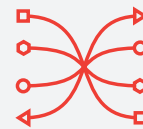
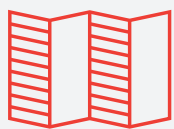


National Pain Audit Final Report

2010 - 2012



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2010 – 2012

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THE BRITISH PAIN SOCIETY



HQIP

Healthcare Quality
Improvement Partnership

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Executive summary

In 2009 the Chief Medical Officer for England reported that “each year over five million people in the United Kingdom develop chronic pain, but only two-thirds will recover. Much more needs to be done to improve outcomes for patients.” An estimated 11% of adults and 8% of children suffer severe pain, representing 7.8m people in the UK. Older age, being female, poor housing and type of employment are significant predictors of chronic pain in the community. The average annual incidence is estimated using health surveys at 8.3% with an average annual recovery rate of 5.4%.

Severe chronic pain is known to have adverse effects on employment status, daily activities, relationships, mood, sleep and all aspects of general health. Daily back pain is known to be associated with greater coronary events.

Patients attending an English Pain Summit held in October 2011 highlighted the impact that pain had on their lives. This was exemplified by Keira Jones, a student: “Everything I do now has a price in pain . . . It’s not really the pain itself that’s the problem. It’s the consequences of the pain that have the biggest disruption on my life.”

People with long-term, persistent or chronic pain that is refractory to usual pain care are seen in outpatient facilities by specialist pain services. This type of pain can significantly disrupt lives. Pain services were developed in response to the recognition in the 1960s that some people in pain may benefit from additional care. Advances in the understanding and treatment of pain have continued at a pace since then, but these have not been well implemented in the UK.

The National Pain Audit was set up in answer to findings from successive reports that pain services were struggling to keep up with demand. There was clear variation in provision of service and no agreed standards of care. The National Pain Audit has explored the quality of specialist pain services serving people with long-term pain. It has sought to evaluate them against known standards and develop new standards where necessary with clinicians and patients. This audit was commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP).

The audit located 161 providers of specialist pain services, totalling 214 clinics. Some PCTs had multiple providers within the same locality or the providers were split over multiple locations. 28 PCTs did not appear to have services available for their patients, though they may be accessing services from neighbouring areas. 91 providers (56%) returned information on case mix. 9,588 of their patients completed a questionnaire about themselves and the impact of pain on their lives. 4,414 patients returned follow-up questionnaires at six months. 3,192 (34%) of these were complete and provided a good understanding of what is happening to patients in 80 services.

“There was clear variation in provision of service and no agreed standards of care.”

The National Pain Audit found that specialist pain services are delivering care to a group of people who report a very poor quality of life. They often have mainly musculoskeletal pain and many are of working age. The greatest impact was upon work. Of those replying to the question on healthcare utilisation, 4,825 (20%) of respondents reported visiting A&E in the past six months in search of help all of whom had seen their GP. 3,469 respondents (66%) had made more than three visits to healthcare providers.

The audit found high variation in access to multidisciplinary care (the essential requirement for specialist chronic pain services). There is also significant variation in waiting times and access to key skills needed to help those with chronic pain. Only 81 out of 204 English clinics (40%) met the minimum multidisciplinary standard by the presence of a psychologist, physiotherapist and physician, although this was not possible to ascertain in 45% of clinics; 60% of services in Wales were multidisciplinary. Some services may be working across boundaries but this was impossible to ascertain. However, integrated, co-ordinated care, which the case mix demands, is then very hard to achieve.

56.5% of clinics showed their patients to have a mean improvement in quality of life after six months using the EQ5D-3L of which pain is a component; 17.6% reported no change. For disease-specific change, measured by the Brief Pain Inventory, 70.6% of the clinics reported an overall reduction in pain severity by an average 0.22 adjusted health gain. For BPI interference, 76.5% of the clinics reported a mean improvement, by a mean of 0.37 adjusted health gain.

The audit, although results are very tentative, suggests that pain services may be able to reduce this burden of care, which poses a massive drain on healthcare resources.

However, pain services appear to focus mainly on spinal pain or other musculoskeletal pain problems despite there being a clearly documented need in the elderly (whose plight is well documented) and other diagnoses beyond musculoskeletal pain, such as pelvic pain or non-musculoskeletal neuropathic pain. This may be a function of how pain services have developed – often alongside spinal services – or the needs of these populations may be being met elsewhere. This requires further exploration.

Many patients report a good experience of their service, especially in terms of support and advice, yet this important activity has no recognised incentive for it to

be provided. Nor is the activity captured through coding mechanisms. However, 52% of patients reported difficulty in understanding chronic pain. Services therefore need to make special provisions to ensure that this is understood by both patients and healthcare professionals managing them outside a specialist environment, to ensure consistency.

Many services fell well below the minimum requirement for an effective pain service, as stipulated by the International Association for the Study of Pain, the world's leading pain professionals' organisation and by the

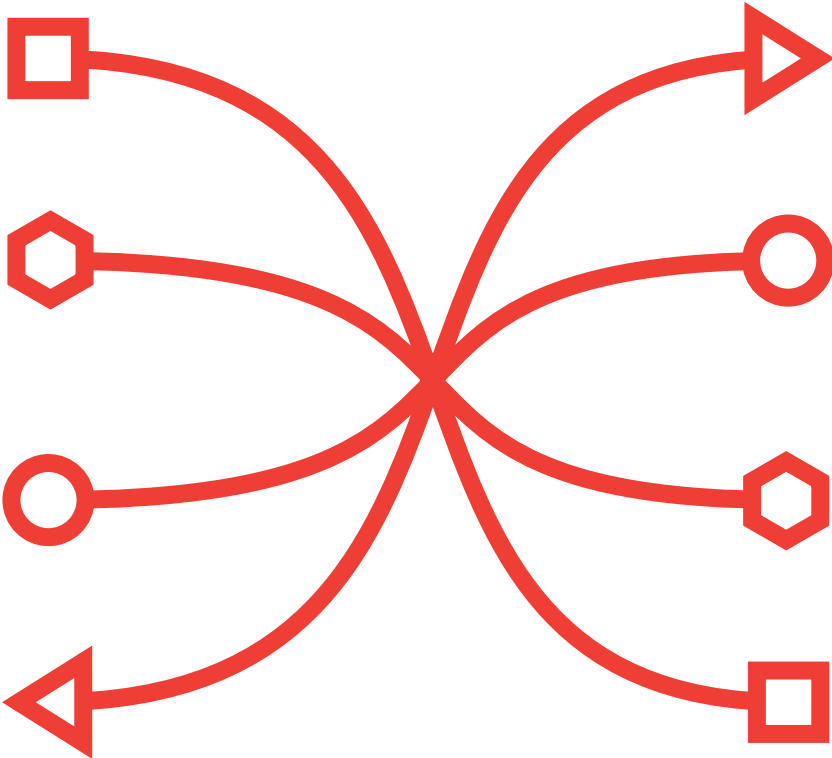
Faculty of Pain Medicine of the Royal College of Anaesthetists. Patients with complex needs where pain is the main problem thus will fail to have their needs adequately met despite clear thresholds and criteria being agreed through guidelines either from NICE or from professional bodies such as the British Pain Society's Map of Medicine persistent pain pathways.

Only medical specialists in pain medicine currently have statutory training requirements, levels of competency and an examination to assess competency to practise. While most professional bodies outside medicine do not require members to undergo statutory training in a specialty area, the exposure

to specialist multidisciplinary pain management is low, with a somewhat circular problem of insufficient staff to supervise juniors caused largely by difficulties in recruitment due to lack of exposure. If trained specialist staff are not available, then the case mix must be reduced accordingly to exclude those with significant emotional distress, taking complex mixtures of medicines or requiring interventional pain management.

Lastly, there were some information challenges. Coding diagnoses was very challenging for the clinicians involved. Further audits requesting information may support clinicians further in gaining expertise and understanding. The dataset needs to be broadened and complexity of diagnoses captured.

“Based on the number of patients who completed the patient feedback questionnaire, pain services can significantly help to improve quality of life (70%), the degree by which pain interferes with their lives (76%) and, to a lesser extent, pain relief.”



Recommendations

OPCS-4

IDENTIFICATION OF SERVICES

- The Information Centre should offer guidance to providers that a treatment specialty code (191) must be applied to all specialist pain services, regardless of setting, to identify them. Currently, the treatment function in administrative hospital data (HES) only applies to acute settings. This should be extended to non-acute settings, and ensure non-medical treatments delivered in the context of a recognisable specialist pain service are included.

ACCESS TO SERVICES

- NHS Choices and other nationally recognised sources of information on services should ensure that information on local pain services is readily available to patients. Each organisation should, as a minimum, provide NHS Choices with accurate information to an agreed standard.
- The Royal College of Anaesthetists should adopt the International Association for the Study of Pain guidance on minimum waiting times for pain services in its Good Practice Guide on pain services. Future audits should establish which category patients fall into.
- NICE should consider making access times that are appropriate to need a key standard for pain services.



STAFF SKILLS MIX

- Given the high rate of anxiety and depression and the clear link between these and poor functioning, far better access to physiotherapy and psychology is essential. Commissioners should ensure that these skills are incorporated into local care pathways for pain.
- Medical consultants should underpin every specialist service to manage risk, and provide expert advice on diagnosis and treatment.
- Future audits should seek to understand the available skills mix and competencies in more detail.
- Given the very poor quality of life that people in pain report, especially its impact upon their ability to work, there needs to be a greater focus on the needs of people with pain seeking to return to employment. The Department of Work and Pensions should consider how to support people in pain through specific provision of vocational rehabilitation.

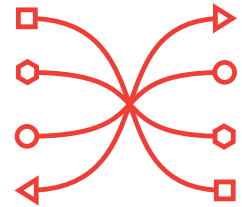


STAFFING COMPETENCIES

- Specialty interest groups in each profession should provide guidance on which competency and skills are required in order to meet patients' needs and to support commissioners and providers in identifying more clearly what skills are commissioned from particular services.

MULTIDISCIPLINARY TEAMS

- Commissioners and providers should ensure a health needs assessment is carried out at a local level to determine the degree to which specialist multidisciplinary care for pain is required.
- Clinical Commissioning Groups should examine whether services they commission match the Royal College of Anaesthetists' Faculty of Pain Medicine's recommended standards on staffing and structures.
- Clinical Commissioning Groups should ensure procurement of an integrated multidisciplinary care model rather than fragmented provision that confuses patients and referrers.
- Clinical Commissioning Groups should ensure that if a service cannot provide multidisciplinary care then it must be able to signpost to services which can. Such services need to be appropriately accessible to patients.



ASSESSING QUALITY OF CARE

- NICE should consider drawing upon the good practice demonstrated by specialist pain services in involving patients in decisions about their health, and this should be used as a standard for good practice.
- NICE should pursue the quality standard for pain with some degree of urgency to ensure services for people in pain are able to meet need based upon integrated multidisciplinary working.



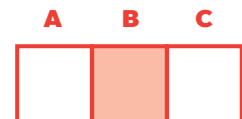
ADVICE ON MANAGING PAIN

- Providers of pain services need to improve the quality of advice given to patients on managing pain, especially in terms of the information that can be provided after a consultation.
- Providers of pain services need to check that patients have understood advice and be prepared to intervene further when it is clear that this has not happened, in line with guidance on safeguarding the care of vulnerable adults.
- Education on the nature of persistent pain is needed for those caring for people in pain.



CODING AND CLASSIFICATION SYSTEMS

- The Information Centre should ensure that disease and treatment classifications are broadened and this type of activity undertaken more frequently to improve the standard of data capture and improve HES coding. Peer review processes may help in future audits.
- Providers should ensure that co-morbidity data be collected in addition to a pain diagnosis.
- The Information Centre should ensure that programme budgets' categories are better able to identify the costs to the NHS of dealing with pain.



IMPACT ON HEALTHCARE RESOURCE USE

- Research funding bodies such as the National Institute for Health Research (NIHR) should ensure that research on optimal models of care for people with chronic pain, including economic modelling, is carried out.

TREATMENT INFORMATION

- Future audits should capture which treatments patients have actually received and whether these were provided in a timely fashion through detailed peer review.

Purpose of the National Pain Audit

The National Audit of Pain Services was initiated to collect detailed data on pain services in England and Wales. The three-year study aimed to improve NHS services for people affected by chronic pain and establish a national data collection system that enables services to monitor performance and share data nationally. Areas of data collection included: patient case mix, demographics, diagnosis, treatment, assessment of condition severity and patient outcomes.

The audit was funded by the Healthcare Quality Improvement Partnership (HQIP) and carried out by a partnership of the British Pain Society and Dr Foster Intelligence Ltd.

