outputs in accordance with NHS Digital guidelines.

### *Variables*

We extracted number of patients admitted, number of admissions, length of stay, and costs of admissions from the database for each financial year (2014 to 2018 inclusive). These variables were used to describe admissions, grouped by sex, age, elective versus non-elective admissions, procedures undertaken during admission, class of admission, and CCG. Admissions were divided into day cases, defined as an inpatient elective admission for treatment during the course of the day without staying overnight; ordinary, defined as inpatient elective admission for treatment and staying for at least one night; and regular, defined as an inpatient elective admission that is part of a planned series of admissions for an ongoing regime of broadly similar treatment in which the patient is discharged the same day. Procedures conducted during an admission were coded using three-level Office of Population Censuses and Surveys Classification of Interventions and Procedures (OPCS) codes, which is used to codify operations, procedures and interventions carried out during inpatient stays in the NHS. Costs were estimated directly by Health IQ based on NHS-reported Healthcare Resource Group (HRG) codes for each hospital stay, which cluster treatments that are both clinically similar and require similar levels of healthcare resources. Each HRG code is associated with a core cost, reported in the NHS National Tariff (17), which guides what the NHS reimburses hospitals for the treatments provided, taking into account certain patient characteristics. As HRGs represent a defined bundle of care, their associated core costs are based on a specific maximum length of stay known as a 'trim point'. The cost of excess bed days are hence calculated by multiplying the number of inpatient stay days beyond the trim point by the additional cost per extra bed day, also reported in the National Tariff, which were included in the cost calculation.

Only the number and age of patients in the comparison irritable bowel syndrome group were extracted.

### *Data analysis and reporting*

Descriptive statistics were used to characterise hospital admissions primarily due to fibromyalgia over the last four financial years. The pattern of hospitalisation was examined with respect to age, sex, and type of admission, including elective versus non-elective

admissions and day case, ordinary and regular admissions. The age distribution of admissions for fibromyalgia were compared to those for inflammatory bowel disease and corresponding population data from the Office of National Statistics for England in 2015 (Source: Office for National Statistics licensed under the Open Government Licence). The ten most common procedures undertaken during inpatient admission in the study period are reported.

The geographical distribution of hospitalisation was visualised by plotting the number of admissions on a map of the CCGs in England. As no data were available for the Northern, Eastern, and Western Devon CCG within this extract of HES APC data, this CCG was not included in the analyses. Raw data and data adjusted for the size of the population served by each CCG and its corresponding budget are presented.

As a sensitivity analysis, the analyses were repeated using admissions where the primary diagnosis reported for the admission was ICD-10 code M79.7, the code for fibromyalgia or M79.1. The latter is used to code for myalgia, including for example myofascial pain, but not myositis. It was included to try and investigate patients who may have been admitted due to symptoms consistent with a diagnosis of fibromyalgia, even if it wasn't reported in the discharge summary, in keeping with previous approaches to capture cases of fibromyalgia (12).

All figures were produced using Stata SE v12.0 (StatCorp, College Station, TX, USA) and Tableau Desktop 2018.3. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement: guidelines for reporting observational studies were used to ensure all relevant details of the study were included (18).

## **Results**

During the four-year study period, there were an estimated 24,295 admissions to hospital primarily due to fibromyalgia, with an associated cost of £20,220,576. When including admissions coded as being primarily due to either fibromyalgia or myalgia, there were an estimated 46,055 admissions, costing £44,681,540.

Figure 1 shows that the number of admissions each month increased during the study period. We did not identify any consistent seasonal variation in the number of admissions for either the fibromyalgia-only or overall cohorts (Supplementary Figure S1). Most of the patients admitted due to fibromyalgia only were women (21,705/24,295, 89%), as were those admitted due to fibromyalgia or myalgia (35,140/46,055, 76%).

The distribution of admissions by age differed to that of the general population, with a peak age for admission between 45 and 55 years (Figure 2). For comparison, only 25,690 hospital admissions were made for irritable bowel syndrome over the same study period, and these admissions were more evenly spread across age groups (Figure 2).

