

Identifying patients with chronic widespread pain in primary care

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Abstract

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Chronic widespread pain (CWP) is common in the general population. It is unclear how people reporting this problem present in primary care; they may regularly consult for regional pains without being recognized as having a generalized condition. Our objectives were to determine the prevalence of people consulting in primary care for musculoskeletal conditions in different body regions on different occasions (recurrent regional pain consultation), the proportion with diagnosed generalized pain and survey-reported widespread pain, and if they have features characteristic of CWP. Phase 1 used electronic records from 12 general practices in North Staffordshire (Consultations in Primary Care Archive) from 2005 to 2009. Phase 2 used linked self-reported health and primary healthcare data from 8,286 people aged 50 plus in eight general practices (North Staffordshire Osteoarthritis Project) between 2002 and 2005. In Phase 1, 11% of registered patients fulfilled criteria for recurrent regional pain consultation. Three-quarters had no recorded CWP-related generalized pain condition (e.g. fibromyalgia). In Phase 2, 53% of recurrent regional pain consulters had survey-reported widespread pain and 88% had consulted for somatic symptoms. Self-reported general health was worse in recurrent regional pain consulters than in single-region consulters, and poorest in those who also reported persistent widespread pain. Recurrent regional pain consulters are a heterogeneous group of frequent consulters sharing features with CWP (e.g. somatic symptoms) but including those less severely affected. They lie on the spectrum of polysymptomatic distress characteristic of CWP and represent a group whose needs may be better met by earlier diagnosis of multi-site pain.

Introduction

Chronic widespread pain (CWP) is characterized by long-lasting pain in multiple body regions, and is associated with other physical symptoms such as fatigue, concentration problems, and psychological distress. CWP is common, with an estimated general population point prevalence of 10%. [26]

In the American College of Rheumatology 1990 (ACR-1990) definition, [42] CWP is the fundamental feature of fibromyalgia, defined as pain lasting three months or longer, located axially, above and below the waist, and on both sides of the body. The updated definition (ACR-2010) [41] emphasizes additional physical symptoms (e.g. fatigue, waking unrefreshed) associated with fibromyalgia and placed fibromyalgia at one extreme on a spectrum of polysymptomatic distress that includes CWP.

Due to the range of symptoms experienced and a multidisciplinary approach to treatment, it has been argued that fibromyalgia and CWP should be managed in primary care. [9,11,12,32,34] However, general practitioners (GPs) may not recognize fibromyalgia as a valid diagnosis, [1,6,22,23] may receive inadequate formal training in fibromyalgia, [1,7,22] and may have limited awareness of diagnostic criteria. [6,7,22] Most UK primary care uses Read codes to summarize patient encounters within electronic records. [3,35] There is no Read code for CWP, although the syndrome will be included in the forthcoming ICD-11 classification of disease. [8] However, whilst a code does exist for fibromyalgia, the disparity between its estimated community and primary care prevalences suggests that the label of fibromyalgia is not often used in general practice. [10,16] This may reflect the controversial nature of fibromyalgia and CWP, or concern about the wider implications of labeling. [2] Patients fulfilling CWP criteria may instead be diagnosed and treated in primary care for individual regional pains (for example, knee pain), rather than for a generalized pain condition. [33]

Electronic health records (EHRs) present opportunities to study health care in large cohorts with many years of follow-up. However, using EHR data relies on the definition of robust clinical phenotypes. [14] Rohrbeck and colleagues [33] mapped the ACR-1990 CWP criteria to primary care consultation patterns for regional musculoskeletal complaints based on a select number of regional musculoskeletal pain Read codes in one general practice (Box 1). Patients identified using this recurrent regional pain consultant definition consulted for more health problems, and reported worse self-reported general health, more sleep problems, and higher levels of fatigue than controls, and were concluded to be potentially unrecognized as having a more generalized condition. If GPs do treat the condition presented at each consultation as a regional problem only, then early opportunities for interventions aimed at generalized pain may be missed and long-term disability exacerbated by incomplete management. A consultation-based CWP definition may prompt earlier

1 identification of patients and more timely management. It would also allow estimates of CWP
2 prevalence, health surveillance, and monitoring of trends over time.
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4 Building on earlier work,[33] our objectives were to: i) determine the prevalence of recurrent regional
5 pain consultation in primary care; ii) assess the extent to which such patients may be under-
6 recognized as having widespread pain; and iii) determine whether they share features characteristic
7 of CWP.
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11 Methods

12 The study consisted of two phases. In Phase 1 we used routinely recorded primary care data to
13 investigate prevalence of recurrent consultation for regional pain conditions and determined the
14 overlap with recorded non-specific generalized pain that may be related to fibromyalgia, to assess the
15 extent to which widespread pain may be unrecognized in UK primary care. In Phase 2 we used linked
16 survey and primary care consultation data to investigate whether patients with recurrent regional
17 pain consultation have survey-reported CWP and have similar characteristics to those self-reporting
18 CWP.
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28 *Phase 1*

29 We used anonymized routinely collected primary care data from general practices contributing to the
30 Consultations in Primary Care Archive (CiPCA) in North Staffordshire, UK. The North Staffordshire
31 Research Ethics Committee gave ethical approval for the use of the CiPCA database for research
32 (reference 03/04). In the UK, 98% of the population are registered with an NHS GP,[15] access to care
33 is free, and GPs act as the entry point to all routine healthcare. Although North Staffordshire is more
34 deprived than the average for England, the practices cover both affluent and deprived areas. Routine
35 clinical data recorded by the practices are regularly audited.[30] Prevalence of musculoskeletal
36 conditions in CiPCA has been demonstrated to be similar to that of larger national primary care
37 consultation databases[17] and international databases.[19] We included the 12 CiPCA practices for
38 which there was complete data for the years 2005–2009, with a denominator population base of
39 79,796 people registered (all ages, with full registration for the five-year study period).
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51 We used the Read coded consultation data for this 5-year period to identify: i) patients fulfilling the
52 original recurrent regional pain consultation algorithm (Box 1) based on a published list of all regional
53 musculoskeletal morbidity codes (n=4,482);[20] and ii) individuals recorded with non-specific (i.e.
54 with no clear established underlying diagnosis) generalized pain conditions related to CWP. These
55 included fibromyalgia, fibrositis, rheumatism, myalgia, arthralgia, and polyalgia. The code lists are
56 available from www.keele.ac.uk/mrr. We excluded patients without complete registration; that is,
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those who were not registered with the same primary care practice for the full five-year period from 2005 to 2009.

Analysis

We calculated the five-year recorded prevalence of recurrent regional pain consultation, fibromyalgia, and non-specific generalized pain, as well as the total prevalence of recurrent regional pain consultation or generalized pain combined. We also re-calculated total prevalence (of recurrent regional pain consultation or non-specific generalized pain combined) after excluding those with specific generalized musculoskeletal diagnoses (i.e. rheumatoid arthritis, systemic lupus erythematosus, polymyalgia rheumatica, ankylosing spondylitis, Sjögren's syndrome, hypothyroidism) during the five-year period. The denominator population was patients registered with the CiPCA practices between 2005 and 2009. We directly standardized prevalence figures using the UK general population age and sex distribution for 2009 provided by the Office for National Statistics.

We then calculated the percentage of recurrent regional pain consulters recorded as also consulting for a non-specific generalized pain complaint and the percentage of non-specific pain consulters who were also recurrent regional pain consulters.

Phase 2

The Phase 2 study population was drawn from the North Staffordshire Osteoarthritis Project (NorStOP), a prospective study of pain and general health of all community-dwelling adults aged 50 years and over registered with eight general practices.[37] The North Staffordshire and Hereford and Worcester Research Ethics Committees granted ethical approval for the NorStOP project. We included those who had responded to both baseline and three-year postal health surveys from the three identically recruited and measured cohorts (NorStOP 1: 2002, NorStOP 2: 2003, NorStOP 3: 2004, 2005), had consented to medical record review, and had a minimum of five years of medical record data available. Questionnaires were mailed with a letter from the GP practice, accompanied by a study information leaflet, and reminders were sent to non-responders after two and four weeks. GPs checked mailing lists prior to mailing to exclude unsuitable patients (for example, patients with terminal illnesses or dementia). Full details of the study protocol and data collection have been published previously.[37]

Pain status

We established consultation-based pain status using linked primary care medical record data for the five-year period starting two years prior to the baseline health questionnaire. We identified those fulfilling the recurrent regional pain consultation algorithm and those consulting for musculoskeletal

problems in a single region (recorded as consulting in just one of the three defined body regions – axial, upper limb, or lower limb – during the five-year study period).