THE AIMS OF THE NATIONAL PAIN AUDIT WERE TO:

- Improve the quality and effectiveness of care by measuring services against existing standards. The audit is a first key step towards achieving this. However, clinics will need to reflect on their performance (which includes non-participation) as part of this.
 - Improve access to specialist pain services for patients and services users.
 - Improve awareness of specialist pain services within the NHS among patients, commissioners and clinicians.
 - Reduce unwarranted variation in care.
 - Accelerate the rate of improvement and development in both the organisation and delivery of care for people with chronic pain.
 - Develop new quality standards relating to the delivery of a high quality pain service.
-

The audit was led by the British Pain Society, which is multi-professional in its remit and has significant patient involvement in its activities. The principle stakeholders have been the Faculty of Pain Medicine of the Royal College of Anaesthetists, the Chronic Pain Policy Coalition and the Royal College of General Practitioners.

The audit consisted of three phases: phase one to identify and collect data from the service providers and phases two and three to collect data on individual patients and their experience. The findings from phase one have already been reported, but for convenience are summarised, together with the new findings from phases two and three, in this report.

Background

Pain is a complex bio-psychosocial experience. Pain that persists longer than expected can be difficult to treat. While many people are able to manage their pain successfully, some require referral to specialist pain services. The definition of a specialist pain service for the purpose of coding in the UK is described as “for the diagnosis and management of complex pain disorders, requiring a multidisciplinary team”. Provision of these services is inconsistent, and chronic pain is not given the priority it requires in view of the extent of its burden on individuals and society.

The prevalence of chronic pain with a high expressed level of need is estimated at 6.4% of the population, depending on the definition. Severe pain is estimated at 11% among adults and 8% among children. Older age, being female, poor housing and type of employment (for example, heavy manual work) are significant predictors of chronic pain. The average annual incidence is 8.3% and average annual recovery rate 5.4%. Severe chronic pain is known to have adverse effects on employment status, daily activities, relationships, mood, sleep and all aspects of general health. Daily back pain is known to be associated with greater coronary events.

Pain is not consistently managed across the whole health and social care system at present. Specialist services in secondary and tertiary care are tasked with managing complex pain, often too late and with few resources. In recent years, more services have been set up in primary care, with or without specialist input. However, little is known about the population served, the services offered and patient outcomes.

The Department of Health's Clinical Services Advisory Group (CSAG) in 2000 found a wide variation in quality of care offered by providers. Half the patients attending a pain management clinic had been referred by their GP and half by their hospital consultant.

The majority of patients (65%) had no prior knowledge of the existence of pain management clinics. A quarter of patients had waited more than 22 weeks for an outpatient appointment in the pain management clinic. The longest wait was 90 weeks. Shortages of specialist psychologists, physiotherapists, occupational therapists and pharmacists hindered a multidisciplinary approach.

There was little attempt to assess provision of pain services in relation to what local people actually needed.

Most of the pain management services felt that pain relief was not adequately recognised. Most (81%) had recently tried to obtain additional funding but 63% had been unsuccessful.

Many patients were positive about their experience of attending a pain management clinic. They said their pain had improved. They felt supported and relieved to discover that expert advice is available. Many felt that they should have been seen at a pain clinic earlier.

However, the Chief Medical Officer in his 2008 annual report described a similar picture, with nearly 50% of people with chronic pain reporting problems conducting social activities, walking, driving or having a normal sex life. In 49% of those with chronic pain there is depression, and this can result in suicide.

“Specialist services in secondary and tertiary care are tasked with managing complex pain, often too late and with few resources.”

There are several ways to assess the quality of pain services. However, services are fragmented and no single process has pulled these together in an attempt to measure these standards of quality of care and their impact upon patient care. NICE guidance does not support clear specific standards for the management of people with chronic pain; instead, guidance on chronic pain is found in a number of areas associated with chronic pain e.g. osteoarthritis, returning people to work, low back pain, neuropathic pain and long-term conditions. It is therefore often regarded as “hidden”. This can lead to considerable challenges when establishing standards of care.

NICE recommends registries for epidural steroids and spinal cord stimulation; guidelines for the management of chronic low back pain, neuropathic pain, headache and osteoarthritis; and management of sickness absence. At present there is no way to assess the impact of these wide-ranging recommendations on processes of care for specialist pain services.

The diversity of recommendations and standards makes it challenging to agree key standards for a National Pain Audit.

The Welsh government published its *Service Development and Commissioning Directive for Chronic Non-malignant Pain* in 2008, setting out its approach to tackling improvements in service provision and care for people living with persistent pain. This highlighted the patchy provision of services in Wales and the need to provide services closer to home for the majority of patients.

Following on from this, local health boards have been audited upon their compliance with the directive to help ensure improved standards of care. However, there has not been any direct return from patients themselves on the standard of care received.

A recent Scottish benchmarking audit for chronic pain demonstrated significant variation in patient care and led to the Scottish government recognising chronic

“The diversity of recommendations and standards makes it challenging to agree key standards for a National Pain Audit.”

EXISTING GUIDANCE

- Standards have been published by the Faculty of Pain Medicine of the Royal College of Anaesthetists (RCOA), on provision of services.
- The RCoA has a chapter on pain management in its Audit Recipe book.
- The International Association for the Study of Pain has published standards on waiting times.
- The British Pain Society provides individual guidance on treatment.
- The NHS Information Centre provides guidance on coding and collection of data for pain services, including programme budget categories for diagnoses and healthcare resource groups, which include treatment codes for pain.
- The former Department of Health 18-week Chronic Pain Consensus Pathway attempted to group treatments by setting and level of specialist care.
- The British Pain Society Pain Patient Pathways Project has defined care and treatment processes according to “care points”.
- Various professional societies produce guidance on knowledge and skills for professionals training in specialist pain management.

pain as a long-term condition in its own right. This has led to a direct intervention from the Health Secretary and has already had a positive impact on patient care.

The Chief Medical Officer in England acknowledged the difficulties in his 2008 annual report, and it was with this in mind that the National Pain Audit was established. This audit aimed to better describe what is happening with English and Welsh pain services. (It did not cover Scotland as its audit had recently been carried out.)

In common with many chronic conditions, there is very little known about how services are matched to needs. Current NHS information systems do not collect data in relation to disability (as opposed to disease) and are incapable of collecting data across groups of disease.

From 1998 to 2003, the British Pain Society ran a clinical audit where members voluntarily submitted data on services on an annual basis. While nowhere near comprehensive in its data coverage, the audit did highlight methodological issues that needed consideration and developed a useful basis for the current audit.

Methodology

To deliver this over a three-year cycle, the audit was divided into three phases:

Phase one

Pain service registration and completion of a service questionnaire to the registrant based upon key standards. Organisational standards were benchmarked against each other and against national and internationally agreed standards, where they could be ascertained. These were refined by the Scientific Committee.

Phase two

Case mix information from both the provider clinicians and patients. Information from patients about the patient journey to a pain service.

Phase three

Outcomes of care from a patient perspective using validated standard questionnaires and questions developed specifically for the audit by both clinicians and patients.



Recruitment: patient identification and admission to audit

PHASE ONE

All services in England and Wales that came under the HES treatment definition of a specialist pain service, regardless of setting, were eligible to participate.

→ *A list of participating centres is given in Appendix 1.*

Centres were located over January 2010 to July 2011 using the following methods:

1. Emailing contacts within primary care trusts in England, local health boards in Wales, hospital audit leads, PCT audit leads, and British Pain Society members.
2. Letter to all chief executives from Sir Liam Donaldson, then Chief Medical Officer, requesting participation.
3. Articles placed in the chief executive's bulletin from Sir Liam Donaldson, the British Pain Society Newsletter and the Faculty of Pain Medicine section of the Royal College of Anaesthetist's bulletin.
4. Location of hospital services using treatment definition code 191 and telephoning those organisations.

Once located, services were emailed a questionnaire to complete describing their services using the fields described in Appendix 2. The questionnaire was based upon the Faculty of Pain Medicine standards for general provision of pain services, the International Association for the Study of Pain's (IASP) classification of pain services, and IASP recommendations on waiting times. Feedback was also specifically invited from the Patient Liaison Committee of the British Pain Society and the Chronic Pain Policy Coalition, which has many patient organisations within the coalition.

→ *A service was classified as meeting agreed standards across a range of domains (Appendix 2), which were described as 'met' or 'not met'.*

PHASE TWO

Providers identified in phase one were asked to enrol patients over a three-month period using an online case mix tool. A pack was sent to them together with instruction, posters and patient information leaflets.

Patients were asked to complete a questionnaire (specific items at www.nationalpinaudit.org) that included the EuroQol 5D-3L, EuroQol 5D Visual Analogue Scale, brief pain inventory (BPI), work-related items, questions regarding the patient journey, support available and an estimate of healthcare resource used.

Clinicians were asked to complete an online case mix tool containing basic demographic data, diagnosis and planned treatment. ICD-10 codes were used to describe diagnoses using those codes in the programme budget category for pain. Only one entry was permitted, though free text was also permitted if the clinician did not feel able to find a code. This was due to the fact that during piloting, concerns were raised that the dataset was inadequate to meet the needs of clinicians.

→ *The codes used are found in Appendix 8.*

Non-responders were sent reminders and highlighted at the British Pain Society annual scientific meeting.

PHASE THREE

Patients who had completed the initial PROMS questionnaire were asked to complete a follow-up questionnaire approximately six months later. This consisted of a follow-up EuroQol 5D-3L questionnaire, EuroQol 5D Visual Analogue Scale, BPI, work-related items and healthcare resource use. They were also asked for their experience of the pain service in a number of ways.

Patients were asked to consent to data being linked to other potential databases, and provided with information about the audit. Consent for the audit was taken according to Department of Health guidance.

→ *Appendix 3 shows the collection time schedule.*

Reporting of data items

PHASE ONE

The purpose of this phase was to identify and characterise the services. Description of type of service, access, facilities and staffing levels were the key domains assessed. It took 15 months to accurately identify all clinics, mainly by word of mouth. Community clinics were especially difficult to identify and characterise as many did not use the treatment specialty code 191 and provided treatment in a very different way to hospital care, with a greater emphasis on support to self-care.

PHASE TWO AND THREE

PATIENT REPORTED OUTCOME MEASURES (PROMS)

The brief pain inventory (BPI) is an 11-item, pain-specific quality of life measure. It is split into two parts: a four-item 'pain severity' domain and a seven-item 'pain interference' scale. It is reported as a total pain severity scale, though for the purposes of chronic pain, pain average is felt to be the most accurate representation of a person's pain. Thus these items were reported separately as well as summarised.

The seven-item subscale 'pain interference' was also reported by each item, in addition to a summed scale. The percentage pain relief subscale was not used at follow-up as usually it is administered either daily or shortly after treatment and it was felt that six months may be too long to accurately record this.

The EQ-5D descriptive system comprises five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each dimension has three

levels: no problems, some problems, or severe problems. The respondent is asked to indicate his/her health state by ticking (or placing a cross) in the box against the most appropriate statement in each of the five dimensions. This decision results in a one-digit number expressing the level selected for that dimension. The digits for five dimensions can be combined in a five-digit number describing the respondent's health state, where one represents perfect health.

The EQ VAS records the respondent's self-rated health on a vertical, 20cm visual analogue scale, where the endpoints are labelled 'Best imaginable health state' and 'Worst imaginable health state'. This information can be used as a quantitative measure of health outcome.

Pain clinic averages were compared with reported UK norms over varying diagnoses (Sullivan 2011).

Other items

Ease of access to pain clinics was reported as mean of the 0–10 scale, median and by source of information. Visits to other non-specialist services for pain were reported as total number and separately. The majority of other items were binary in response and thus were reported as such and by missing data.

→ The full list of data items can be found in Appendix 2.

Data entry & transmission

Data were reported by organisation. Thus a service may be spread over several organisations but each was reported individually; several services were reported in one organisation but these were amalgamated together for the purpose of the audit.

Services were reported by: alphanumeric data for population served,

average waiting times, PCT/LHB served and location of service. After piloting the methods of data collection in 12 centres, the services completed an online web tool to register a patient. PROMS data were collected from each clinic then scanned in using a barcode reader.

Key audit standards

Data completeness

Standards for data completeness were set as follows:

- 100% of all fields completed for phase one.
- 100% of all fields completed by provider for phase two on case mix tool.
- 100% of all fields completed by patient for phase two on PROMS questionnaire.
- 100% of all fields completed by patient for phase three on PROMS questionnaire.

Type of clinic

Services were classified by self-assessment according to the IASP definitions:

1. Modality orientated clinic: clinic carrying out one treatment only.
2. Pain clinic: clinic carrying out more than one treatment but service has single profession.
3. Multidisciplinary pain clinic: service carrying out more than one treatment, with more than one type of healthcare professional.
4. Multidisciplinary pain centre: as per multidisciplinary pain clinic but also carrying out research.

Staffing standards

Minimum staffing levels of a consultant physician (specialist pain consultant), psychologist and physiotherapist were established. The audit followed guidance by the Faculty of Pain Medicine on staffing and facilities.