Table 1 summarises the types of admission over the four-year study period. Day case care was the most prevalent admission type each year. Most of the hospital admissions were elective 22,350/24,285 (92%). Non-elective admissions were longer in duration, with an average stay of 3.15 bed days compared with 0.14 bed days for elective admissions. A similar pattern was seen for admissions due to fibromyalgia or myalgia cohort, with (33270/46055, 72%) elective admissions and an average stay of 1.40 bed days for non-elective admissions, compared with 0.12 bed days for elective admissions.

Table 2 summarises the most frequent procedures undertaken during hospital admissions for fibromyalgia. Many of the procedures had radiological input for diagnostic or therapeutic purposes, therapeutic infusions, or musculoskeletal injection therapy. Similar results were found for the fibromyalgia or myalgia cohort (Supplementary Table S1). Table 2 and Supplementary Table S1 also report the average estimated cost per admission and the total estimated costs associated with the selected procedures.

Figure 3 illustrates the geographical regional variation in the number of admissions due to fibromyalgia for each CCG during the financial year ending 31 March 2018. The raw data (Figure 3A) revealed a 100-fold variation in the number of admissions across the country, with particularly high numbers of admissions in North Lincolnshire, Lincolnshire West, Wakefield, West Cheshire, Walsall, Coventry and Nene. After adjusting for the number of all-case admissions for each CCG (Figure 3B), areas such as Wakefield, North Lincolnshire, Lincolnshire

West, and West Cheshire continued to have up to 60-fold higher admission rates. Similar patterns were seen when the analysis was expanded to include the the fibromyalgia or myalgia cohort (Supplementary Figure S2).

Figure 4 shows the pattern of spending on fibromyalgia across England. Unadjusted figures (Figure 4A) show a 15-fold difference between the low- and high-spend CCGs. Areas such as Sheffield and Rushcliffe appear among the top spenders but not among the top admitters. The average cost per fibromyalgia or myalgia admission (Figure 4B) also demonstrates geographical variation in spending that differs from the patterns seen in the volume of admissions across the country. The geographical variation in spending was more marked in the fibromyalgia or myalgia cohort (Supplementary Figure S3).

## **Discussion**

This is the first study, to our knowledge, to examine the inpatient costs of managing patients diagnosed with fibromyalgia in England. An estimated 24,295 admissions, costing £20,220,576, were recorded over the four-year study period. This represents a small minority of the number of people who meet the criteria for fibromyalgia in England, which is likely to fall between 671,720 and 3,022,760 (4). Most patients were women (76%), with a peak age of admission of between 45 and 55 years. Most admissions were elective (72%), with day cases the most common class of admission. Many invasive therapeutic procedures were undertaken during these inpatient stays, with 21% of admissions including a continuous intravenous infusion. We found geographical variation in both the admission of patients with a diagnosis of fibromyalgia and the cost of inpatient care delivered across the country, even after adjusting for the size of CCGs.

### **Strengths and weaknesses of study**

This study has some limitations. As only aggregate data were available, individual-patient-level analyses could not be conducted. As inpatient HES data were used, relevant activity within accident and emergency services not resulting in hospital admission was also not captured. Our use of small number suppression may have influenced the results for less common outcomes. The accuracy and resolution of the data are limited by that of the coding procedures in place in hospitals and the HES database, which are both subject to potential



mis coding errors. The study design also has strengths. We used contemporary real-world data capturing all actual hospital admissions across the country, rather than limiting the study to a sample of the population. The size of the dataset allowed us to assess the trends in patient care across the country.

#### Comparison with other studies

Only data from studies in the United States are available for comparison. This is of limited value given the marked differences between the two healthcare systems. The US also demonstrated a clear female preponderance and a similar peak age range of between 45 to 64 years of age for admissions to hospital for fibromyalgia (10, 12, 13, 19). A gradual increase in fibromyalgia-related admissions was also demonstrated between 1999 and 2007 in the US (12). This pattern of increasing admissions for fibromyalgia over time matches both our results and other UK epidemiological data, which have shown an increase in the diagnosis of fibromyalgia over time and that this increase is most marked in women and in those aged 40-59 years (20). We believe this is unlikely to reflect an increase in the prevalence of the disease, but instead a growing recognition of fibromyalgia.