Self-reported pain status was collected by postal questionnaire at baseline and three-year follow up. A self-completed body manikin was used to establish the location of body pain lasting for one day or longer in the past four weeks. Pain diagrams have been demonstrated to be a reliable means of classifying widespread pain based on existing criteria.[24] ACR-1990 widespread pain was defined as axial pain, pain in the left and right sides of the body, and pain above and below the waist.[42] Owing to the limitations of the self-reported data, we were unable to ascertain chronicity using the ACR-1990 definition of three months duration or longer. Widespread pain reported at both baseline and three years was therefore used as a marker of ‘persistent’ widespread pain. Self-reported widespread pain was classified into two categories as: 1) ACR-1990 widespread pain at baseline *or* three years; and 2) ACR-1990 widespread pain at baseline *and* three years (persistent widespread pain).

General health measures

Consultation-based measures were collected from medical records over the five-year period. These were: somatic symptom count, frequent attendance, and musculoskeletal and non-musculoskeletal consultation counts.

CWP is often associated with additional symptoms such as fatigue and concentration problems. The ACR-2010 fibromyalgia definition[41] emphasizes the importance of these somatic symptoms by including them in the fibromyalgia case definition. We identified the number of somatic symptoms (e.g. fatigue, insomnia, and nausea) recorded for each patient over the five-year study period. We used the symptoms itemized in the ACR-2010 fibromyalgia criteria to identify corresponding Read codes.

CWP patients have been found to consult more frequently than patients with no pain, independent of their level of psychological distress,[21] suggesting that frequent attendance is a feature of CWP. Research has demonstrated an association between CWP and help-seeking behavior for health problems.[13] We defined a frequent attender status as being in the top 10% of consulters for non-musculoskeletal problems over the five-year period. Frequent attendance defined in this way is also an indirect measure of comorbidity. Non-musculoskeletal consultations were defined as primary care contacts recorded with any Read code (including numeric Chapters 0–9: history, examination, procedural and administrative codes, and Chapters A–Z: diagnostic codes) except the musculoskeletal codes.[20]

1 We collected self-reported health status from baseline health questionnaire responses. General
2 health was assessed using the SF-12 physical health component summary score.[39] Psychological
3 health was assessed using the anxiety and depression scores of the Hospital Anxiety and Depression
4 Scale (HADS).[43] Cognitive impairment was measured using the alertness subscale of the Sickness
5 Impact Profile (SIP).[5] Sleep was assessed by four questions, in which respondents were asked if they
6 had the following sleep problems on most nights: i) trouble falling asleep; ii) waking at night; iii)
7 trouble staying asleep; and iv) waking up tired. A positive response to any of the four sleep questions
8 was used to indicate a reported sleep problem.
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14 Analysis

16 We descriptively compared recurrent regional pain consulters, those who consulted for pain in a
17 single region (axial, upper limb, or lower limb), and all respondents with self-reported persistent
18 widespread pain by age, sex, consultation-based health measures, and self-reported health measures.
19 We then determined the positive predictive values of the recurrent regional pain consultation
20 definition for each of the self-reported widespread pain definitions.
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26 For the main analysis we compared different patterns of pain consultation with self-reported
27 persistent widespread pain status (defined as having ACR-1990 widespread pain at both baseline and
28 three years), by consultation-based health measures and self-reported health measures. Specifically,
29 we compared the following four mutually exclusive groups of patients: A) recurrent regional pain
30 consulters who also reported persistent widespread pain; B) recurrent regional pain consulters who
31 did not report persistent widespread pain (but may have reported widespread pain on either baseline
32 or three-year surveys); C) respondents reporting persistent widespread pain but not meeting the
33 recurrent regional pain consuler definition; and D) single-region consulters not reporting persistent
34 widespread pain. For this analysis, single-region consulters not reporting persistent widespread pain
35 were the control (reference) group.
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45 We compared these four groups on frequent attendance, recording of one or more somatic
46 symptoms, reporting one or more sleep problems on most nights, SF-12 physical component
47 summary score, SIP cognitive impairment score, and HADS anxiety and depression scores, using
48 logistic or linear regression as appropriate, and adjusting for age and sex.
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Results

Phase 1

The five-year denominator (all ages) in CiPCA was 79,796. 9,172 patients fulfilled the recurrent regional pain consultation criteria and 6,466 patients were recorded with non-specific generalized pain conditions

Prevalence

Standardized five-year consultation prevalence ranged from 0.36% (95% confidence interval [CI] 0.32%, 0.40%) for recorded fibromyalgia to 14.61% (95% CI 14.36%, 14.86%) for the combined prevalence of recurrent regional pain consultation or a code recorded for a non-specific generalized pain condition (**Table 1**). Five-year prevalence of recurrent regional pain consultation was 9.87% (95% CI 9.66%, 10.07%). The age and sex distribution of recurrent regional pain consultation was similar to that of non-specific generalized pain conditions, except that prevalence dipped slightly for non-specific generalized pain consultation in the highest age band but continued to increase for recurrent regional pain consultation (**Figure 1**).

Overlap of recurrent regional pain consultation with non-specific generalized pain

Of the 6,466 patients with a record of a non-specific generalized pain condition, 290 (4%) were recorded with a specific fibromyalgia code. Thirty-three percent (2,106/6,466) of non-specific generalized consulters also fulfilled the recurrent regional pain consulter definition. The recurrent regional pain consultation algorithm identified 42% (123/290) of those recorded with fibromyalgia codes. Twenty-three percent (2,106/9,172) of recurrent regional pain consulters had a recorded non-specific generalized pain condition.

Phase 2

Of 26,129 eligible participants at baseline, 71% (n=18,497) responded to the baseline health survey questionnaire. Of those consenting to follow-up and still registered with the GP (n=11,900), 81% (n=9,665) responded to the three-year follow up questionnaire. Of the 9,665 people responding to both baseline and three-year questionnaires, 9% (n=831) did not consent to medical record review and 6% (n=548) had access to less than five years of medical record data available, leaving 8,286 participants eligible for inclusion in this study (**Supplementary Figure S1**).

Incomplete responders (either baseline-only responders or baseline and three-year responders without five years of medical record data) showed generally small differences from the study population on all baseline variables assessed (**Supplementary Table S1**). Non-responders at baseline were slightly older (mean difference = 0.86 years, 95% CI 0.53, 1.18), and more likely to be male (non-

1 responders: 49% male; study population: 46% male, percentage difference: 3.15%, 95% CI 1.59%,
2 4.71%) than the study population.
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4 Of the 8,286 individuals in the study population, 85% (n=7,076) self-reported musculoskeletal pain at
5 either baseline or three years. Two thousand, eight hundred and three (35%) reported ACR-1990
6 widespread pain on one or both surveys, of whom 1,190 (14% of all the study population) reported
7 ACR-1990 widespread pain at both baseline and three years (persistent widespread pain).
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10 Eighty percent (6,611/8,286) of the study population had at least one recorded musculoskeletal
11 consultation in the five-year period. Twenty-two percent (n=1,786) of the population were identified
12 as recurrent regional pain consulters, and 24% (n=1,979) consulted for a musculoskeletal problem in
13 only one region during the five-year study period.
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19 Patient characteristics

20 Descriptive statistics for participants with recurrent regional pain consultation and/or self-reported
21 persistent widespread pain are presented in **Table 2**. Mean age was similar (64 to 65 years) across
22 pain definitions. Sixty-four percent of patients with self-reported persistent widespread pain were
23 female, which was similar to the figure of 61% observed in recurrent regional pain consulters. Eighty-
24 eight percent (n=1,567) of recurrent regional pain consulters had at least one recorded consultation
25 for a somatic symptom, compared to 81% (n=963) of those with persistent widespread pain. In
26 participants consulting for a single region, 48% were female, mean age was 64, and 62% (n=1,111)
27 self-reported persistent widespread pain.
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37 Agreement between consultation-based and self-reported pain status