Diagnosis and treatment coding standards

Diagnoses were made according to ICD-10 and treatments grouped according to those established by the previous Pain Audit database. The standard was that all should be codable in order to facilitate data collection about a service.

Waiting times

The UK government has an elective wait time target of 18 weeks. This was therefore chosen as a key standard. Times were reported by provider, PCT and SHA per 100K population.

Multidisciplinary care

The minimum standard for multidisciplinary care was defined by the availability of medical, rehabilitation and psychological expertise. This was agreed by the Scientific Committee on the basis that treatment with the strongest evidence base is, first, interdisciplinary cognitive behavioural therapy requiring confirmation of diagnosis and management of distress and disability due to chronic pain, and second, prescription of medication for the treatment of musculoskeletal pain and neuropathic pain.

These were reported in NHS Atlas format, which gives a pictorial guide to variation in care by PCT and SHA. Services were reported by the number of PCTs that provided services. This then gave an indication of which PCTs were meeting these key standards both by easy access to care in terms of time patients had to wait for care, and by how far patients had to travel to receive care. These were elements considered important by both professional and patient groups.

Thus, for example, a patient could have access to multidisciplinary care but would have to travel many miles to receive it. It was not ascertained at this stage how patients made these choices.

Change in pain and quality of life affected by pain

BRIEF PAIN INVENTORY

The four outcomes that matter most to people with chronic pain, according to a US survey (Turk et al., 2008), are enjoyment of life, tiredness, emotional wellbeing and physical activity. With the exception of tiredness, these are reasonably well approximated by BPI interference and by quality of life scales.

Although patients would like large changes in pain and pain-related quality of life this has not been

achievable in treatment trials. The endpoint is also important; there is obviously a difference between the patient whose pain changes from an average of 4 to 2 (moderate to mild), which may allow him or her to return to functioning relatively normally, and the patient whose pain changes from an average of 9 to 4.5 (severe to moderate), who may still be relatively disabled in everyday life.

However, since function is also affected by other variables, notably psychological status, pain interference was rated directly in seven different domains, which are averaged. A consensus conference, which also considered the few empirical papers on the topic, concluded that a change of 1 to 2 points in the BPI mean interference score (0-10) was clinically meaningful in clinical trials – not in individual casework – and distinguished reasonably well between patients who were and were not satisfied with treatment. So it is not unreasonable to use this with reservation as a margin for improvement (Dworkin et al., 2009).

When asked about how much change they would like in overall disability or quality of life, patients often give figures between 50% and 100%, but these are far greater than most treatment trials achieve. This audit, therefore, considered a change of 1 point or half a standard deviation on the BPI interference score a good change.

Numbers receiving advice and guidance on managing pain

We felt that this should be 100% of all patients. However, as the audit relied upon recall of this information, perhaps several months after it was given, the National Pain Audit took a figure of 80% recalling being given advice and guidance as reasonable.

Data analysis

Data validation

PHASE ONE

Data were validated using the following methods:

1. Initial scan of return for obvious errors e.g. duplication, fields mismatched, numerical errors by project team that included clinicians.
2. Phone call to the clinical lead identified in the questionnaire to confirm data.
3. Cross reference of information to that contained within Hospital Episode Statistics (HES) for England.
4. Establishing a public-facing website with the data contained within it and inviting comment on accuracy.
5. Presentation of preliminary findings at specialist Society Annual Scientific Meeting and feedback from the British Pain Society Council and the Faculty of Pain Medicine clinicians as to validity.
6. Cross referencing of items within the questionnaire, e.g. verifying that the staffing and resources stated matched the clinic type classification. Discrepancies were noted and reported on.

PHASE TWO

Missing data were reported by overall proportion per provider reporting as mean/median/upper and lower deciles. These were checked by double entry.

The percentage of patients completing case mix data were cross referenced with HES data. Completed PROMS questionnaires as a percentage of the total number of patients were reported per provider. The denominator was calculated by the numbers reported as estimated being seen in the phase one audit, by providers. HES data was wildly at variance with the actual number of patients seen and thus was not used as a comparator.

Where the field or data item was a continuous variable, a summary of the maximum and minimum values, the mean and median as well as the quartiles were given. Counts were also provided of the valid fields as well as nulls or spoiled returns, i.e. questions not filled in or questions with unreadable responses.

PHASE THREE

Items were reported as for phase two. Additionally, a case mix adjustment model was designed and potential outliers identified (further details below).

Data analysis

Case mix items were collected as described in Appendix 2. Age was calculated. Only one type of pain was permitted and only one ICD-10 diagnosis at three-character code level (Appendix 9) unless more than 5% of patients were reported at four-character code level. Duration of symptoms was analysed by year. Only one source of referral was possible and others excluded from analysis.

Referrals to a clinic

Using the patient registered PCT population data from 2010 we calculated the crude rates for each clinic as the ratio of the number of admissions from provider PCT to that of the reported PCT population (as of 2010 – the latest figures that Dr Foster Intelligence possesses). Although pain clinics receive patients from a number of locations, in order to understand variation we assumed that each clinic receives most of its patients from a single PCT. For every clinic, we counted the number of admissions and divided by the relevant PCT population count in order to derive the crude rate.

In order to assess the structural difference in the way pain is handled in primary care across the NHS we also calculated the age-sex standardised admission rates per clinic. The standard European population (a notional population of 200,000; see, for example, Setting Levels of Ambition for the NHS Outcomes Framework, Department of Health, published 4 July 2012) is used for the direct standardisation calculation.

For each age-sex stratum we found the crude rate for every clinic. Each stratum-specific rate was then multiplied by the standard population head count for that stratum. This gives an expected figure for their stratum. We then summed the expected figure at the clinic level to obtain the Standardised Admission Rate (SAR).

PROMS

BRIEF PAIN INVENTORY (BPI)

The BPI short form was reported by mean per item and then amalgamated into its two-factor structure of pain intensity and pain interference. Pain relief was reported as a percentage. Pain intensity was divided into mild (0–3), moderate (4–6) and severe (7–10). Pain interference items were reported separately. All were reported by mean, median and standard deviation, upper and lower quartile, minimum and maximum.

EUROQOL

The EuroQol 5D-3L measure is a quality of life questionnaire that has been widely accepted as a generic measure of quality of life. While it does have floor and ceiling effects these are less so than other measures such as the SF36. It has also been used in national PROMS projects with such painful musculoskeletal conditions as osteoarthritis of the hip and knee.

CASE MIX ADJUSTMENT

From work done previously by the National Clinical Audit Advisory Group in relation to PROMS, important variables are considered to be:

- demographic and other patient characteristics including socio-economic factors;
- prior health-related factors ;
- clinical factors;
- patients' beliefs and expectations/appraisal of the service.

However, not all were included in the model. In order to make meaningful comparisons across pain clinics, a methodology based upon the report Patient Reported Outcome Measures (PROMS) in England: the case mix adjustment methodology (published by the Department of Health, April 2012) was implemented.

Relative Performance Factors (RPF) were constructed for each patient and then summed across clinics, scaled by the national average and finally benchmarked against the national performance, resulting in a provider-level RPF measure of the way in which pain scores evolved across the stages of the National Pain Audit, by clinic.

Data and possible bias

The dataset (new referrals to the service, which also included re-referrals) against which linear models were constructed consisted of the 3,192 fully completed follow-up questionnaires, providing post-treatment scores on the three measures of interest: the EQ5D-3L measure, the BPI interference measure and the BPI severity measure. These patient records were matched to original returns using unique barcode indices. In this way pre (prior to treatment) and post (follow-up after 6 months) scores were obtained.

This dataset represents approximately 30% of patients returning an initial questionnaire. Since it is unlikely that the 70% of missing questionnaires were “missing at random”, it is important to note that the sample on which models were constructed is probably a biased sample of the original population. For example, it may be that attrition is largely or partly due to improvements in the patients' pain experience, to the extent that a patient drops out of the study. Other clinic-level sources of bias may exist in the follow-up questionnaires. Further work is needed to characterise this sub-group.

MODEL VARIABLES

The original PROMS case mix methodology designates scores Q2 as the post-score and Q1 as the pre-score.

Variables considered in the estimation step of the case mix analysis consisted of age, sex, ICD-10 diagnosis code, walking ability, overall health (baseline) score and category. These are now described in more detail.

WALKING ABILITY

A proxy for mobility obtained as the score from 0 to 10 on question 6, part C, of the PROMS Pain Audit Questionnaire: “Mark the one number that describes, how, during the last seven days, pain has interfered with your walking ability”. A score of 0 indicates no interference, increasing to a score of 10, indicating complete interference.

ICD-10 CODE

Diagnosis codes for patient referral to the pain clinic were obtained. In the Modelling Data set, a highly unbalanced representation of such codes is found. We took the decision to provide a balanced design by banding ICD-10 codes into four groups, obtained by stripping the code of all characters after the first:

- Group G (neurological pain)
- Group M (musculoskeletal pain)
- Group R (widespread or non-specific pain)
- Group O (others)
- Overall health (baseline) score

This is the thermometer scale VAS baseline score.

AGE

This was treated as a continuous variable as far as model building was concerned.

CATEGORY

A categorical variable provided a description of the type/location of pain suffered by the patient concerned. It consisted of the following levels:

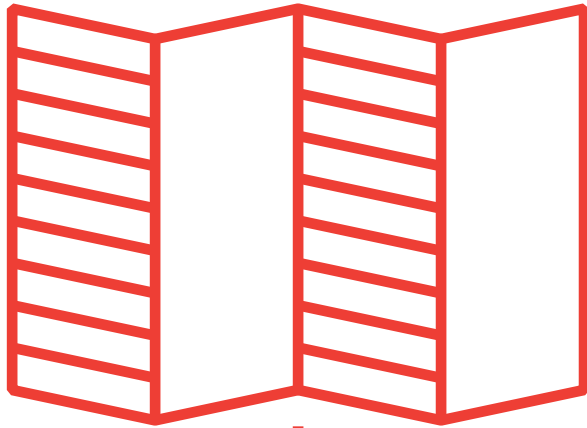
- Musculoskeletal pain
- Non-specific pain
- Neurological pain
- Visceral pain

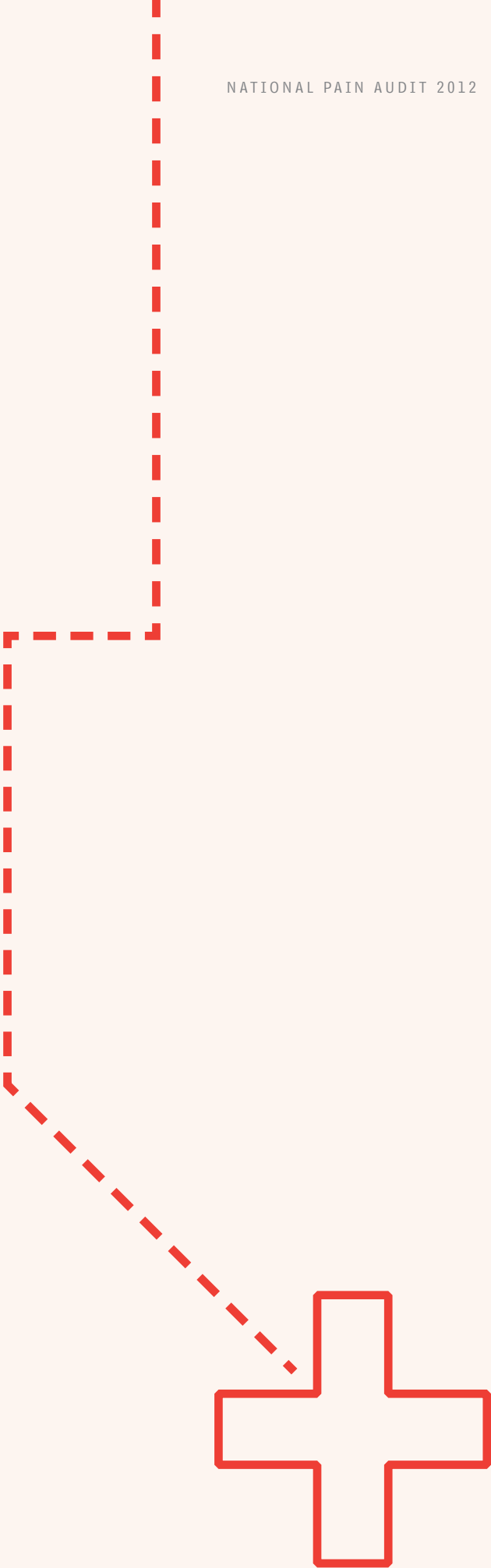
Management of outliers

The case mix-adjusted average health gain was the primary metric of interest to identify potential outliers. The national mean was the benchmark to identify potential outliers. Funnel plots were also used to identify potential outliers.