Previous studies have not distinguished between different forms of inpatient care as we did (elective versus non-elective admissions, or day case versus ordinary admissions). One previous study did distinguish between “routine” admissions and those originating via the emergency room, which can be considered a surrogate marker for the proportion of elective versus non-elective admissions (10). This US-based study showed that hospital admissions arose more commonly from the emergency room (66.2%) than routine admission (31%) (10). This result is strikingly different from ours (72% elective admissions) and could be due to the general differences between the two healthcare systems, differences in care for patients diagnosed with fibromyalgia, or changes in global treatment strategies over the seven years between the two datasets.

The US study found many of the same procedures undertaken during admission as our UK results, including “Other diagnostic procedures on musculoskeletal system,” “Injections and aspirations of muscles; tendons; bursa; joints and soft tissue,” and “Other therapeutic procedures on muscles.” They also found procedures not identified in our UK study. For

example, cardiac investigations accounted for 17.52% of procedures undertaken in the US cohort. Details of healthcare resource use within the accident and emergency setting are required for a complete understanding of the total burden of care for this patient group, especially as this patient group is more likely to visit the emergency room than be hospitalised in the US (13).

### Meaning of the study

Fibromyalgia is a complex, debilitating, multifactorial condition that can be difficult to manage. The current evidence-based treatment recommendations for fibromyalgia include a range of modalities such as patient education, physical therapy, cognitive therapy, and pharmacotherapy (7, 21). All of these evidence-based therapeutic options can be adequately delivered in the outpatient setting. We found that many patients were admitted for inpatient care of their fibromyalgia in England and that their most common procedure was the continuous infusion of a therapeutic substance. However, evidence-based treatment recommendations do not include any form of infusion therapy. Although it is impossible to know what substance or substances were infused, one likely possibility is intravenous lidocaine, which is used as an infusion in some pain management centres across the country (22, 23). There have been reports of the analgesic effects of systemically administered local anaesthetic agents for various pain syndromes since the late 1940s (24). Despite some controlled trials assessing the efficacy of intravenous lidocaine in treating acute and neuropathic pain (25-29), the evidence for its use in fibromyalgia is limited to small, predominantly unblinded, non-placebo-controlled studies, with huge variation in the duration of effect seen (30-34). The evidence does not support additional analgesic benefit over currently approved drugs such as amitriptyline (33, 35). Definitive studies are needed to provide an evidence base for either recommending or restricting its use. The risks of frequent use of non-evidence based treatments for fibromyalgia are all too apparent as highlighted by the current opioid crisis, most clearly demonstrated in the USA. There is clear mechanistic (36, 37) and trial (38) evidence questioning the utility of opioids in patients with fibromyalgia. Although results from a recent meta-analysis suggest that a small group of patients (12%) are likely to benefit, prescription opioid consumption has extended beyond this minority of patients who have been shown to experience small, short-term improvements in pain, functioning and sleep quality (39).

Our results suggested an increased healthcare burden within certain regions of the Midlands. We could not directly investigate the potential confounding or explanatory factors for this observation. However, there is striking similarity with the national pattern of multiple deprivation (40). Fibromyalgia is more common among people with lower socioeconomic status (20, 41), and patients with a diagnosis of fibromyalgia from a lower socioeconomic status report more debilitating symptoms despite having similar levels of pain, depression, and anxiety (42). The relationship between hospital admission rates and socioeconomic status was reversed in the US, where hospitalisation was more frequent among patients with a higher income (10). This discrepancy may be a function of the difference between the UK's national healthcare system and the US's privatised system, in which non-life-threatening conditions are not prioritised in those who rely on state-run provision such as "Medicaid."