38 **Table 3** shows the agreement between consultation-based pain status and self-reported pain status.
39 Virtually all recurrent regional pain consulters (97%, n=1,727) had self-reported pain. Fifty-three
40 percent (942/1,786) of recurrent regional pain consulters reported widespread pain on one or both
41 surveys, while 25% (445/1,786) reported persistent widespread pain at both baseline and three years.
42 Patients recorded as consulting for single-region (axial, upper or lower limb) pain reported less
43 widespread pain than recurrent regional pain consulters – with 27% (532/1,979) reporting
44 widespread pain on one or both surveys, and 10% (194/1,979) reporting widespread pain at both
45 baseline and three years. Recurrent regional pain consulters represented 37% (445/1,190) of those
46 reporting persistent widespread pain. However, individuals from the large group who consulted with
47 more than single-site musculoskeletal pain but who did not meet the definition for recurrent regional
48 pain consultation (other musculoskeletal consultations) represented 40% (473/1,190) of those
49 reporting persistent widespread pain.
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1 The single-region controls without self-reported persistent widespread pain had the best
2 consultation-based and self-reported health. The two groups of recurrent regional pain consulters
3 had the most severe consultation-based health on all measures, with those also reporting persistent
4 widespread pain having the worst consultation-based health (**Table 4**). For example, the odds of being
5 a frequent attender for non-musculoskeletal conditions compared to the control group (single-region
6 consulters) were: 7.07 (95% CI 5.21, 9.58) in recurrent regional pain consulters with persistent
7 widespread pain; 4.99 (95% CI 3.87, 6.43) in recurrent regional pain consulters without persistent
8 widespread pain; and 2.55 (95% CI 1.86, 3.48) in those with persistent widespread pain who were not
9 recurrent regional pain consulters.

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16 Individuals both self-reporting persistent widespread pain and identified as recurrent regional pain
17 consulters were the most severely affected on all self-reported health measures, followed closely by
18 those with persistent widespread pain but not fulfilling the recurrent regional pain consultation
19 definition. Those fulfilling the recurrent regional pain consulter definition but not reporting persistent
20 widespread pain had poorer self-reported health than the control group. For example, the odds of
21 reporting a sleep problem compared to the control group were: 3.07 (95% CI 2.47, 3.81) in recurrent
22 regional pain consulters with persistent widespread pain; 2.97 (95% CI 2.48, 3.54) in those with
23 persistent widespread pain but not recurrent regional pain consulters; and 1.42 (95% CI 1.22, 1.64) in
24 recurrent regional pain consulters without persistent widespread pain.

33 Discussion

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36 The first phase of our study determined a prevalence of recurrent regional pain consultation to
37 primary care similar to estimates based on self-reported CWP in the general population.[26] Three-
38 quarters of recurrent regional pain consulters did not have a code recorded for generalized pain
39 conditions related to CWP (e.g. fibromyalgia). They therefore had widespread pain potentially
40 unrecognized as such by their GP.

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46 In the second phase we established some overlap between consultation-based and self-reported
47 widespread pain, with half of all recurrent regional pain consulters over a five-year period self-
48 reporting widespread pain at least once. However, only one-quarter reported persistent widespread
49 pain during this period. Conversely, only a minority of all those who self-reported CWP (37%) fulfilled
50 the recurrent regional consulter definition during the five-year period.

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56 There were similar patterns of poor health (e.g. more somatic complaints) with recurrent regional
57 pain consultation and self-reported CWP; although this was more marked for consultation measures
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2 of poor health in recurrent regional pain consulters, and for survey measures in those with self-
3 reported CWP.

4 The primary care coding prevalence of fibromyalgia was considerably lower than predicted by
5 community prevalence, even accounting for a proportion of patients not consulting for their
6 symptoms. This is consistent with findings from two large database studies.[10,16] The combined
7 five-year prevalence of recurrent regional pain consultation ('unrecognized' CWP) and non-specific
8 pain complaints ('recognized' CWP), after excluding specific generalized musculoskeletal diagnoses,
9 was slightly higher, at 13%, than general population point prevalence estimates for CWP (10%).[26]
10 Combined with our findings from Phase 2, this indicates that prevalence of widespread pain based on
11 consultation data may give similar prevalence estimates to general population surveys based on strict
12 CWP criteria, but will not represent an identical group of people.
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21 Recurrent regional pain consultation was more common in females and increased with age,
22 consistent with that reported for CWP in the general population.[26] It was associated with more
23 somatic symptoms, self-reported sleep problems and cognitive impairment, and poorer self-reported
24 physical and mental health than observed in those consulting only for single-region problems. These
25 are all features consistent with CWP. Somatic symptoms are a part of the ACR-2010 definition for
26 fibromyalgia, including fatigue and waking unrefreshed.[41] Other research has also shown
27 fibromyalgia and CWP to be associated with poor self-reported mental and physical health.[38,40]
28 Recurrent regional pain consulters were more likely to be frequent attenders, which is consistent with
29 research linking frequent attendance to both CWP[13,21,27] and medically unexplained
30 syndromes.[31,36] However, it may also be a feature of the self-fulfilling nature of a definition that
31 requires repeated consultation, although we excluded musculoskeletal conditions from our definition
32 of frequent attendance.
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43 Half of recurrent regional pain consulters did not self-report widespread pain at either of the two
44 survey points three years apart, and only a third of those self-reporting persistent widespread pain
45 fulfilled the recurrent regional pain consuler definition. Fulfilling recurrent regional pain consultation
46 criteria was associated with worse consultation-based health than self-reporting persistent
47 widespread pain, while persistent widespread pain was associated with worse self-reported health
48 than recurrent regional pain consultation. Rather than identifying all CWP patients who consult their
49 GP, the recurrent regional pain consultation definition identifies a specific group of patients who may
50 be unrecognized as having a generalized condition, and therefore, through their consultation
51 behavior, are expressing a need that may remain unmet. This group is consequently an important
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1 one, since identifying them and managing them appropriately has the potential to improve their
2 health and reduce consultation demands.