We adopted the convention of identifying “alarms” using 99.8% control limits and “alerts” using 95% control limits within the PROMS outlier policy. Symmetric control limits were applied; however, in cases where the volume was less than 150 (as many were) some judgement was applied if the provider was close to the funnel limit. If any unit was very near to the line then it was given the benefit of the doubt.

A list of potential outliers is published as part of the final report. The audit board took the view that it is up to the provider to take action to explore and improve its performance. During the feedback of the final report, providers will be asked to consider if there are other factors that may explain their presented results, other than variation in performance.





Findings of the National Pain Audit

Data returns

Phase one data have already been reported in 2011. Details of this are available at www.nationalpainaudit.org. Highlights of that report are presented only where it was felt that it would enrich information from phase two and three.

In England, 136 clinics were based in acute trusts and 31 in community trusts. Their setting was not clear in 37 cases. The majority of PCTs and LHBS had one to two services located within them. However, this was subject to considerable variation. Some providers stated that they had multiple pain clinics, and five clinics based in a single PCT (Hertfordshire) returned data.

For 28 PCTs there appeared to be no service or insufficient information was returned. Data returns were poorest in the Midlands and South East. One provider claimed that it would paint its service in a bad light if it returned data. Some providers counted up the total number of sub-clinics rather than an overall service. These were merged into a single provider.

A final count of 161 specialist pain clinics returned data for phase one in England and Wales.

For phase two, 91 clinics returned data, giving a response rate of 56%. 9,430 patients were entered on to the case mix tool.

For phase two, there were 9,588 returned questionnaires in total together with the case mix. Many questionnaires, however, were only partially completed.

For phase three, of the patients that had returned PROMS questionnaires, 4,414 returned a final PROMS questionnaire (63%). Of these, 3,192 were complete (34%). Of note is the fact that over 300 patients on the first date of receipt of the questionnaire telephoned Dr Foster, the collection company, to highlight difficulties with getting the care they had been led to expect.

Patients were drawn from 107 centres. However, several of these were sites within the same provider, so these were merged to report at provider level a total of 94 sites that completed phase three. Patients from a total of 80 providers submitted sufficient data to calculate quality of life measures.

The final patient numbers represent 34% of the initial numbers enrolled. Appendix 1 shows the participating providers in phase one. Appendix 4 shows the providers who reached the end of phase three.

Phase one

Waiting times

For the 18 weeks key standard, 80% of clinics in England reported meeting the standard, 2.5% explicitly did not meet the standard, and the remainder did not answer the question. The question on waiting times has one of the highest completions rates, which is unsurprising given that waiting times are a key government target. In Wales, where targets are somewhat different, 50% of clinics achieved 18 weeks for elective waits, with a lower completion rate of 70%. There was significant variation in wait times in England. Where waiting times were more than 18 weeks the median wait was 20 weeks in England and 33 weeks in Wales.

Multidisciplinary working

As outlined in the phase one report, although clinics were asked to rate their ability to deliver multidisciplinary care, the Scientific Committee felt it would be best demonstrated by the presence of key personnel (physiotherapist, psychologist and physician) to provide a stricter basis on which to assess multidisciplinary status.

64% of English services and 80% of Welsh services assess themselves as multidisciplinary. The findings from this stricter approach were that 81 out of 204 English clinics (40%) could be defined as multidisciplinary by the presence of a psychologist, physiotherapist and physician. The respective figure for Wales is 60%. However, despite several attempts at validating the data in the remaining English clinics and one Welsh clinic, the fields were either left blank or contained invalid data so their status could not be ascertained.

Both the Midlands and South East Coast seem relatively poorly served by multidisciplinary services using the stricter approach to multidisciplinary: if data are analysed by the presence of key professionals who are necessary to provide multidisciplinary pain care, then the number of multidisciplinary clinics was substantially lower than the number self-rating as multidisciplinary. There is wide geographical variation; in some areas patients need to travel great distances to receive multidisciplinary care. Key personnel are often patchily available.

Audit standard: clinical staffing

For those services reporting that they provided psychologically based rehabilitation, 48% in England and 60% in Wales reported the presence of a clinical psychologist. That means more than half of services in England were attempting psychologically based rehabilitation without a psychologist. This is also important as 51% of patients reported anxiety/depression at referral.

For English services reporting specialist medication management (92%), the presence of a consultant was confirmed in 71% of them, suggesting that up to 29% of clinics may not offer senior support. Given that GPs have struggled to manage medication in this group, and that prescription may involve strong opioids on a long-term basis and medicines with significant side effects, these figures are concerning.

In contrast, 90% of clinics in Wales had access to consultant support for medication management.

Given that medicines management is so challenging in this group, the Faculty of Pain Medicine also recommends that a service has access to a clinical pharmacist. 78% of responders in England reported access to an onsite pharmacy but only 30% in Wales.

Senior medical staff are needed for the provision of interventional pain management. This is an area that requires careful management as the evidence base is unclear and patients often need to be considered on individual merit. 81% of English clinics carried out interventional pain management, with 72% able to offer a consultant-led interventional pain service. In Wales 70% of clinics reported carrying out interventional pain management, with all of these having access to a consultant.

Physiotherapy posts

Only 52% of services in England reported having access to a physiotherapist (60% for Wales). Given that pain may severely limit physical activity they should be regarded as key personnel in any pain service, and the skills required to work effectively with chronic pain are not the same as routine outpatient physiotherapy care. We were only able to locate standards from the 1990s for physiotherapy. The NHS Institute for Innovation and Improvement praised good practice and the contribution

of extended scope physiotherapists in patient assessment and management in musculoskeletal assessment in 2009. However, application has not been widespread.

Audit standard: service has access to administrative staff to support its smooth operation

This section had a high completion rate (94% for England and 90% for Wales); 84% of English services and 80% of those in Wales reported having dedicated administrative staff.

Audit standard: IT support

IT support is essential for management of a patient in a specialist service. Information needs to be clearly communicated to others in a timely fashion, appointments need to be scheduled efficiently and team members often need to liaise with other health and social care personnel.

This standard was well completed, attaining 92% completion rates for England and 90% for Wales. However, in England only 57% of services reported that they had good access to patient information systems. In Wales, 80% reported good access to patient information systems.

Audit standard: wheelchair access

As the population attending pain services is frequently highly disabled, good wheelchair access is essential. 93% of respondents completed this section with all of these stating that they had wheelchair access. Similarly, of the 80% of services in Wales who responded, all reported good access for those with disabilities.

Audit standard: supporting professional activities

These activities ensure continuity of service and maintenance of high standards. Without training new staff, services would face significant challenges to sustainability. Clinical audit ensures that services are able to maintain a high standard of care.

The Faculty of Pain Medicine states that services should “carry out regular supporting professional activities”. Services were asked to report on their ability to perform audit and teach various professions.

In general there was a high completion rate (around 90%) for this section of the audit. 74% of English services reported that they were able to carry out clinical audit. 53% of services reported being able to teach medical students and physiotherapists. 66% reported being able to teach nursing staff.

90% of services in Wales carry out regular audit, 50% teach medical students, 70% teach physiotherapists and 80% teach nursing staff.

Commentary

Audit appears to be a core activity of many pain services, which should drive quality. However, only around half of services are able to train medical students, with numbers somewhat better for other staff. This lack of training of medical staff in the management of long-term pain has been highlighted elsewhere.

Audit standard: research

56 clinics in England (27%) self-reported that they regularly carry out clinical research. Of the English clinics defining themselves as multidisciplinary clinics or centres, 47 (36%) reported that they carry out research. Two of the self-reported multidisciplinary pain clinics in Wales carried out research.

Phase two

Case mix including patient report of severity and quality of care prior to arrival in a specialist pain service

The following summarises the data in returned questionnaires and the case mix tool.

NUMBER OF PATIENTS ADMITTED TO THE AUDIT

The numbers of patients completing data at initial assessment varied widely from clinic to clinic. We were unable to obtain an accurate estimate of the actual number of patients from HES data. The funnel plot of the standardised arrival rates exhibit over-dispersion; that is, greater variability in arrival rates than would be expected based upon binomial critical limits.

The team felt that, rather than scale the plot using a dispersion parameter to reduce this effect, the plot potentially shows the great variability in load that pain services experience, or that there was high variability in the numbers entered into the audit. Without a clear denominator, it is impossible to tell.

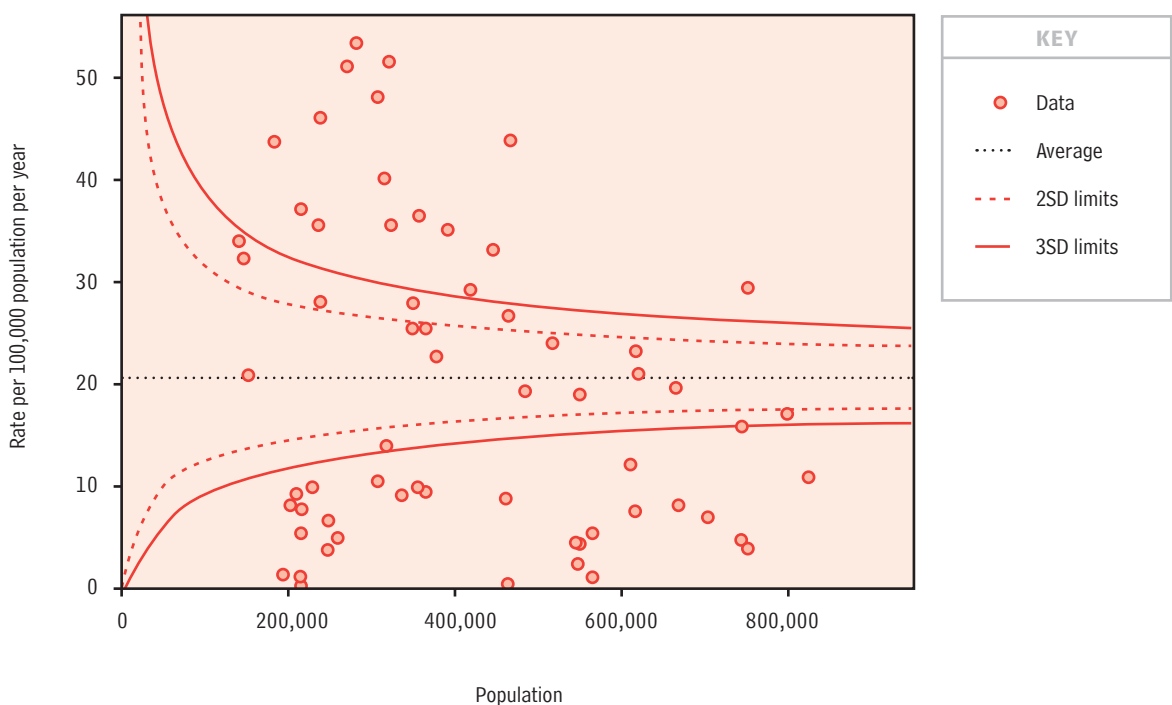
The Standardised Admission Rate also varied widely per clinic. This may be a function of few patients being entered on the database or a wide variation in numbers referred. Some services are highly fragmented, with multiple providers in the same locality (e.g. Sheffield and Southampton) giving very low numbers per centre. It is unclear whether specialists work across these providers or how the case load is distributed.

AGE

The average age of those entered on the case mix tool was 53.8 (1st–3rd Interquartile Range 42–66). The minimum age was one year; maximum 98 years. Thus the majority of patients referred are of middle age. Three returns were spoilt by having values >26,000.