The variation in treatment approach may also be partly explained by the provision of pain management programmes across England. Pain management programmes are a multidisciplinary approach to the management of pain, delivered in a group setting. They include education on pain physiology, psychology, general health, and pain self-management, alongside supervised exercise, activity management, and goal setting. The psychological approach to pain management focuses on identifying and changing unhelpful beliefs and ways of thinking about pain and provides training in relaxation techniques. There is a good evidence base for the effectiveness of pain management programmes as part of an integrated approach to pain management (43). However, a national directory of pain management programmes across the UK compiled by the British Pain Society demonstrated inequality in the availability of this service nationwide (44). More invasive interventions may be undertaken in areas that have a high volume of cases and a lack of adequate pain rehabilitation resources (Figures 3B and 4B).

#### Unanswered questions and future research

In summary, we have demonstrated that although evidence-based treatments for fibromyalgia and myalgia are suitable for outpatient settings, many patients are admitted for treatment of these conditions. There is also significant variation in practice across the country. Further work is needed to fully describe the patient flow between inpatient,

outpatient, and accident and emergency services to identify areas of resource use that can be rationalised and diverted to more effective, evidence-based treatment approaches. The significant variation in use of certain treatment modalities for fibromyalgia and myalgia, such as continuous intravenous infusions, highlights the need for a definitive study to support or refute this practice so that all patients can benefit from receiving safe, effective therapies. Finally, in order to streamline therapeutic options, and improve health related outcomes for patients with a diagnosis of fibromyalgia, there is a need for individualised treatment algorithms: identified as the most important area for research in fibromyalgia by a recent James Lind Alliance Priority Setting Partnership comprising clinicians, patients and carers (45). This ultimately requires better understanding of the neurobiological mechanisms underpinning the pain experienced by individual patients, which is most likely to be achieved by combining current clinical approaches (46, 47) with research techniques such as neuroimaging, which provides a non-invasive, objective method to further our understanding of the pain mechanisms in patient populations (48, 49).

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All authors have completed the [Unified Competing Interest form](#) (available on request from the corresponding author) and declare: Dr. Soni reports grants from Oxford-UCB Prize Fellowship during the conduct of the study; Professor Tracey reports grants from Abide Therapeutics, personal fees from Amgen (Neuroscience division), personal fees and other from CannBioRex, grants from Innovative Medicines Initiative - PainCare, outside the submitted work. All the authors had full access to all of the data in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR, the Department of Health, or the University of Oxford.

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**Contributor and guarantor information**

Anushka Soni: substantial contributions to the study conception and design, acquisition of data, analysis and interpretation of data, drafting the article and final approval of the article to be published. Andrew Segerdahl: substantial contributions to the study conception and design, analysis and interpretation of data, revising the article critically for important intellectual content and final approval of the article to be published. Stephanie Santos-Paulo: substantial contributions to the study conception and design, analysis and interpretation of data, revising the article critically for important intellectual content and final approval of the article to be published. M Kassim Javaid: substantial contributions to the study conception and design, analysis and interpretation of data, revising the article critically for important intellectual content and final approval of the article to be published.

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Anushka Soni is responsible for the overall content as guarantor and accepts full responsibility for the work and the conduct of the study, had access to the data, and controlled the decision to publish. Anushka Soni affirms that the manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as originally planned have been explained.

## Tables

Table 1: Number of admissions to hospital for fibromyalgia or myalgia in the English NHS, divided by class of admission, by financial year, from 2014/2015 to 2017/2018.

Class of admission	Number of admissions							
	Fibromyalgia or myalgia				Fibromyalgia only			
	2014/2015	2015/2016	2016/2017	2017/2018	2014/2015	2015/2016	2016/2017	2017/2018
Day case	5,425 (57%)	6,325 (60%)	7,590 (62%)	8,445 (61%)	3,165 (68%)	4,125 (75%)	5,035 (73%)	5,290 (73%)
Ordinary	3,385 (36%)	3,230 (31%)	3,215 (26%)	4,070 (29%)	860 (18%)	565 (10%)	585 (8%)	655 (9%)
Regular attender	690 (7%)	910 (9%)	1,355 (11%)	1,410 (10%)	640 (14%)	805 (15%)	1,270 (18%)	1,290 (18%)
Other	5.00 (0.05%)	0 (0%)	0 (0%)	0 (0%)	5 (0.11%)	0 (0%)	0 (0%)	0 (0%)
Total	9,505	10,465	12,160	13,925	4,670	5,495	6,890	7,235

Table 2: The ten most commonly reported procedures conducted for patients admitted with fibromyalgia to the English NHS between the 2014/2015 and 2017/2018 financial years\*.