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4 The recurrent regional pain consulter definition represents a promising phenotype for EHR studies as
5 it identifies patients with non-local pain who have higher rates of disability and health care use.
6 However, given the disparity between self-reported CWP and recurrent regional pain consultation,
7 it is possible we should consider other approaches to developing a consultation-based definition of
8 CWP,
9 based on two observations. First, only 7% of all those with persistent widespread pain had no
10 record of a musculoskeletal consultation during the study period; musculoskeletal consultation
11 thereby represents a reasonable sampling frame for identifying and managing CWP in the population.
12 Second, single-site musculoskeletal consultation appears to represent a low-severity group (by both
13 consultation and self-report measures). Given this, it may be that systematically seeking information
14 about other pain sites could be a simple way to ensure that GPs consider the extent of pain in their
15 care and management of patients, and may be useful for future development of EHR-based pain
16 phenotypes. The highest severity group – those with combined recurrent regional pain consultation
17 and self-reported CWP – suggests that both sources of information could be useful for care and
18 prevention.
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20 We performed this study in two large samples of patients, using high-quality primary care data and
21 validated self-report instruments. The studies were limited to one area of the UK (North Staffordshire)
22 and the use of an older age group in Phase 2. However, sensitivity analyses using the CiPCA data (not
23 presented) demonstrated minimal differences in number of recorded somatic symptoms and
24 musculoskeletal consultations between recurrent regional pain consulters from all age groups and the
25 subgroup aged 45 plus. Less than a third of the eligible population (i.e. those invited to take part in
26 the baseline study) was included in analyses in Phase 2, and we cannot exclude participation bias.
27 However, we demonstrated that differences between the study sample and non- and partial-
28 responders were small.
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30 Not all patients with a problem will consult their GP for it; consequently, consultation prevalence will
31 be lower than community population prevalence estimates. For chronic conditions, a diagnostic label
32 for a repeatedly-consulted complaint may only be coded at diagnosis.[18] The use of a five-year
33 period to define recurrent regional pain consultation would mean it is less likely we have missed a
34 relevant diagnosis in the Phase 1 study, but it is possible some patients were recorded with
35 fibromyalgia or other diagnosis outside of this period.
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37 We have attempted to define a relatively newly identified phenotype, a group of recurrent pain
38 consulters in primary care, with a prevailing symptom of chronic musculoskeletal pain, who are
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1 potentially unrecognized by their GPs as having a generalized condition associated with somatic
2 symptoms. We therefore had no reference standard against which to compare the recurrent regional
3 pain consulters identified by our algorithm. However, the recurrent regional pain consultation
4 phenotype is closely related to fibromyalgia/CWP, and these conditions have been studied extensively
5 using the ACR-1990 definition. We were able to demonstrate that recurrent regional pain consulters
6 share many characteristics with CWP.
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10 We included 4,482 regional musculoskeletal Read codes in the definition of recurrent regional pain
11 consultation based on previous consensus work. However, the codes may not always indicate
12 musculoskeletal pain (e.g. unstable ankle), and the list includes codes for conditions that may not be
13 appropriate for use in CWP, such as structural derangements (e.g. meniscal tears), infections, and
14 inflammatory arthropathies. There may be other codes with the potential to represent
15 musculoskeletal problems. Evidence of widespread pain and somatic symptoms may also be 'hidden'
16 in the free-text of the consultation.
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24 Our study suggests that recurrent regional pain consulters represent a heterogeneous subgroup of
25 frequent consulters, with chronic musculoskeletal problems as the prevailing symptom of their
26 polysymptomatic distress, who may not be recognized as having a more generalized pain condition
27 associated with somatic symptoms. They include those less severely affected, who do not necessarily
28 fit established and strict CWP criteria, and therefore reflect an overlapping rather than identical group
29 of persons. They nonetheless still exist on the spectrum of polysymptomatic distress characteristic of
30 CWP and fibromyalgia.
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38 The recurrent regional pain consultant algorithm highlights the existence of a substantial group of
39 patients with potentially unmet needs. Treatment focused on regional pain syndromes alone may be
40 sub-optimal if the added burden of pain elsewhere in the body – and the additional characteristics
41 associated with it (such as pain severity and propensity for long-term persistence) – are not identified
42 and taken into account in explanation, advice and care given to the patient.[4,25]
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47 There is some under-recognition of CWP in primary care, implying a need for specific training for GPs.
48 If some patients are not recognized as having generalized pain conditions with associated somatic
49 symptoms, they may be inappropriately managed (as multiple episodes of regional pain). Ineffective
50 management may lead to poor patient outcomes and contribute unnecessarily to primary care
51 workload (continued consultation for unresolved symptoms). Screening for multi-site pain in patients
52 presenting with single-site musculoskeletal complaints may be a simple way for GPs to consider the
53 extent of pain in their management. Future research should explore this clinically important group of
54 chronic consulters. Whilst there appear to be effective treatments for patients with widespread pain,
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1 we do not yet understand how best to help those recurrently consulting for regional musculoskeletal
2 pain. Recurrent consultation for local musculoskeletal pain offers a means of identifying a clinically
3 relevant group of high users of primary care. Further research to investigate changes in their health
4 over time, the financial cost of their management, and possible interventions would offer insights into
5 long-term health outcomes, current economic burden and management of individuals who consult
6 with non-local pain complaints.
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38 *Contributions*

39 KJ had the original idea for the study. All authors were involved in the study design. KM undertook the
40 data management, primary analysis and wrote the first draft. All authors contributed to further drafts
41 and approved the final manuscript. KM had full access to the data in the study and takes responsibility
42 for the integrity of the data and the accuracy of the data analysis.
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48 *Conflict of interest statement*

49 The authors have no conflicts of interest to declare.
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52 *Date sharing*

53 We are unable to share individual-level data.
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Tables and figures

Figure legends

Box 1. The recurrent regional consulter definition.[33]

<<Insert Box 1 here>>

Figure 1. Phase 1: Age and sex distribution for the five-year consultation prevalence of: i) recorded fibromyalgia coding; ii) recorded non-specific generalized pain coding; and iii) recurrent regional pain consultation for all those fully registered with the CiPCA practices from 2005 to 2009.

<<Insert Fig. 1 here>>

NB: Y-axis scale varies between Figure i and Figures ii and iii.
CiPCA: Consultations in Primary Care Archive.

Table headers

Table 1. Phase 1: Five-year prevalence of recorded pain in those registered in CiPCA practices for the full five-year period from 2005 to 2009 (all ages).

Table 2. Phase 2: Age, sex, consultation-based health, and self-reported health characteristics by single-region consulter, recurrent regional pain consulter, and self-reported CWP status (ACR-1990 at baseline and three years), age 50 years and over.

Table 3. Phase 2: Overlap of consultation-based pain and self-reported pain status (n, row %, (column %)).

Table 4. Phase 2: Results of logistic/linear regression analyses to compare consultation-based and self-reported health characteristics between recurrent regional pain consultation and self-reported persistent widespread pain status.