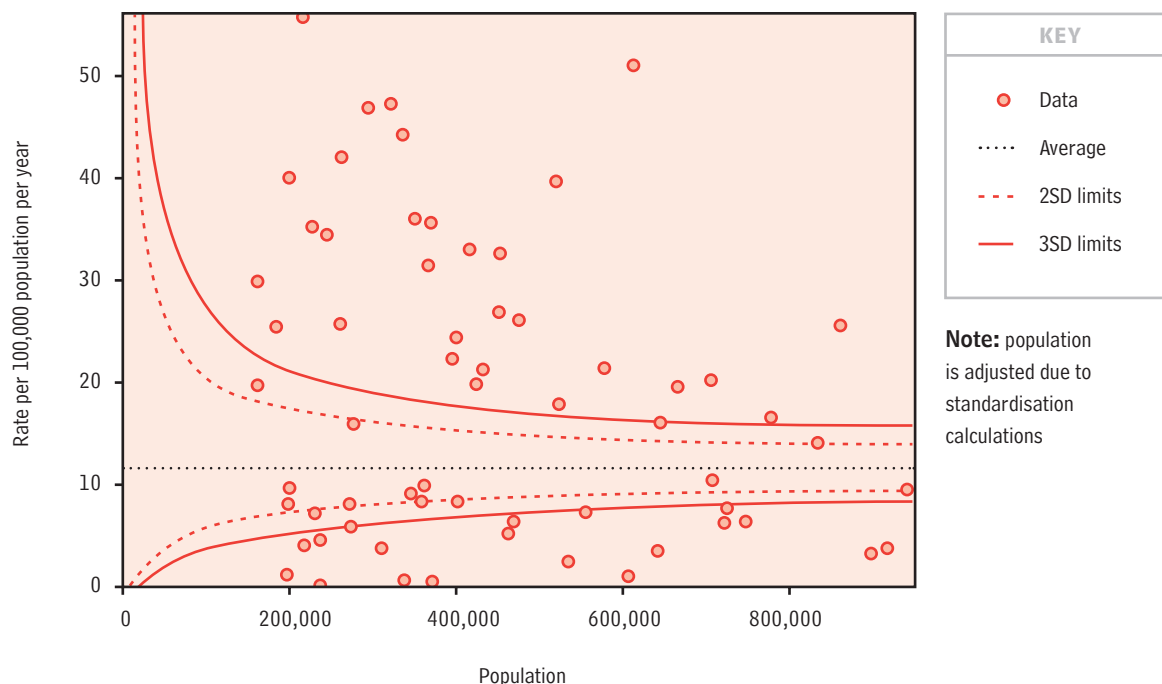
Crude admission rates for pain clinics

Source: PROMS



SAR for pain clinics

Source: PROMS



KEY
 ● Data
 Average
 - - - 2SD limits
 — 3SD limits

Note: population is adjusted due to standardisation calculations

SEX

Female: 6,158	Male: 3,430
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For 5,514 patients this was their first attendance. For 1,605, although it was a new episode of care, they had previously attended. 2,463 did not reply. 5,027 had received treatment for their pain in the past six months, 1,046 had not, with 3,289 not replying to this question.

Many (75%) had been to see their GP, and 53% had seen other healthcare professionals for their pain (2,583). 965 (20%) had attended A&E, and none of these had seen another healthcare professional about their pain.

Many had made multiple visits to healthcare professionals for help with their pain over the preceding six months (see table below). A significant proportion had made more than ten visits to their provider in search of help.

N° of visits	N° pre pain service	6 months follow-up
1-3	1,753	33%
4-6	1,659	32%
7-9	741	14%
10+	1,069	20%
(Other): 10	37	1%
Total	5,259	100%
Non-responders	4,329	

EASE OF ACCESS

Patients rated this on average 4, meaning it was moderately difficult to gain access. Most had been through traditional routes i.e. GP or consultant.

HOW DID YOU FIND OUT ABOUT THE PAIN SERVICE?

GP	3,286
Hospital consultant	2,390
GP & hospital consultant	439
Other source	366
Word of mouth	185
Other	401
No response	2,521

PRIOR TO GOING TO THE PAIN SERVICE DID YOU FEEL YOU HAD ADEQUATE SUPPORT IN UNDERSTANDING YOUR CONDITION?

	N°	%
Yes	4,249	44%
No	2,652	28%
Unsure	55	1%
No response	2,632	27%
Total	9,588	

Many people did feel reasonably well supported in managing their condition.

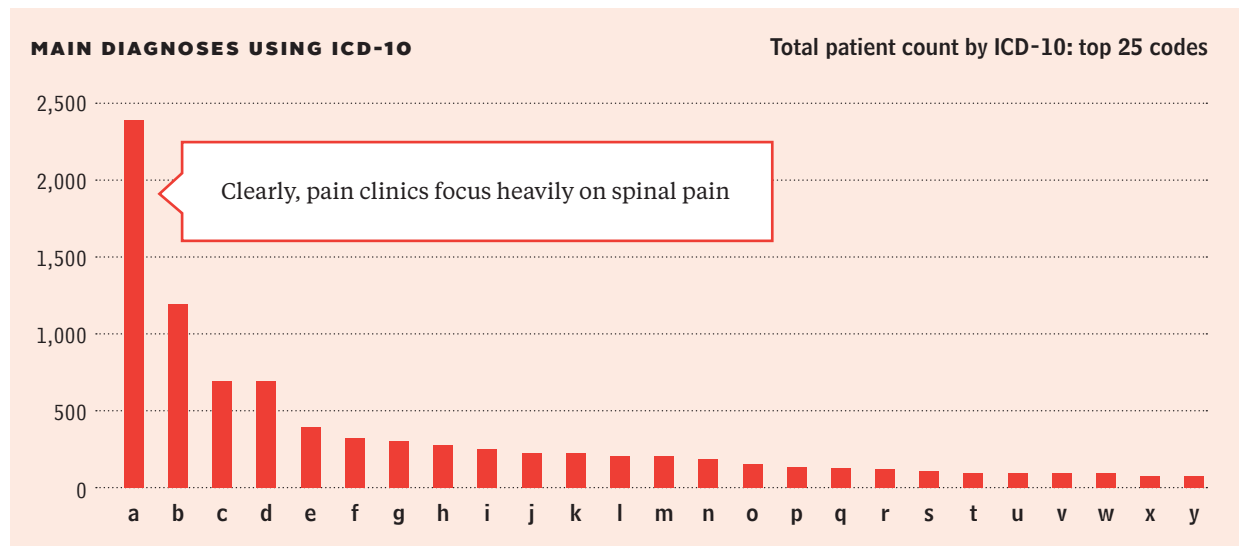
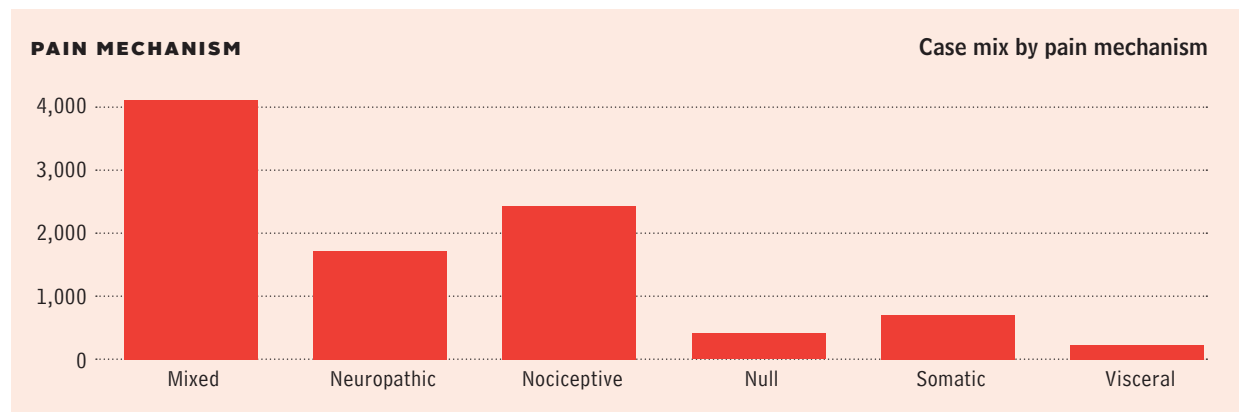
IMPACT ON WORK

	Prevented from working	Had to reduce hours	Prevented from voluntary work	Had to reduce voluntary work
No response	3,206 (33)	3,088 (32)	3,306 (34)	3,066 (33)
No	2,474 (26)	1,189 (12)	2,433 (25)	512 (5)
Yes	3,869 (40)	1,185 (12)	3,829 (40)	298 (3)
Partially	39 (1)	14 (1)	20 (1)	4 (0)
N/A		4,105 (43)		5,468 (59)

The majority of people attending the clinics who replied to this question were either unable to work or had had to cut their hours. This applied equally to voluntary and paid work.

Clinician-reported case mix data

Of note is the fact that 67% of patients had musculo-skeletal pain. This is in line with population surveys (Croft 2010).



- a. Low back pain
- b. Lumbago with sciatica
- c. Cervicalgia
- d. Pain in joint
- e. Radiculopathy
- f. Chronic pain syndrome
- g. Other chronic pain
- h. Sciatica
- i. Pain in limb
- j. Myalgia
- k. Chronic intractable pain
- l. Other dorsalgia
- m. Pelvic and perineal pain
- n. Other chronic post-procedural pain
- o. Algoneurodystrophy
- p. Pain localised to other parts of lower abdomen
- q. Postlaminectomy syndrome, not elsewhere classified
- r. Lesion of sciatic nerve
- s. Neuralgia and neuritis, unspecified
- t. Atypical facial pain
- u. Dorsalgia, unspecified
- v. Pain, unspecified
- w. Other disorders of peripheral nervous system
- x. Spinal stenosis
- y. Causalgia

EUROQOL 5D-3L INITIAL SCORE

EQ5D-3L health state	Mobility (%)	Self-care (%)	Usual activities (%)	Pain (%)	Anxiety/depression (%)
No problems (0)	1,388	3,572	565	100	2,051
Some impact (1)	5,724	3,488	5,173	3,524	3,838
Severe impact (2)	69	174	1,479	3,407	1,105
Two responses	41	30	2	237	37
Three responses	16	27	3	0	2
(Other)	9	5	0	5	0
Null	2,341	2,332	0	2,315	2,555

OVERALL EUROQOL SCORES AT ENTRY TO THE AUDIT

Average score	Min	Max	Median	1st quartile	3rd quartile
0.403974	-0.073	0.845	0.357	0.201	0.596

The average EuroQol score was 0.4 where 1 represents perfect health, suggesting overall quality of life for people with chronic pain was very poor.

EQ5D VAS SCORE

This is a health thermometer where individuals are asked to rate their overall quality of life from 0–100. The median quality of life was 50, and the mean 52.5 (IQR = 35 to 70). The total number of non-responders was 2,870.

Phase three

Outcomes of care six months after admission to the audit from a patient perspective, using validated standard questionnaires and questions developed specifically for the audit by both clinicians and patients

4,414 patients replied to the follow-up questionnaire. 91% of patients who replied to the follow-up questionnaire continued to have pain.

We examined the characteristics of patients who replied to the audit in terms of age, sex and quality of life measurements beforehand. We compared these with the

overall population who completed phase two. The population completing all three phases did not differ substantially from those just completing phase two.

Visits to other healthcare professionals

Of the subset that returned a follow-up questionnaire, notwithstanding the null responses, there appears to be a substantial drop in the number visiting A&E by this point. The number not replying to this question increased considerably. More analysis is needed of

healthcare use by people in pain that was beyond the scope of this current audit. But the data would suggest that pain services can ensure that patients are receiving planned support to manage pain.

NUMBER OF VISITS TO HEALTHCARE PROVIDERS BY TYPE IN PAST SIX MONTHS (PATIENT RECALL)

Type of visit	Nº	Entry to pain service	6 months post-entry to pain service %
No response	1,920	16%	39%
General practice	1,954	38%	39%
Other	609	12%	12%
Hospital A&E	434	16%	9%
Other unmatched data	70	18%	1%

NUMBER OF VISITS TO HEALTHCARE PROFESSIONALS IN PAST SIX MONTHS (PATIENT RECALL)

The trend appears downwards for healthcare visits, though this was by recall and a significant number did not reply. The group that responded to the follow-up

audit reported less visits initially as a sub-group. Caution needs to be exercised, therefore, in interpreting this data.

Number of visits	Before pain service	% of responders	Six months follow-up	% of responders
1-3	864	20%	1,136	26%
4-6	828	19%	716	16%
7-9	339	8%	251	6%
10+	454	10%	317	7%
Other	20	0%	14	0%
Total responders	2,505	57%	2,434	55%
Non-responders	1,909	43%	1,980	45%
Total	4,414	100%	4,414	100%

Quality of life questionnaires

BRIEF PAIN INVENTORY (BPI)

Mean, median, range and centiles were calculated for pain average and pain interference at phase two and at phase three (follow-up) for the sub-set of responders. These results are not adjusted for age, sex or other variables and are thus not reported by provider. The overall trend was improvement over time.

	PAIN AVERAGE		MEAN PAIN INTERFERENCE SCORE	
	Pre-visit	Follow-up	Pre-visit	Follow-up
Mean	6.4	6.1	6.7	6.4
Median	6.4	6.1	6.7	6.4
Minimum	4.5	4.3	4.6	2.3
Maximum	8.3	8.5	8.0	8.9
25th centile	6.0	5.6	6.3	5.9
75th centile	6.7	6.5	7.1	7.0

BPI PAIN SEVERITY SCORES AT FOLLOW-UP:

	Pain least	Pain worst	Pain average	Pain now
Minimum	0	0	0	0
1st quartile	3	5	4	4
Median	4	6	7	6
Mean	4.4	5.95	6.1	5.9
3rd quartile	6	7	8	8
Maximum	10	10	10	10

BPI PAIN INTERFERENCE SCORES AT FOLLOW-UP

	Activity	Mood	Walking	Work	Sleep	Enjoyment
Pre-visit [mean, median (IQR)]	7.1, 6 (6, 9)	6.5, 7 (5, 8)	6.6, 7 (5, 9)	7.3, 8 (5, 9)	6.7, 7 (5, 8)	7.2, 8 (6, 9)
Post-visit [mean, median (IQR)]	6.6, 5 (5, 9)	6.1, 7 (4, 8)	6.3, 7 (4, 9)	6.8, 8 (5, 9)	6.3, 7 (4, 9)	6.7, 7 (5, 9)

Patient scores ranged from 0 (no interference) to 10 (worst possible interference) over seven domains.