Procedure (OPCS code)	Number of admissions (% of total)	Average cost of procedure	Estimated total cost (% of total)
Continuous Infusion of therapeutic substance (X29)	13,800 (46%)	£511	£7,046,314 (35%)
Approach to organ under image control (Y53)	1,400 (5%)	£646	£903,830 (5%)
Intramuscular injection (X37)	1,050 (4%)	£528	£554,636 (3%)
Other operations on peripheral nerve (A73)	775 (3%)	£540	£418,184 (2%)
Puncture of joint (W90)	615 (2%)	£727	£447,007 (2%)
Radiology procedures (Y98)	370 (1%)	£1277	£472,470 (2%)
Other operations on spine (V54)	365 (1%)	£627	£228,875 (1%)
Therapeutic epidural injection (A52)	265 (1%)	£582	£154,192 (1%)
Operations on bursa (T62)	205 (1%)	£784	£160,707 (1%)
Diagnostic imaging of central nervous system (U05)	175 (1%)	£1143	£200,006 (1%)

\*The following procedure codes, originally found amongst the 10 most common, were excluded from this list as they were not specific: Laterality of operation (Z94), Other muscle (Z60), Joint of pelvis or upper leg (Z84), Other region of body (Z92), Muscle of shoulder or upper arm (Z54), Levels of spine (V55), Arm region (Z89), Vertebra (Z66), Spinal nerve root (Z07), Intervertebral joint (Z67).