Summary

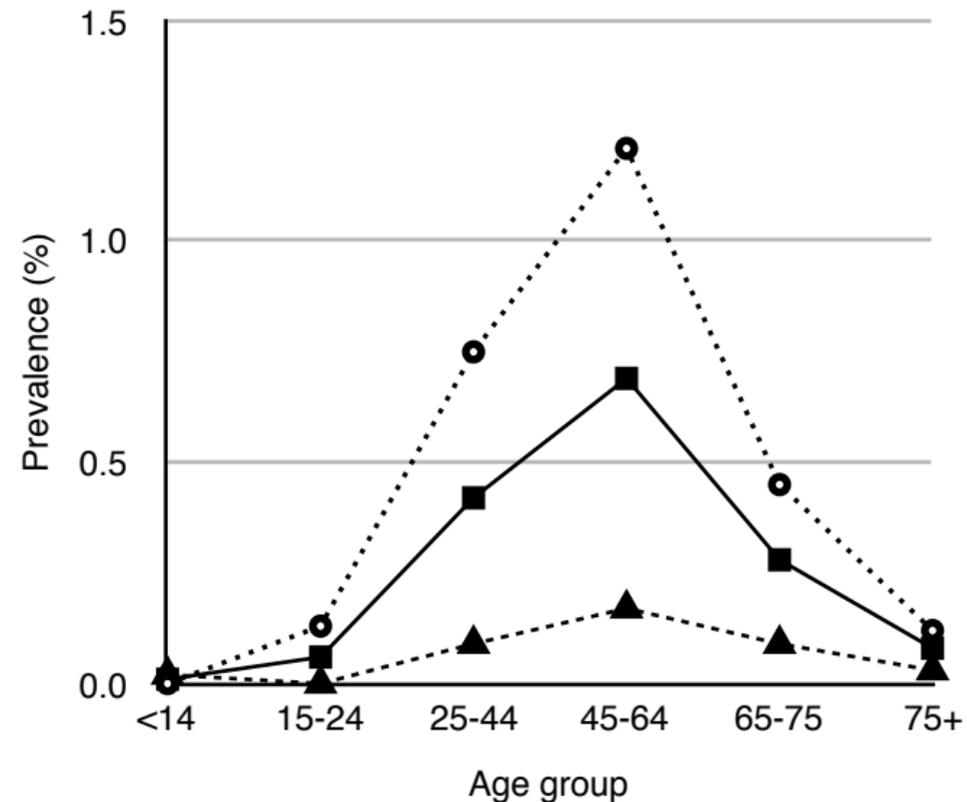
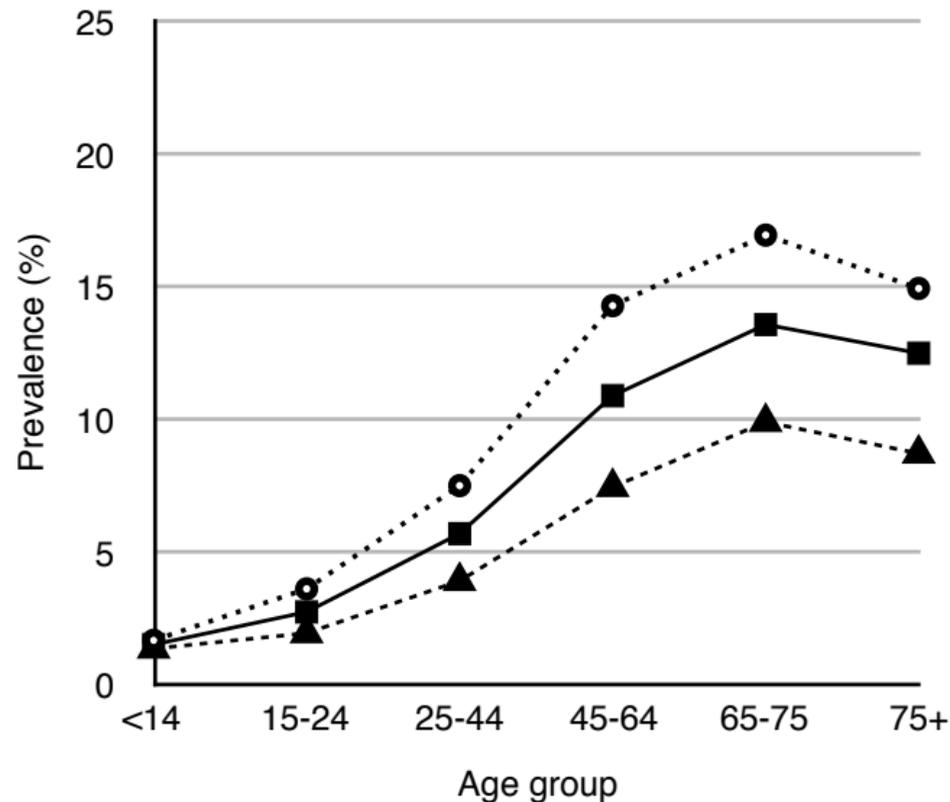
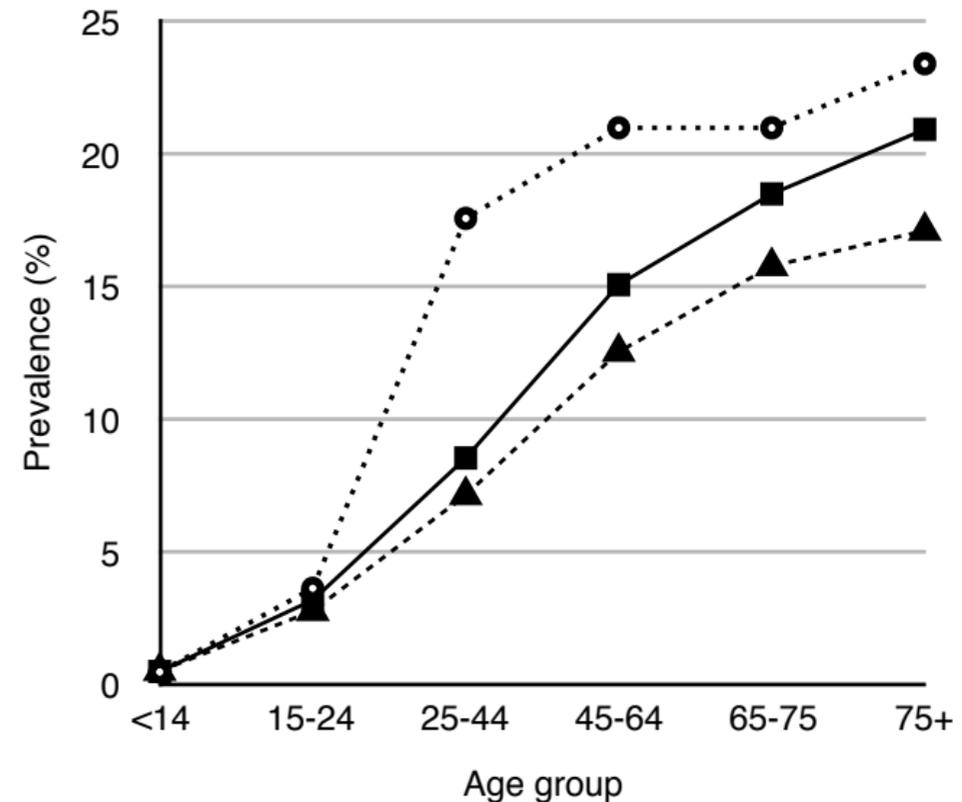
Chronic widespread pain patients may regularly consult in primary care for regional pain without being recognized as having a generalized condition.

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Box 1. The recurrent regional **pain** consultant definition.[33]

In a period of 5 consecutive years, a patient fulfils all of 1–4:

1. At least 1 consultation for a musculoskeletal complaint in the axial skeleton (neck & back);
2. At least 1 consultation for an upper or lower limb complaint;
3. At least 1 consultation for a regional musculoskeletal complaint in each of 3 separate years;
4. At least 4 consultations for regional musculoskeletal complaints during the 5-year period.

i) Fibromyalgia**ii) Non-specific generalized pain****iii) Recurrent regional pain consultation**

○ Female ▲ Male ■ Total

Table 1. Phase 1: Five-year prevalence of recorded pain in those registered in CiPCA practices for the full five-year period from 2005 to 2009 (all ages).

Consultation-based pain definition	n	Five-year recorded prevalence % (95% CI)	
		Crude	Standardized**
Fibromyalgia	290	0.37 (0.33 to 0.42)	0.36 (0.32 to 0.40)
Non-specific generalized pain	6,644	8.10 (7.92 to 8.29)	6.91 (6.73 to 7.08)
Recurrent regional pain consultation	9,172	11.49 (11.27 to 11.72)	9.87 (9.66 to 10.07)
Recurrent regional pain consultation and/or non-specific generalized pain	13,532	16.96 (16.70 to 17.22)	14.61 (14.36 to 14.86)
Recurrent regional pain consultation and/or non-specific generalized pain excluding specific generalized musculoskeletal diagnoses*	12,364	15.49 (15.25 to 15.75)	13.44 (13.19 to 13.68)

*Excludes any patients recorded with rheumatoid arthritis, systemic lupus erythematosus, polymyalgia rheumatica, ankylosing spondylitis, Sjögren's syndrome, or hypothyroidism.

** Directly standardized to UK general population figures for 2009, source: Office for National Statistics.

CiPCA: Consultations in Primary Care Archive

Table 2. Phase 2: Age, sex, consultation-based health, and self-reported health characteristics by single-region consulter, recurrent regional pain consulter, and self-reported CWP status (ACR-1990 at baseline and three years), age 50 years and over.

	Non-mutually exclusive groups		
	Consultation-based pain		Self-reported persistent widespread pain
	Single-region consulters	Recurrent regional pain consultation	ACR-1990 baseline and 3 years
Number	1,979	1,786	1,190
Mean age (SD)	64 (9)	65 (9)	64 (9)
Female; number (%)	959 (48)	1,084 (61)	758 (64)
Consultation-based health			
Mean somatic symptom count (SD)	1.24 (1.41)	2.66 (2.10)	2.21 (1.99)
One or more recorded somatic symptoms (%)	1,258 (64)	1,567 (88)	963 (81)
Mean non-musculoskeletal consultation count (SD)	27 (20)	44 (27)	39 (25)
Mean musculoskeletal consultation count (SD)	2 (2)	12 (8)	8 (9)
Frequent attenders (non-musculoskeletal consultations); number (%)	101 (5)	405 (23)	209 (18)
Self-reported mental and physical health*			
Mean (SD) SF-12 physical component summary (0 worst health–100 best health) ^a	44.5 (11.7)	36.8 (11.8)	31.7 (10.6)
Mean (SD) anxiety score (0 best health–21 worst health) ^b	6.1 (4.0)	7.5 (4.1)	8.5 (4.4)
Mean (SD) depression score (0 best health–21 worst health) ^b	3.9 (3.3)	5.2 (3.5)	6.4 (3.8)
Mean (SD) cognitive impairment score (0 best health–100 worst health) ^c	10.9 (19.9)	16.1 (22.8)	21.7 (25.8)
Number (%) reporting sleep problems on most nights**	683 (35)	818 (46)	710 (60)

a. 12-item short form health survey – physical component summary [39]: high score = best health (scores are normalized to a general population mean of 50).

b. Hospital Anxiety and Depression Scale[43]: high score = worst health

c. Sickness Impact Profile – Alertness subscale[5]: high score = worst health

*Data on these variables were incomplete with n ranging from: 1,550 to 1,741 for recurrent regional pain consulters, and 1,056 to 1,178 for persistent widespread pain.