ADJUSTED OUTCOMES

We used adjusted health gain modelling (Appendix 5) to adjust each clinic's score. Various potential factors were examined. Walking ability, age, sex and diagnosis were found to be potential important variables. We therefore adjusted for these.

In order to describe potential explanatory variables for the follow-up scores, three models were estimated for each of the scores: EuroQol 5D, BPI severity and BPI interference – these included walking ability, age, sex and diagnosis. All three models exhibited low explanatory power, suggesting that significant predictors may

be missing. However, the proxy for walking ability taken from the response to the initial BPI questionnaire was significant for all three models. An overwhelming count of diagnoses involving lower back pain led to ICD-10 codes not being significant.

70.6% of the clinics reported an overall reduction in BPI pain severity score (mean -0.22, standard deviation of 0.59 where a negative number represents improvement). For BPI interference, 76.5% of the clinics reported a mean improvement, again represented by a negative number, (mean of -0.37, s.d. 0.66). However, this is not

weighted by the number of patients providing a response from each clinic. A small number of responses from a clinic may skew results and thus caution should be applied to any clinic reporting small numbers only. Neither pain severity nor pain interference scores followed a normal distribution; however, the audit team felt that the

distribution approximated normality sufficiently well for the purposes of the audit.

Given that half a standard deviation on such scales often represents significant improvement, this is achieved using data from all clinics in pain interference, and nearly all by pain severity.

EUROQOL 5D-3L

	Post-health state (0-100)	Overall post EQ5D (1 = perfect health)
Minimum	0	-0.023
1st quartile	30	0.201
Median	50	0.428
Mean	49	0.418
3rd quartile	70	0.637
Maximum	100	0.814

EQ5D-3L health state	Mobility	Self-care	Activities	Pain	Anxiety/ depression
No problems	856	2,052	483	162	1,355
Some impact	3,324	2,061	2,967	2,192	2,259
Severe impact	86	154	831	1,863	649
Two responses	13	20	28	0	27
Three responses	14	4	0	0	0
(Other)	3	0	0	2	2
Null	127	123	98	117	122

Reporting by clinic mean EQ5D-3L score, 56.5% of clinics showed their patients to have a mean improvement in quality of life, and 17.6% reported no change. Mean change was 0.01, and s.d. 0.06. In this case, positive numbers represent improvement.

ADVICE ON MANAGING PAIN PROVIDED BY THE PAIN SERVICE

As advice on managing pain was felt to be a basic function of a service this outcome was broken down by provider and reported in Appendix 7. The number who recalled being provided with advice varied from 67% to 100%. We took a number of 80% recalling being provided with advice and guidance as being a reasonable cut-off. The numbers in some centres were very small; overall, however, for those with greater than 10 respondents 84% of clinics reached the cut-off figure.

None	592
Verbal	1,308
Leaflets	262
Verbal and leaflets	411
Other	1,651
No response	190

QUALITY OF ADVICE GIVEN BY THE PAIN SERVICE

	Nº	%
Poor	699	18%
Satisfactory	1,559	40%
Good	1,299	33%
Excellent	387	10%
No response	464	
Valid responses	3,944	

ADDITIONAL SUPPORT OFFERED TO COPE WITH PAIN

	N ^o	%
Not offered	1,546	66%
Group	530	22%
Telephone	170	7%
Other	113	5%
No response	268	
Valid responses	2,359	

TREATMENTS RECEIVED FROM NHS PAIN SERVICE BY THE TIME OF THE FOLLOW-UP QUESTIONNAIRE

Treatment description	N ^o	%
Null	78	1%
Advice	570	6%
Complementary therapy	325	3%
Further investigation (includes MRI/blood tests/X-ray)	125	1%
Injections	1,614	17%
Medication	5,336	56%
Neuro-modulation (includes TNS / spinal cord stimulation)	290	3%
Physiotherapy (includes occupational therapy)	903	9%
Psychology	287	3%
Total	9,528	

The majority had by six months received predominantly medical treatments. The amount of psychology and physiotherapy is very low. This may be a function of the way that clinics operate and requires more in-depth review to understand this fully.

QUALITY OF INFORMATION REGARDING THE RISKS AND BENEFITS OF TREATMENT

	Risks	Benefits
Poor	565	571
Satisfactory	1,383	1,445
Good	1,477	1,498
Excellent	686	616
Other	11	8
No response	292	276
Total	4,414	4,414

Information on risks (N^o = 4,111) and on benefits (N^o = 4,130) was rated similarly. Just over 50% of respondents described the information as good or excellent on risks and benefits, and a further 35% described it as satisfactory. 14% described information on risks or benefits of treatment as poor.

SATISFACTION WITH INVOLVEMENT IN PLANNING CARE

	N ^o
Poor	797
Satisfactory	1,460
Good	1,280
Excellent	581
Other	–
No response	296
Total	4,118

81% of patients (N^o = 4,118) rated themselves as satisfied or very satisfied with their involvement in planning their care, with 19% describing their satisfaction as poor.

DID THE PAIN SERVICE HELP YOU IN UNDERSTANDING AND MANAGING PAIN?

	N ^o	%
No	1,795	41%
Unsure	16	0%
Yes	2,286	52%
No response	317	7%
Other	11	8
No response	292	276

0.18% of patients were admitted to hospital as an emergency following commencement of pain treatments.

Discussion

The National Pain Audit, which ran over three years, was set up in response to findings from successive reports that pain services were struggling to keep up with demand.

The audit has found that people attending specialist services report a very poor quality of life and pose a significant burden on the health service. Yet there is wide variation in provision of specialist care, with 67% of services in England and 70% in Wales falling below recommended minimum staffing standards.

Despite this, patients clearly value the support. To date, epidemiological studies have estimated the prevalence of pain. This is the first time that there has been an extensive attempt to understand the population attending English and Welsh specialist pain clinics and how they fare.

Differences in service provision may occur due to the desire of some PCTs/health boards to ensure that services are located conveniently to patients rather than being centralised, or to the desire to encourage competition. There is a conflict between the sustainability of a multidisciplinary team and a number of small but conveniently located clinics. It may be very confusing for both patients and referrers to understand which clinic to refer to, incurring considerable delay. The National Pain Audit has established a look-up table for patients based upon postcode but such information ought to be more widely available. NHS Choices captures such information and would be a useful repository.

The audit has established useful methodologies to facilitate data collection in predominantly outpatient services. Phase one provider responses totalled 216 in England and 10 in Wales. There were multiple clinics within individual organisations so in total we found 161 providers of specialist pain services in England and Wales.

Many clinics struggled to maintain their engagement with the audit, with 80 completing the whole process. Whether this was due to audit being a low priority or due to time pressure we cannot ascertain. It has been shown with other specialties that engagement is better and data quality improves when a group re-audits.

Data quality is always an issue: we anticipate that technological development will make the process easier and more robust but differing methodologies ought to be considered to look at staffing and treatment pathways.

A key benefit has been that the profile of the British Pain Society has been raised and the need for audit is better appreciated by clinicians. It has also brought about consensus on measures and standards to be applied to pain services.

WAITING TIMES STANDARDS

While coverage was not 100%, it is unlikely that one region will have returned less data than another. Therefore, there is significant variation between regions in terms of pain clinic coverage for the population.

Patients state that the time they waited to be seen is critical to a good experience. Research has established that patients with chronic pain deteriorate while waiting for treatment. The deterioration includes escalating pain and depression and decreased health-related quality of life. In addition, an international survey of IASP presidents and other key informants identified that problems with wait times for appropriate service or with lack of access to service occur in many countries. IASP has therefore defined minimum standards on waiting times as:

- Immediate: acute painful conditions (e.g. sickle cell painful crises and pain related to trauma or surgery).
- Most urgent (one week): a painful, severe condition with the risk of deterioration or chronicity, such as the acute phase of complex regional pain syndrome (CRPS), pain in children, or pain related to cancer or terminal or end-stage illness.
- Urgent or semi-urgent (one month): severe undiagnosed or progressive pain with the risk of increasing functional impairment, generally of six months' duration or less (back pain that is not resolving or persistent post-surgical or post-traumatic pain).
- Routine or regular (eight weeks): persistent long-term pain without significant progression.

EPIDEMIOLOGY AND DEMOGRAPHICS

The epidemiology of pain is poorly understood, and attempts to compile comprehensive epidemiologic data concerning chronic pain have been patchy. Pain in Europe (PIE), a survey throughout Europe based on >46,000 interviews, showed a prevalence of one in five adults with persistent pain and one in three households with someone with chronic pain.

PIE revealed that 43% of those with chronic pain were aged 41–60, comparable to our study where 42% were aged 43–65. The prevalence of pain in the population is equally divided between the sexes but presentation at clinic had a strong female bias (64%). How to engage male patients in processes that may help them needs to be explored. Pain services need to be aware of this and consider ways to better engage men.

Approximately 72% of patients were of working age. The case mix shows that 77% of patients present with musculoskeletal pain so the need for good musculoskeletal assessment and management is imperative for the national economy. However, the prevalence of chronic pain has been estimated at between 45% and 80% among older people, but this was not represented by their numbers in the services, and this needs exploring.

The association between psychological factors and pain has also been confirmed in childhood. Provision for children's pain is sparse and needs addressing through child-focused clinics.

The overall quality of life score using the EQ5D-3L was 0.4 where 1 represents perfect health. This is on a par with enduring neurological disorders such as Parkinson's Disease (0.432). This audit did not seek to ascertain whether patients were suffering from significant other co-morbidities which would contribute to such low scores. However, it is known that there is a positive association of painful conditions with other common morbidities such as cardiovascular disease and depression (Barnett 2012) The UK EQ5D scores catalogue (Sullivan 2011) describes the average EQ5D-3L back pain score (a significant proportion of the cohort) as 0.71 and that of osteoarthritis as 0.595. The scores of this cohort are significantly lower suggesting that significant co-morbidities are present.

Complex management strategies blending a variety of approaches are likely to be required. Collaborative care has been recommended for those with multi-morbidity. It is hard to see how fragmented services in some places such as we found could achieve this. Further work is needed to understand the case mix of pain services that incorporates determination of multimorbidities.

MULTIDISCIPLINARY TEAM STANDARDS

Multidisciplinary teams are essential to deal with complex patients who have a variety of health needs. The Good Practice Guide to Chronic Pain Management published by the Faculty of Pain Medicine of the Royal College of Anaesthetists recommends close multidisciplinary team working. The audit found that the definition of multidisciplinary varied widely and we recommend a stricter definition in relation to staffing.

A better understanding of how teams function is needed, including how many teams have protected time to foster good team working. It was unclear from this audit whether protected clinical time is available to teams to ensure they function as a multidisciplinary team. This could feature in successive audits.

People with chronic pain who require specialist care have, by definition, been unsuccessfully treated by their GPs. A significant number will have severe pain and not be amenable to pain relief available from most GPs, and a significant number are likely to be both severely physically and psychologically disabled by their pain. Therefore, a range of specialist skills is required along with clear lines of accountability.

If relevant specialist staff are not available, then the case mix must be reduced accordingly to exclude those

with significant emotional distress, taking complex mixtures of medicines or requiring interventional pain management. Around three-quarters of responding pain services had a consultant physician to support medication management and interventional pain medicine. This suggests that around a quarter of services may not have consultant support, despite offering complex interventions and treatments. Given the complexity of case mix and risk of significant harm if complex treatments do not have senior input, this is worrying. A detailed peer review audit may clarify working arrangements better.

Pain medicine is the only profession involved in pain management in the UK to have an examination (run by the Faculty of Pain Medicine at the Royal College of Anaesthetists) to ascertain competency to practise pain medicine. The Faculty has also developed a clear set of standards to support re-validation. Standards for physiotherapists working in pain management date from 1996. Training courses for physiotherapists are provided for pain management but none is designed to test competency and none is based on any accepted guidelines.

Psychologists have no specific standards or recognised qualification beyond variable teaching and supervised practice during their generic training.

“This lack of provision is concerning, as psychological distress has long been recognised as a consistent accompaniment of chronic pain.”

The audit committee found the low numbers of psychologists and physiotherapists surprising. This lack of provision is concerning, as psychological distress has long been recognised as a consistent accompaniment of chronic pain, both as a precursor and, more importantly, as a consequence. Our respondents showed both high levels of anxiety and depression, with just under half the clinics in England and just over half the clinics in Wales having no psychologist as part of the team. The CSAG report in 2000 suggested a pathway for rehabilitation which included physiotherapist and psychologist, but across the country this has not been applied.

by results. Appendices 9–11 show the overall codes used. Appendix 10 ought to be considered for addition to the overall pain map of codes.