## Figures

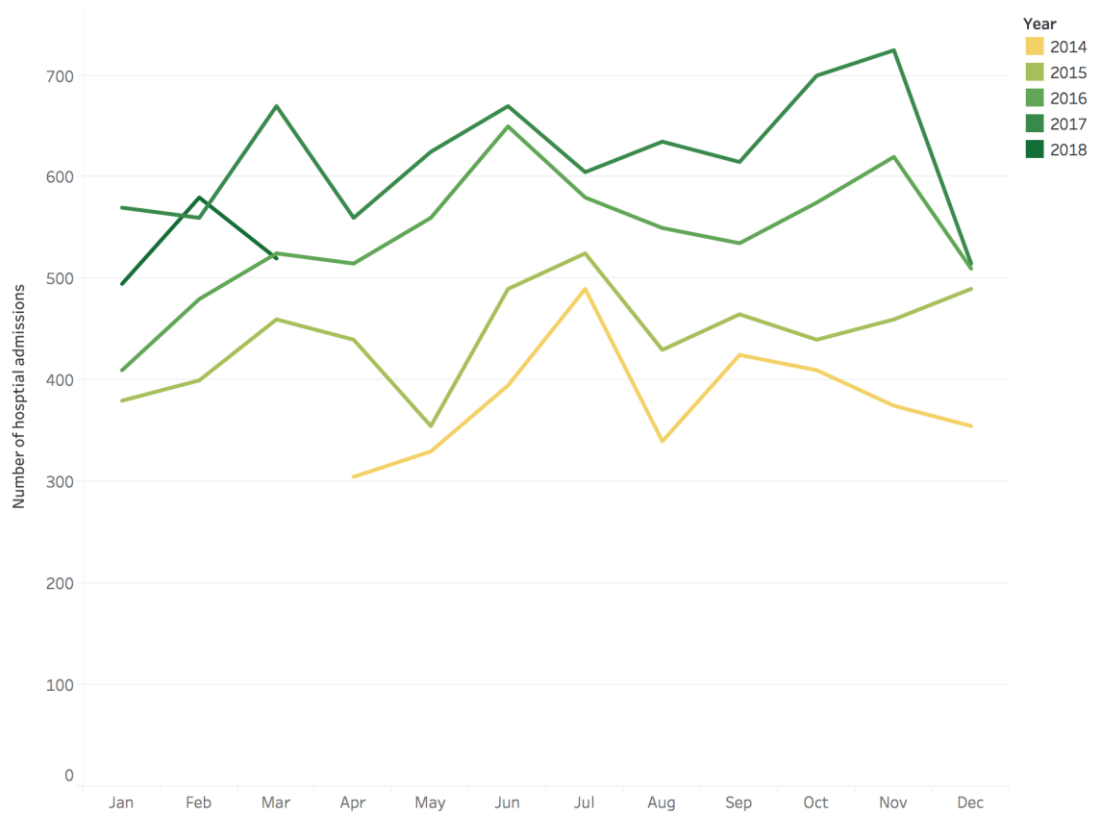


Figure 1: Comparison of number of admissions to hospital for fibromyalgia in the English NHS each month between 2014 and 2018.

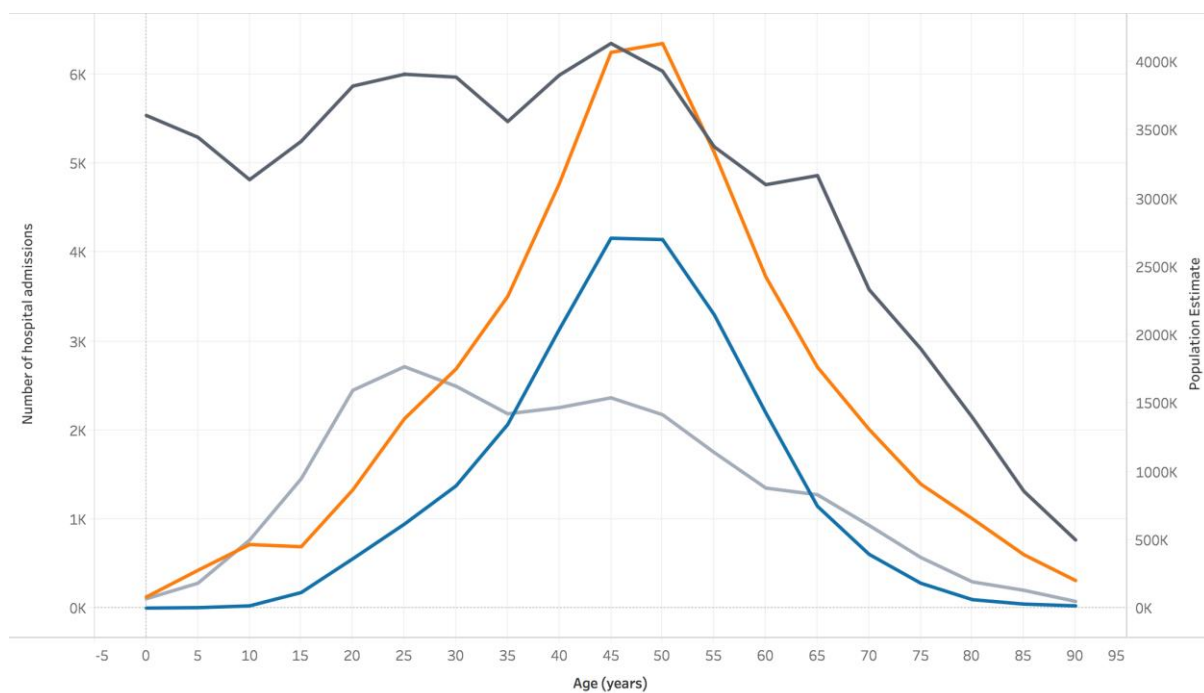


Figure 2: Distribution of admissions to hospital by age for fibromyalgia (blue), fibromyalgia or myalgia (orange), irritable bowel syndrome (light grey), compared to the population estimate by age (dark grey).