**Percentages calculated based on n equal to participants providing valid responses only.

SD: Standard deviation

CWP: Chronic widespread pain

Table 3. Phase 2: Overlap of consultation-based pain and self-reported pain status (n, row %, (column %)).

Self-reported pain	Primary care recorded pain								Total
	No recorded musculoskeletal pain		Single-region musculoskeletal pain		Other musculoskeletal consultations		Recurrent regional pain consulters		
No self-reported pain	532 (31.8%)	<i>44.0%</i>	331 (16.7%)	<i>27.4%</i>	288 (10.1%)	<i>23.8%</i>	59 (3.3%)	<i>4.9%</i>	1,210 (14.6%)
Pain that is not widespread	873 (52.1%)	<i>20.8%</i>	1,116 (56.4%)	<i>26.6%</i>	1,429 (50.2%)	<i>34.0%</i>	785 (44.0%)	<i>18.7%</i>	4,203 (50.7%)
Non-persistent widespread pain (baseline <i>or</i> 3 years)	192 (11.5%)	<i>11.4%</i>	338 (17.1%)	<i>20.1%</i>	656 (23.0%)	<i>39.0%</i>	497 (27.8%)	<i>29.5%</i>	1,683 (20.3%)
Persistent widespread pain (baseline <i>and</i> 3 years)	78 (4.7%)	<i>6.6%</i>	194 (9.8%)	<i>16.3%</i>	473 (16.6%)	<i>39.7%</i>	445 (24.9%)	<i>37.4%</i>	1,190 (14.4%)
Total	1,675	<i>20.2%</i>	1,979	<i>23.9%</i>	2,846	<i>34.3%</i>	1,786	<i>21.6%</i>	8,286

Row %s are shown in italics next to the n that they are associated with.

Column %s are shown in brackets below the n that they are associated with.

NB: Column %s represent positive predictive values of consultation-based definitions for self-reported pain.

Table 4. Phase 2: Results of logistic/linear regression analyses to compare consultation-based and self-reported health characteristics between recurrent regional pain consultation and self-reported persistent widespread pain status.

	Number (%) / Mean (SD)	Effect estimate (95% CI)	Type of effect estimate
Consultation-based			
Frequent attendance^a			
Recurrent regional pain consulter and persistent widespread pain	121 (27%)	7.07 (5.21, 9.58)	odds ratio*
Recurrent regional pain consulter not persistent widespread pain	284 (21%)	4.99 (3.87, 6.43)	odds ratio*
Persistent widespread pain not recurrent regional pain consulter	88 (12%)	2.55 (1.86, 3.48)	odds ratio*
Single-region consulters not persistent self-reported widespread pain (reference)	87 (5%)	reference	odds ratio*
One or more somatic symptoms^b			
Recurrent regional pain consulter and persistent widespread pain	396 (89%)	4.73 (3.45, 6.47)	odds ratio*
Recurrent regional pain consulter not persistent widespread pain	1,171 (87%)	4.03 (3.34, 4.86)	odds ratio*
Persistent widespread pain not recurrent regional pain consulter	567 (76%)	1.89 (1.55, 2.30)	odds ratio*
Single-region consulters not persistent self-reported widespread pain (reference)	1,111 (62%)	reference	odds ratio*
Self-reported			
Reporting of sleep problems on most nights^c			
Recurrent regional pain consulter and persistent widespread pain	269 (60%)	3.07 (2.47, 3.81)	odds ratio*
Recurrent regional pain consulter not persistent widespread pain	549 (41%)	1.42 (1.22, 1.64)	odds ratio*
Persistent widespread pain not recurrent regional pain consulter	441 (59%)	2.97 (2.48, 3.54)	odds ratio*
Single-region consulters not persistent self-reported widespread pain (reference)	573 (32%)	reference	odds ratio*
SF-12 physical component summary^d			
Recurrent regional pain consulter and persistent widespread pain	30.3 (SD 9.5)	-15.53 (-16.72, -14.34)	mean difference**
Recurrent regional pain consulter not persistent widespread pain	39.04 (SD 11.66)	-6.42 (-7.23, -5.61)	mean difference**
Persistent widespread pain not recurrent regional pain consulter	32.62 (SD 11.08)	-13.18 (-14.15, -12.21)	mean difference**
Single-region consulters not persistent self-reported widespread pain (reference)	45.69 (11.07)	reference	mean difference**
HADS anxiety score^e			
Recurrent regional pain consulter and persistent widespread pain	8.8 (SD 4.2)	2.72 (2.30, 3.15)	mean difference**
Recurrent regional pain consulter not persistent widespread pain	7.03 (SD 4.00)	1.07 (0.78, 1.36)	mean difference**
Persistent widespread pain not recurrent regional pain consulter	8.38 (SD 4.44)	2.34 (1.99, 2.69)	mean difference**
Single-region consulters not persistent self-reported widespread pain (reference)	5.87 (SD 3.91)	reference	mean difference**
HADS depression score^e			
Recurrent regional pain consulter and persistent widespread pain	6.6 (SD 3.6)	2.95 (2.60, 3.31)	mean difference**
Recurrent regional pain consulter not persistent widespread pain	4.68 (SD 3.33)	1.00 (0.75, 1.24)	mean difference**
Persistent widespread pain not recurrent regional pain consulter	6.31 (SD 3.96)	2.65 (2.36, 2.94)	mean difference**
Single-region consulters not persistent self-reported widespread pain (reference)	3.69 (SD 3.08)	reference	mean difference**
Cognitive impairment score^f			
Recurrent regional pain consulter and persistent widespread pain	22.6 (SD 26.1)	12.79 (10.45, 15.12)	mean difference**
Recurrent regional pain consulter not persistent widespread pain	13.95 (SD 21.21)	3.99 (2.41, 5.57)	mean difference**
Persistent widespread pain not recurrent regional pain consulter	21.22 (SD 25.61)	11.46 (9.54, 13.38)	mean difference**
Single-region consulters not persistent self-reported widespread pain (reference)	9.87 (SD 19.01)	reference	mean difference**

* Odds ratio calculated using logistic regression controlling for age and sex, with single-region consulters without persistent self-reported widespread pain as the reference group.

** Mean difference (recurrent regional pain consulter/persistent widespread pain group minus single-region consulter not persistent widespread pain group) calculated using linear regression controlling for age and sex.

a. Frequent attendance model $\chi^2(5) = 334.96$, $p < 0.001$

b. One or more somatic symptoms model $\chi^2(5) = 373.65$, $p < 0.001$

c. Reporting of sleep problems on most nights $\chi^2(5) = 246.72$, $p < 0.001$

d. b. 12-item short form health survey – physical component summary[39]: high score = best health

e. Hospital Anxiety and Depression Scale[43]: high score = worst health

f. Sickness Impact Profile – Alertness subscale[5]: high score = worst health

SD: standard deviation.

CI: confidence interval

Recurrent regional pain consulter and persistent widespread pain: $n = 445$

Recurrent regional pain consulter not persistent widespread pain, $n = 1,341$

Persistent widespread pain not recurrent regional pain consulter, $n = 745$

Single-region consulters not persistent widespread pain, $n = 1,785$

The RECORD statement – checklist of items, extended from the STROBE statement, which should be reported in observational studies using routinely collected health data.