The information collected from the codes shows the high prevalence of musculoskeletal disorder presentations in the clinics. Indeed, many descriptors were variants of spinal pain. Thus it appears that pain clinics are being commissioned (or are providing) care almost exclusively for people with back pain.

There are many services for people with low back pain available in primary care and many guidelines exist to support care. The British Pain Society has recently

“... it appears that pain clinics are being commissioned (or are providing) care almost exclusively for people with back pain.”

The problem of low numbers of psychologists and physiotherapists is also attributable to the specialties themselves, as neither has a designated specialist group that determines standards of knowledge, skills or training. Also, as a consequence of the low status of physical health problems within clinical psychology, relatively few psychologists are interested in entering the specialty.

DIAGNOSTIC CLASSIFICATION STANDARDS

The National Pain Audit's vision was to compare outcomes for various clinical conditions. The conditions were grouped into the International Classification of Diseases (ICD-10 structure).

The ICD is the standard diagnostic tool for epidemiology, health management and clinical purposes. It is used to monitor the incidence and prevalence of diseases and other health problems, and for reimbursement and resource allocation decision-making.

The clinicians who completed the first assessment were asked to submit an ICD code or a clinical description. The clinicians were unused to the rigor of the classifications and there was a larger than desirable number of descriptors submitted.

When designing the study, in addition to ICD-10 coding which was felt to be restrictive, it was decided to allow free descriptive text on diagnosis to capture any data limitation within the ICD-10 classification. It had been felt at audit pilot stage that ICD-10 was restrictive. This led to a large amount of free text data entry which had to be reclassified within the ICD-10 coding by members of the scientific committee.

It was felt that most of the free text descriptors could be coded within the current ICD code classification. Clinicians are to be encouraged to work within the ICD-10 classification framework as they are crucial to generation of HRG codes for treatment interventions under payment

published care maps to support these in more detail via Map of Medicine. Yet this audit suggests that the needs of people with back pain are not being adequately met by primary care services.

The pathway from initial contact with health services to specialist pain care needs to be audited to understand where problems arise and the pathway could be developed using the joint PROMS and case mix methodology devised in this audit. Equally, other areas of need, such as widespread pain, neuropathic pain, pelvic pain and headache, could also usefully be audited to understand whether better access to specialist advice is needed using the care mapping approach and methodologies of this audit.

TREATMENT CLASSIFICATION STANDARDS

The scope of treatments covered and how they are described is too narrow. There needs to be coding to incentivise and capture team discussions of patients (virtual clinics or MDT as for palliative care) and a code for information advice and guidance, since it forms such an important and significant part of workload.

PROMS STANDARDS

Six months after their first appointment, patients who had consented to the audit were contacted and questioned about their outcomes. This process awakened in some patients a feeling of abandonment and they contacted the Dr Foster group to say they had had no treatment, raising ethical concerns on the part of the audit organisers. This was addressed through the governance processes and the conclusion was that delays in expected treatment were an important issue to highlight. While guidance on referral to treatment standards has been published, it appears that this has not been achieved. This would benefit from further exploration.

The overall response rate was not as good as hoped for at 34%. The patients were questioned at six months, but their replies suggest that this was probably too soon, as improvement often takes longer.

A notable issue was that very few patients had seen a psychologist within this time. The issue of sparse psychological care within the six months may be a result of few clinics having true MDT assessment at the first appointment and instead relying on a slow internal referral process. Or it may be that psychology is so underprovided that waiting times are more than six months. This requires further exploration in future audits.

Further research is needed on the cost effectiveness of multidisciplinary CBT to enable commissioners to make decisions about where to ensure return on investment.

Changes at follow-up on the EQ5D are smaller than in BPI interference – a roughly similar outcome. The important difference is that the BPI interference scale asks patients specifically about problems associated with pain, whereas the EQ5D takes a broader and cruder approach to quantifying problems in five domains without explicit reference to pain, so its smaller changes were not surprising.

Using the adjusted average health gain (Appendix 5), 70.6% of the clinics reported an overall improvement, represented by a negative number, in BPI pain severity score, with a mean of -0.22 and standard deviation of 0.59. For BPI interference, 76.5% of the clinics reported a mean improvement, again represented by a negative number with a mean of -0.37 and s.d. 0.66. This is not weighted by the number of patients providing a response from each clinic.

However, given that half a standard deviation on such scales often represents significant improvement, this is achieved by three-quarters of the clinics in pain interference, and by nearly that number in pain severity. Using

this rule of thumb, however, assumes a normal distribution which neither BPI pain severity nor interference approximated by strict standards, but is perhaps adequate for the purpose of the audit.

81% of patients reported that pain services involved them fully in planning care. Given the highly personal and distressing nature of chronic pain, such practice is to be applauded. However, a substantial number continued to report difficulty in understanding their condition. Given the poor understanding generally of chronic pain and bearing in mind the impact pain often has on cognitive function, this suggests that pain services need to find comprehensive ways of delivering this information. We felt, however, that pain services overall reached a satisfactory standard on this.

The number of emergency healthcare visits and GP visits made prior to attendance at a pain service was very high. While it is well known that people in pain attending in A&E services report poor provision of quality information and help for their pain, this suggests that there is a significant unmet need that is placing a high burden of care on already stretched parts of the NHS.

Patients reported a significant drop in visits to A&E units after attendance at a pain service (16% to 9%), though results need to be interpreted with caution due to the high number of non-responders at follow-up for this question and the fact that it was based upon recall. It may be that pain services meet some of the urgent care needs, and/or that the patient became more able to manage his/her own pain. Access arrangements need to be more flexible and better standards applied to ensure that the burden on urgent care services is less. Prospective data is needed on healthcare utilisation of people with chronic pain both in general and to understand the impact of specialist pain services.

“Access arrangements need to be more flexible and better standards applied to ensure that the burden on urgent care services is less.”

Conclusions

Overall, patients report that specialist pain services in England and Wales perform well in helping them feel involved in treatment decisions. Many services also help patients enjoy a better quality of life and reduce the burden of care elsewhere.

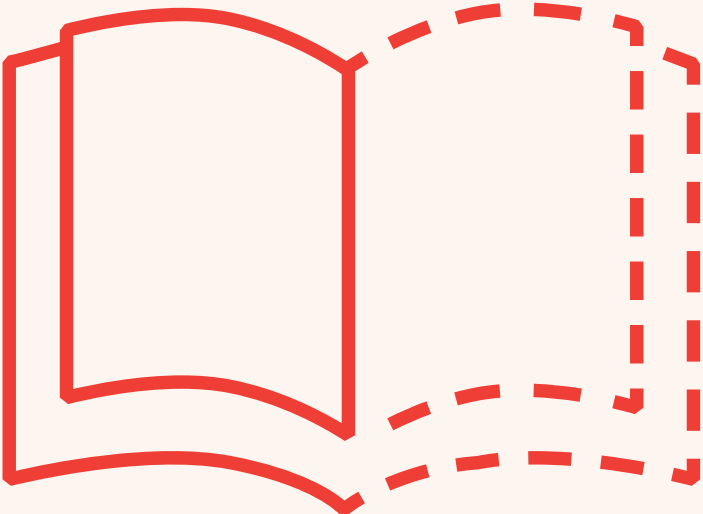
However, many people with chronic pain attending such pain services endure a very low quality of life compared to all health conditions in the UK. Further information on other conditions that a patient may be suffering from is needed.

Waiting times, however, appear to be long, especially for definitive treatment. Commissioners of healthcare need to ensure adoption of standards of good practice such as suggested by the Faculty of Pain Medicine of the Royal College of Anaesthetists. Adoption of the IASP waiting time standards for more urgent cases may have an impact on unscheduled visits.

Future audits should seek to improve quality of diagnostic coding, and to clarify staffing arrangements,

which may cross usual divisions between providers, sites or treatment content. Other morbidities that may be contributing to quality of life also need to be recorded. Pathways of care for patients arriving at specialist pain services need to be better mapped to understand which upstream provision is lacking. The number of emergency visits and level of visits suggest significant gaps, but further exploration is necessary.

More formal research is needed to define best practice pathways that offer fully informed choice to patients and that constitute cost-effective optimal models of care. Given the high level of need expressed by patients and the services, such research could usefully be commissioned by NIHR.



Appendix 1

Providers participating in the National Pain Audit

	Provider name	Sites
	Abertawe and Bro Morgannwg HB	1
RBS	Alder Hey Children's NHS Foundation Trust	1
	Aneurin Bevan Health Board	
RTK	Ashford and St Peter's Hospitals NHS Trust	1
RF4	Barking, Havering and Redbridge Hospitals NHS Trust	2
RNJ	Barts and The London NHS Trust	1
RDD	Basildon and Thurrock University Hospitals NHS Foundation Trust	1
RN5	Basingstoke and North Hampshire NHS Foundation Trust	1
	Betsi Cadwaladr HB	3
5PG	Birmingham East and North PCT	1
RXL	Blackpool Fylde and Wyre Hospitals NHS Foundation Trust	1
5HQ	Bolton PCT	2
5NY	Bradford and Airedale Teaching PCT	1
RAE	Bradford Teaching Hospitals NHS Foundation Trust	1
RXH	Brighton and Sussex University Hospitals NHS Trust	2
	Bronllys HB	
RXQ	Buckinghamshire Hospitals NHS Trust	2
RWY	Calderdale and Huddersfield NHS Foundation Trust	2
RGT	Cambridge University Hospitals NHS Foundation Trust	1
	Cardiff and Vale HB	2
	Central Manchester University Hospitals NHS Foundation Trust	
RQM	Chelsea and Westminster Hospital NHS Foundation Trust	1
RFS	Chesterfield Royal Hospital NHS Foundation Trust	1
5C3	City and Hackney Teaching PCT	1
RLN	City Hospitals Sunderland NHS Foundation Trust	1
REN	Clatterbridge Centre for Oncology NHS Foundation Trust	1
RDE	Colchester Hospital University NHS Foundation Trust	3
RJR	Countess of Chester Hospital NHS Foundation Trust	1
RXP	County Durham and Darlington NHS Foundation Trust	2
	Cwm Taf HB	1
RN7	Dartford and Gravesham NHS Trust	1
RP5	Doncaster and Bassetlaw Hospitals NHS Foundation Trust	1
RBD	Dorset County Hospital NHS Foundation Trust	1
RC3	Ealing Hospital NHS Trust	1
RWH	East and North Hertfordshire NHS Trust	2
RVV	East Kent Hospitals University NHS Foundation Trust	2

	Provider name	Sites
RXR	East Lancashire Hospitals NHS Trust	1
RXC	East Sussex Hospitals NHS Trust	2
5QA	Eastern and Coastal Kent PCT	1
RVR	Epsom and St Helier University Hospitals NHS Trust	1
RDU	Frimley Park Hospital NHS Foundation Trust	1
RR7	Gateshead Health NHS Foundation Trust	1
RLT	George Eliot Hospital NHS Trust	1
RTE	Gloucestershire Hospitals NHS Foundation Trust	1
RN3	Great Western Hospitals NHS Foundation Trust	1
RJ1	Guy's and St Thomas' NHS Foundation Trust	1
HCHC	Hampshire Community Health Care	1
RR1	Heart of England NHS Foundation Trust	1
RD7	Heatherwood and Wexham Park Hospitals NHS Foundation Trust	1
RQX	Homerton University Hospital NHS Foundation Trust	1
RWA	Hull and East Yorkshire Hospitals NHS Trust	1
5NX	Hull Teaching PCT	1
RYJ	Imperial College Healthcare NHS Trust	2
RGQ	Hywel Dda HB	2
5QT	Ipswich Hospital NHS Trust	1
RGP	Isle of Wight NHS Primary Care Trust	1
RNQ	James Paget University Hospitals NHS Foundation Trust	1
RJZ	Kettering General Hospital NHS Foundation Trust	1
RAX	King's College Hospital NHS Foundation Trust	1
RXN	Kingston Hospital NHS Trust	1
RY6	Lancashire Teaching Hospitals NHS Foundation Trust	1
RR8	Leeds Community Healthcare NHS Trust	1
5PA	Leeds Teaching Hospitals NHS Trust	2
REP	Leicestershire County and Rutland PCT	2
RC9	Liverpool Women's NHS Foundation Trust	1
RWF	Luton and Dunstable Hospital NHS Foundation Trust	1
RPA	Maidstone and Tunbridge Wells NHS Trust	1
5PX	Medway NHS Foundation Trust	1
RJD	Mid Essex PCT	2
RXF	Mid Staffordshire NHS Foundation Trust	2
RNH	Mid Yorkshire Hospitals NHS Trust	2
RM1	Newham University Hospital NHS Trust	1
RVJ	Norfolk and Norwich University Hospitals NHS Foundation Trust	1
RNL	North Bristol NHS Trust	1
TAN	North Cumbria University Hospitals NHS Trust	2
RAP	North East Lincolnshire Care Trust Plus	1
RVW	North Middlesex University Hospital NHS Trust	1
RV8	North Tees and Hartlepool NHS Foundation Trust	2
RNS	North West London Hospitals NHS Trust	2
RBZ	Northampton General Hospital NHS Trust	1
RJL	Northern Devon Healthcare NHS Trust	1
RTF	Northern Lincolnshire and Goole Hospitals NHS Foundation Trust	1
5EM	Northumbria Healthcare NHS Foundation Trust	4
RX1	Nottingham City PCT	1
RTH	Nottingham University Hospitals NHS Trust	1