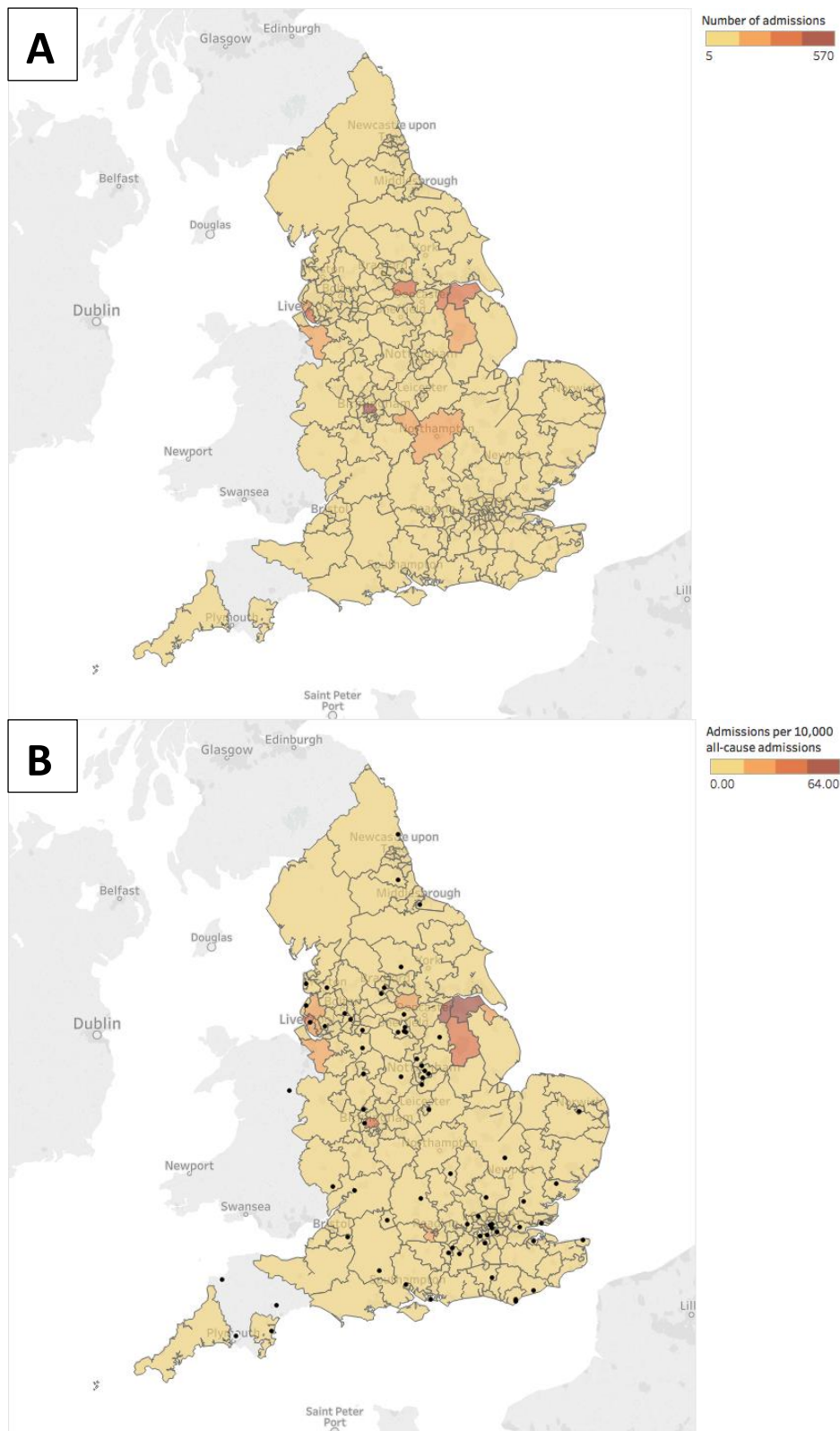


Figure 3: Geographic heat maps of the distribution of admissions to hospital for fibromyalgia only in the English NHS during the 2017/2018 financial year, aggregated by clinical commissioning group, showing A) total number of admissions and B) admissions per 10,000 all-cause admissions. Black dots indicate pain management centres.