	Item No.	STROBE items	Location in manuscript where items are reported	RECORD items	Location in manuscript where items are reported
Title and abstract					
	1	(a) Indicate the study's design with a commonly used term in the title or the abstract (b) Provide in the abstract an informative and balanced summary of what was done and what was found	(a) We have not indicated the study design in the abstract using a commonly used term, as our study does not neatly fit the description of a standard cohort, survey or cross-sectional design. Our study consisted of two phases: i) Phase 1 analysed data collected prospectively over a 5-year period (cohort data) using a cross-sectional analysis; and ii) Phase 2 used survey data from two time points linked to 5-years of prospectively collected electronic health record data and analysed it using a cross-sectional design. (b) Methods summarised in abstract (p2).	<p>RECORD 1.1: The type of data used should be specified in the title or abstract. When possible, the name of the databases used should be included.</p> <p>RECORD 1.2: If applicable, the geographic region and timeframe within which the study took place should be reported in the title or abstract.</p> <p>RECORD 1.3: If linkage between databases was conducted for the study, this should be clearly stated in the title or abstract.</p>	(1.1) Reference made to CiPCA and NorStOP made in abstract (p2). (1.2) Abstract outlines that both studies based in North Staffs, UK, and: i) Phase 1 study 2005 to 2009; and ii) Phase 2 study recruited from 2002 to 2005 (p2). (1.3) Use of linkage between NorStOP survey data and electronic health record data stated in the abstract (p2).
Introduction					
Background rationale	2	Explain the scientific background and rationale for the investigation being reported	Scientific background and rationale for study is presented in the Introduction section (p3).		
Objectives	3	State specific objectives, including any prespecified hypotheses	Specific aims of the study presented are in Introduction section (p4).		
Methods					
Study Design	4	Present key elements of study design early in the paper	Key elements of the study design are introduced in the Introduction section of the paper (pp3-4) and expanded in the Methods section (p4).		
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	Setting, locations, study dates are presented under the in the Methods section (pp4-5).		

	Item No.	STROBE items	Location in manuscript where items are reported	RECORD items	Location in manuscript where items are reported
Participants	6	<p>(a) <i>Cohort study</i> - Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up</p> <p><i>Case-control study</i> - Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls</p> <p><i>Cross-sectional study</i> - Give the eligibility criteria, and the sources and methods of selection of participants</p> <p>(b) <i>Cohort study</i> - For matched studies, give matching criteria and number of exposed and unexposed</p> <p><i>Case-control study</i> - For matched studies, give matching criteria and the number of controls per case</p>	<p>(a) Eligibility criteria, and sources and methods of participant selection are presented for Phase 1 (p4) and Phase 2 (p5) in the Methods section.</p> <p>(b) This study is not matched.</p>	<p>RECORD 6.1: The methods of study population selection (such as codes or algorithms used to identify subjects) should be listed in detail. If this is not possible, an explanation should be provided.</p> <p>RECORD 6.2: Any validation studies of the codes or algorithms used to select the population should be referenced. If validation was conducted for this study and not published elsewhere, detailed methods and results should be provided.</p> <p>RECORD 6.3: If the study involved linkage of databases, consider use of a flow diagram or other graphical display to demonstrate the data linkage process, including the number of individuals with linked data at each stage.</p>	<p>(6.1) A detailed explanation of how the study population for each phase were identified is presented in the Methods section (Phase 1: p4; Phase 2: p5).</p> <p>(6.2) The study aimed to develop and validate an electronic health record definition of pain consultation – part of this process included validation of the codes used to define consultation-based pain.</p> <p>(6.3) Phase 2 used linked survey and to electronic health record data. Full details have been published elsewhere (ref 37).</p>
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable.	We have defined all variables used including both consultation-based definitions, and self-reported definitions in the methods section (pp4-7)	RECORD 7.1: A complete list of codes and algorithms used to classify exposures, outcomes, confounders, and effect modifiers should be provided. If these cannot be reported, an explanation should be provided.	A complete list of codes used to classify all variables is available for download from: www.keele.ac.uk/mrr an online clinical codes repository (p5).
Data sources/ measurement	8	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	Each variable used is identified in either the CiPCA dataset or NorStOP survey with linked electronic record data. A clear definition of all variables used is presented in the appropriate sections of the Methods section (pp4-7). Variable definitions are the same for different groups of patients.		

	Item No.	STROBE items	Location in manuscript where items are reported	RECORD items	Location in manuscript where items are reported
Bias	9	Describe any efforts to address potential sources of bias	Phase 1: The study population may not be representative of the UK population – we have therefore standardised prevalence rates to the UK general population. Phase 2: We have compared non-responders and incomplete responders to the study population to assess the possibility of selection bias.		
Study size	10	Explain how the study size was arrived at	For both phases of the study we used all eligible individuals from the datasets used (Phase 1: p4; Phase 2: p5). The flow diagram presented in appendix Figure S1 illustrates the creation of the study population and reasons for exclusions.		
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen, and why	Methods section (Phase 1: p5; Phase 2: p7)		

	Item No.	STROBE items	Location in manuscript where items are reported	RECORD items	Location in manuscript where items are reported
Statistical methods	12	<p>(a) Describe all statistical methods, including those used to control for confounding</p> <p>(b) Describe any methods used to examine subgroups and interactions</p> <p>(c) Explain how missing data were addressed</p> <p>(d) <i>Cohort study</i> - If applicable, explain how loss to follow-up was addressed</p> <p><i>Case-control study</i> - If applicable, explain how matching of cases and controls was addressed</p> <p><i>Cross-sectional study</i> - If applicable, describe analytical methods taking account of sampling strategy</p> <p>(e) Describe any sensitivity analyses</p>	<p>(a) Statistical methods used are presented under the 'Analysis' subheadings of the Methods section for each study Phase (Phase 1: p5; Phase 2: p7).</p> <p>(b) N/A.</p> <p>(c) Phase 1 studies were based on recording of specific morbidity codes in electronic health records and therefore not subject to missing data. In Phase 2, responses to some survey items were missing, however, because the proportion of missing data for specific variables was a maximum of 13%, we conducted a complete case analysis using n equal to participants providing valid responses only.</p> <p>(d) Loss to follow-up is not applicable to this design we only included those with complete data (supplementary appendix Table S1 shows a comparison of non-responders, incomplete responders and the study population).</p> <p>(e) N/A.</p>		
Data access and cleaning methods		..		<p>RECORD 12.1: Authors should describe the extent to which the investigators had access to the database population used to create the study population.</p> <p>RECORD 12.2: Authors should provide information on the data cleaning methods used in the study.</p>	<p>(12.1) KM had full access to datasets (p14)</p> <p>(12.2) Methods section (pp4-7).</p>

	Item No.	STROBE items	Location in manuscript where items are reported	RECORD items	Location in manuscript where items are reported
Linkage		..		RECORD 12.3: State whether the study included person-level, institutional-level, or other data linkage across two or more databases. The methods of linkage and methods of linkage quality evaluation should be provided.	(12.3) Phase 2 included person-level data linkage. Data linkage of NorStOP survey data and electronic health data is documented in a previous publication cited in the paper (p5, ref 37).
Results					
Participants	13	(a) Report the numbers of individuals at each stage of the study (<i>e.g.</i> , numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed) (b) Give reasons for non-participation at each stage. (c) Consider use of a flow diagram	(a) Phase 1: N/A. Phase 2: The number of individuals at each stage of the study is presented in Figure S1 in the Appendix. (b) Phase 1: N/A. Phase 2: Reasons for exclusions at each stage are also presented in Figure S1 in the Appendix. (c) Phase 1: N/A. Phase 2: See Figure S1 in the Appendix.	RECORD 13.1: Describe in detail the selection of the persons included in the study (<i>i.e.</i> , study population selection) including filtering based on data quality, data availability and linkage. The selection of included persons can be described in the text and/or by means of the study flow diagram.	Phase 1: N/A Phase 2: See Figure S1 in the Appendix.
Descriptive data	14	(a) Give characteristics of study participants (<i>e.g.</i> , demographic, clinical, social) and information on exposures and potential confounders (b) Indicate the number of participants with missing data for each variable of interest (c) <i>Cohort study</i> - summarise follow-up time (<i>e.g.</i> , average and total amount)	(a) Phase 1: N/A. Phase 2: See Table 2. (b) Phase 1: N/A. Phase 2: See Table 4 footnotes. (c) N/A.		
Outcome data	15	<i>Cohort study</i> - Report numbers of outcome events or summary measures over time <i>Case-control study</i> - Report numbers in each exposure category, or summary measures of exposure <i>Cross-sectional study</i> - Report numbers of outcome events or summary measures	N/A descriptive study.		

	Item No.	STROBE items	Location in manuscript where items are reported	RECORD items	Location in manuscript where items are reported
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (e.g., 95% confidence interval). Make clear which confounders were adjusted for and why they were included (b) Report category boundaries when continuous variables were categorized (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	(a) N/A descriptive study. (b) N/A. (c) N/A.		
Other analyses	17	Report other analyses done—e.g., analyses of subgroups and interactions, and sensitivity analyses	N/A.		
Discussion					
Key results	18	Summarise key results with reference to study objectives	Presented at beginning of Discussion section (p10).		
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	Limitations discussed in the Discussion section (p12-13).	RECORD 19.1: Discuss the implications of using data that were not created or collected to answer the specific research question(s). Include discussion of misclassification bias, unmeasured confounding, missing data, and changing eligibility over time, as they pertain to the study being reported.	Limitations related specifically to using routinely collected health data for research are discussed in the Discussion section (pp12-13).
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	Overall interpretation of the results is presented in the Discussion section (pp10-12).		
Generalisability	21	Discuss the generalisability (external validity) of the study results	Generalisability of study results discussed in Discussion section (p12).		
Other Information					
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	Source of funding acknowledged at the end of the manuscript under the 'Funding' subheading (p14).		
Accessibility of protocol, raw data, and programming code		..		RECORD 22.1: Authors should provide information on how to access any supplemental information such as the study protocol, raw data, or programming code.	We are unable to share individual-level data (p14).

*Reference: Benchimol EI, Smeeth L, Guttman A, Harron K, Moher D, Petersen I, Sørensen HT, von Elm E, Langan SM, the RECORD Working Committee. The REporting of studies Conducted using Observational Routinely-collected health Data (RECORD) Statement. *PLoS Medicine* 2015; in press.

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Appendix 1

Phase 2 – Participation bias

Figure S1. Phase 2: Participation flowchart

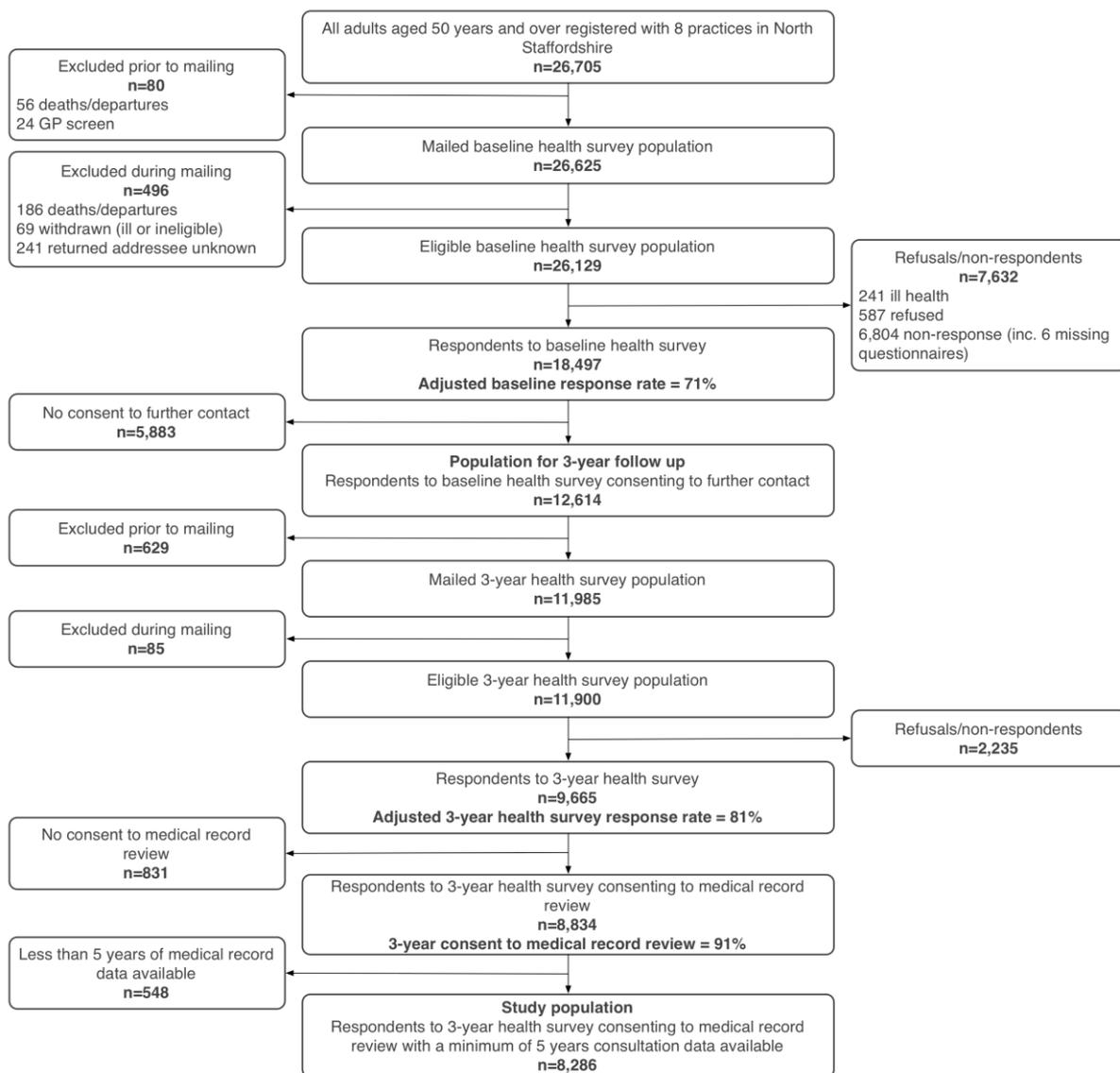


Table S1. Phase 2: Descriptive comparison of responders and non-responders. Data are frequencies (%) except where indicated otherwise.

	Non-responders (n=7,632)	Incomplete responders** (n=10,211)	Study population (n=8,286)
Female	3,883 (51)	5,834 (57)	4,477 (54)
Age, mean (SD)	65.3 (11.7)	67.6 (10.8)	64.5 (9.1)
Married or cohabiting*	-	6,493 (65)	6,007 (72)
Current employment*	-	2,348 (24)	2,513 (30)
Social class^a *			
High	-	1,357 (13)	1,701 (21)
Middle	-	1,471 (14)	1,546 (19)
Low	-	6,181 (61)	4,546 (55)
Deprivation score^b, mean (SD)*	-	12,836 (7,574)	13,953 (7,451)
Self-reported health at baseline			
SF-12 physical component summary (0-100) ^c , mean (SD)*	-	40.5 (12.6)	42.4 (12.2)
Anxiety (0-21) ^d , mean (SD)*	-	6.8 (4.2)	6.5 (4.1)
Depression (0-21) ^d , mean (SD)*	-	5.1 (3.8)	4.3 (3.5)
Cognitive impairment (0-100) ^e , mean (SD)*	-	16.3 (25.2)	12.4 (20.9)
Baseline self-reported pain*	-	6,750 (66)	5,989 (72)
Baseline ACR-90 widespread pain*	-	1,892 (19)	1,850 (22)
Baseline Manchester widespread pain*	-	1,145 (11)	1,125 (14)

a. Higher = higher managerial, higher professional or lower managerial/professional. Middle = intermediate occupations or self-employed. Lower = lower supervisory/technical, semi-routine or routine occupations[28].

b. Rank index of multiple deprivation[29] (low score = high deprivation)

c. 12-item short form health survey – physical component summary[39] (100 best health)

d. Hospital Anxiety and Depression Scale[43] (21 = worst health)

e. Sickness Impact Profile – alertness subscale[5] (100 = worst health)

SD. standard deviation

*Data on these variables were incomplete with n values ranging from 8,456 to 10,210 for incomplete responders and 7,444 to 8,283 for the study population.

** Baseline-only responders or responders to baseline and 3 years with either no consent to medical record review or access to less than 5 years of medical record data.