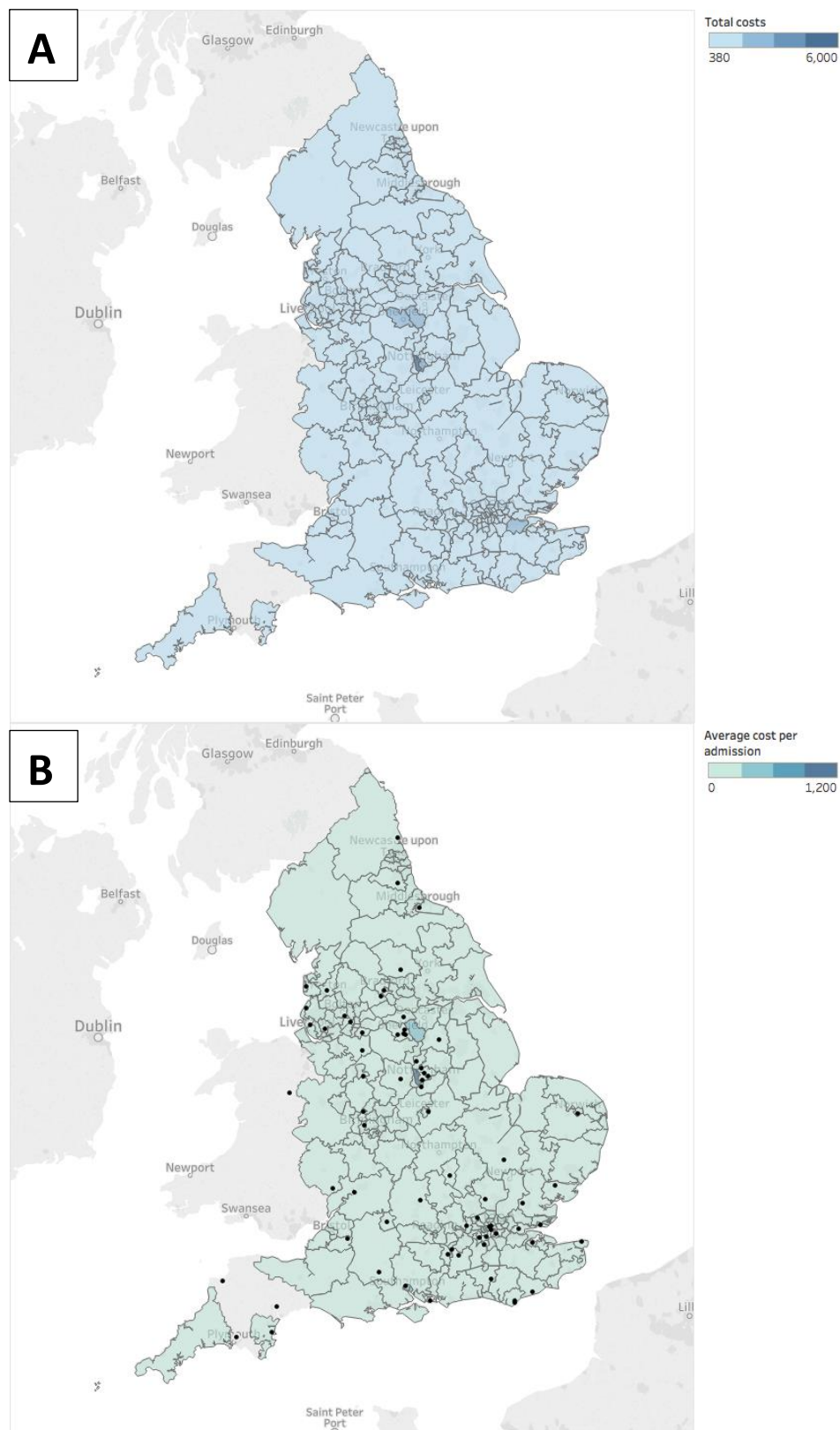


Figure 4: Geographic heat maps of the costs incurred through hospital admissions due to fibromyalgia only in the English NHS during the 2017/2018 financial year, aggregated by clinical commissioning group, showing A) total costs incurred and B) average cost per admission. Black dots indicate pain management centres.