	Provider name	Sites
RGM	Oxford Radcliffe Hospitals NHS Trust	1
RW6	Papworth Hospital NHS Foundation Trust	1
RGN	Pennine Acute Hospitals NHS Trust	4
RK9	Peterborough and Stamford Hospitals NHS Foundation Trust	1
5F1	Plymouth Hospitals NHS Trust	1
RD3	Plymouth Teaching PCT	1
5FE	Poole Hospital NHS Foundation Trust	1
RHU	Portsmouth City Teaching PCT	1
RL1	Portsmouth Hospitals NHS Trust	1
RHW	Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	1
RMC	Royal Berkshire NHS Foundation Trust	2
RT3	Royal Bolton Hospital NHS Foundation Trust	1
REF	Royal Brompton and Harefield NHS Foundation Trust	2
RH8	Royal Cornwall Hospitals NHS Trust	1
RAL	Royal Devon and Exeter NHS Foundation Trust	1
RQ6	Royal Free Hampstead NHS Trust	1
RBB	Royal Liverpool and Broadgreen University Hospitals NHS Trust	1
RAN	Royal National Hospital for Rheumatic Diseases NHS Foundation Trust	1
RA2	Royal National Orthopaedic Hospital NHS Trust	1
RD1	Royal Surrey County Hospital NHS Trust	1
5F5	Royal United Hospital Bath NHS Trust	1
RXK	Salford Royal NHS Foundation Trust	2
5PF	Salisbury NHS Foundation Trust	1
RCC	Sandwell and West Birmingham Hospitals NHS Trust	1
5NJ	Sandwell PCT	1
RCU	Scarborough and North East Yorkshire Health Care NHS Trust	1
RHQ	Sefton PCT	1
RK5	Sheffield Children's NHS Foundation Trust	1
5M2	Sheffield Teaching Hospitals NHS Foundation Trust	1
5QL	Sherwood Forest Hospitals NHS Foundation Trust	1
RA9	Shropshire County PCT	1
RYQ	Somerset PCT	2
RTR	South Devon Healthcare NHS Foundation Trust	1
RJC	South London Healthcare NHS Trust	3
RHM	South Tees Hospitals NHS Foundation Trust	3
RAJ	South Warwickshire General Hospitals NHS Trust	1
RVY	Solent Healthcare Community Trust	1
RJ7	Southampton University Hospitals NHS Trust	1
RBN	Southend University Hospital NHS Foundation Trust	1
RWJ	Southport and Ormskirk Hospital NHS Trust	1
RTP	St George's Healthcare NHS Trust	1
RMP	St Helen's and Knowsley Hospitals NHS Trust	1
RBA	Stockport NHS Foundation Trust	1
RNA	Surrey and Sussex Healthcare NHS Trust	1
RAS	Tameside Hospital NHS Foundation Trust	1
RJ2	Taunton and Somerset NHS Foundation Trust	1
RTD	The Dudley Group of Hospitals NHS Foundation Trust	1
RQW	The Hillingdon Hospital NHS Trust	1
RCX	The Lewisham Hospital NHS Trust	1

	Provider name	Sites
RDZ	The Newcastle Upon Tyne Hospitals NHS Foundation Trust	1
RPY	The Princess Alexandra Hospital NHS Trust	2
RRJ	The Queen Elizabeth Hospital King's Lynn NHS Trust	1
RL4	The Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust	1
RXW	The Royal Marsden NHS Foundation Trust	1
RET	The Royal Orthopaedic Hospital NHS Foundation Trust	1
5C4	The Royal Wolverhampton Hospitals NHS Trust	1
RM4	The Shrewsbury and Telford Hospital NHS Trust	1
RWD	The Walton Centre NHS Foundation Trust	1
RRV	Tower Hamlets PCT	1
RRK	Trafford Healthcare NHS Trust	1
RJE	United Lincolnshire Hospitals NHS Trust	3
RM2	University College London Hospitals NHS Foundation Trust	1
RA7	University Hospital Birmingham NHS Foundation Trust	1
RKB	University Hospital of North Staffordshire NHS Trust	2
RWE	University Hospital of South Manchester NHS Foundation Trust	1
RTX	University Hospitals Bristol NHS Foundation Trust	1
RBK	University Hospitals Coventry and Warwickshire NHS Trust	1
RWG	University Hospitals of Leicester NHS Trust	1
RGR	University Hospitals of Morecambe Bay NHS Trust	1
5P6	Walsall Hospitals NHS Trust	1
RYR	West Hertfordshire Hospitals NHS Trust	5
RGC	West Suffolk Hospitals NHS Trust	1
RKE	West Sussex PCT	2
RN1	Western Sussex Hospitals NHS Trust	1
5NK	Whipps Cross University Hospital NHS Trust	1
RBL	Whittington Hospital NHS Trust	1
RWP	Winchester and Eastleigh Healthcare NHS Trust	1
RRF	Wirral PCT	1
RA4	Wirral University Teaching Hospital NHS Foundation Trust	1
RCB	Worcestershire Acute Hospitals NHS Trust	1
	Wrightington, Wigan and Leigh NHS Foundation Trust	1
	Yeovil District Hospital NHS Foundation Trust	1
	York Hospitals NHS Foundation Trust	1

Appendix 2

Data items collected

CASE MIX

- Date of birth
- Sex
- Diagnosis codes [ICD-10]: three-level code overall and report more common four-level codes where >5% of patients on average
- Type of pain = nociceptive/neropathic/mixed/unknown (should be one of)
- Duration of pain/symptoms in years analysed by <1 year, >1 year
- Source: from GP/other/consultant (should be one of)
- Intended treatment plan

PATIENT REPORTED OUTCOME MEASURES

Pain-specific Patient Reported Outcome Measure brief pain inventory short form.

GENERIC PATIENT REPORTED OUTCOME MEASURE

The EQ-5D descriptive system comprises five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each dimension has three levels: no problems, some problems, severe problems. The respondent is asked to indicate his/her health state by ticking (or placing a cross) in the box against the most appropriate statement in each of the five dimensions. This decision results in a one-digit number expressing the level selected for that dimension. The digits for five dimensions can be combined in a five-digit number describing the respondent's health state.

The EQ VAS records the respondent's self-rated health on a vertical, 20cm visual analogue scale where the endpoints are labelled 'Best imaginable health state' and 'worst imaginable health state'. This information can be used as a quantitative measure of health outcome.

ACCESS

- How easy was it for you to find out about your local pain services?
- 0–10 score (numerical rating scale)

DURATION OF PAIN

- When did you first seek medical help for your pain condition? (In years)

WORK STATUS

- Does the pain prevent you from working or being able to seek work? Y/N
- If you are in work have you had to reduce your hours due to your pain? Y/N

Healthcare resource use:

- Is this your first attendance at the pain facility? Y/N
- Due to your pain have you received medical treatment within the NHS in the past six months? Y/N/NA
- If Yes, did this treatment include a visit or visits to: General Practice (GP), hospital A&E department, physiotherapy, other

Appendix 3

Data collection schedule

	March 2010	April 2010	January 2011	May 2011	September 2011	January 2012	June 2012
Launch of pain audit							
Collection of provider questionnaire							
Piloting of data collection							
Collection of case mix data/ PROMS form clinics							
Collection of outcomes data							
Data analysis							

Appendix 4

Number of services participating in all three phases and percentage submitting final complete questionnaire

Original source	Original completed questionnaires	Completed follow-ups	% completed follow-up questionnaires 3 Aug 2012
Addenbrooke's Hospital	158	57	36.1
Barnsley Hospital	33	16	48.5
Basingstoke and North Hampshire Foundation Trust	53	16	30.2
Bognor Regis War Memorial Hospital	103	51	49.5
Broomfield Hospital	262	43	16.4
City Hospital Sandwell and West Birmingham Hospital	253	134	53
Colchester General Hospital	135	57	42.2
Conquest Hospital East Sussex	96	35	36.5
Countess of Chester Hospital	13	7	53.8
Cumberland Infirmary	127	57	44.9
Derriford Hospital	141	65	46.1
Dewsbury Hospital	97	49	50.5
Dove Primary Care Centre	159	50	31.4
Eastbourne District General Hospital	137	70	51.1
George Elliot Hospital	111	60	54.1
Gloucestershire Royal Hospital	73	9	12.3
Grantham and District Hospital	39	21	53.8
Great Ormond Street Hospital	17	1	5.9
Great Western Hospital	105	33	31.4
Ipswich Hospital	156	72	46.2
James Cook University Hospital	175	71	40.6
King's Mill Hospital	139	42	30.2
Kingston Hospital	236	100	42.4
Leicester Royal Infirmary	44	13	29.5
Lincoln Hospital	120	65	54.2
Luton and Dunstable Hospital	55	9	16.4
Montagu Hospital	268	53	19.8
North Manchester General Hospital	494	186	37.7
Northampton General Hospital	92	27	29.3
Northern General Hospital	12	4	33.3
Nottingham City Hospital	36	13	36.1
Orsett Hospital	127	48	37.8
Pain Management Centre, Norwich	223	123	55.2

Original source	Original completed questionnaires	Completed follow-ups	% completed follow-up questionnaires 3 Aug 2012
Pontefract Hospital	128	62	48.4
Poole Hospital	36	19	52.8
Queen Alexandra Hospital	158	67	42.4
Queen Elizabeth Hospital	19	9	47.4
Queen Mary's Hospital	137	55	40.1
Royal Bournemouth Hospital	95	49	51.6
Royal Cornwall Hospital	199	76	38.2
Royal Cornwall Hospitals Trust	143	61	42.7
Royal Free Hospital	58	21	36.2
Royal National Hospital for Rheumatic Diseases	23	3	13
Royal National Orthopaedic Hospital	85	31	36.5
Royal Preston Hospital	233	96	41.2
Royal Surrey County Hospital	131	64	48.9
Russells Hall Hospital	143	70	49
Salford Royal	180	72	40
Salisbury District Hospital	41	22	53.7
Sheffield Children's Hospital	31	9	29
Solihull Hospital	199	64	32.2
South London Healthacre-Bromley Hospital	108	45	41.7
South Warwick NHS Warwick Hospital	49	10	20.4
Southlands Hospital	18	0	0
St Albans City Hospital	53	26	49.1
St George Centre Leeds	23	10	43.5
St Mary's Hospital	112	21	18.8
St Michael's Hospital Bristol	145	55	37.9
St Peter's Hospital	114	39	34.2
St Thomas' Hospital	68	19	27.9
Sunderland Royal Hospitals	179	76	42.5
Sutton Hospital	141	59	41.8
Tameside General Hospital	112	54	48.2
Tewkesbury Hospital	74	22	29.7
The Churchill Hospital	88	29	33
The Hillingdon Hospital	311	108	34.7
The Queen Elizabeth Hospital	85	16	18.8
The Walton Centre	101	35	34.7
The Yorkshire Clinic	21	6	28.6
Torbay Hospital Pain Clinic	53	25	47.2
Trafford General Hospital	24	10	41.7
University Hospital Coventry and Warwickshire NHS Trust	156	59	37.8
University Hospital of North Tees	134	66	49.3
Velindre Hospital	25	9	36
Wansbeck General Hospital	49	23	46.9
West Suffolk Hospital	106	29	27.4
Withybush Hospital	127	45	35.4
Wythenshawe Hospital	28	10	35.7
York Hospital NHS Foundation Trust	137	79	57.7

Appendix 5

Adjusted health gain models

MODEL ESTIMATION

Three models were estimated for each of the scores: EuroQol 5D, BPI severity and BPI interference. In each case the methodology proceeded similarly. The variables were selected as described on page 20.

The estimation part of the methodology uses a Generalised Least Squares (GLS) fixed effects model. This allows us to adjust for the factors present in the patient's score that the clinic does not have control over. The developed model takes the form:

$$Q2_i = \alpha + \beta_1 Q1_i + x^T \beta_2 + z^T \beta_3 + u_j + \varepsilon_{ij}$$

For patient i at provider j . Here, $Q2$ is the post-score and $Q1$ is the pre-score in the relevant measure (EuroQol 5D, BPI severity and BPI interference scores), x is a vector of patient characteristics, z is a vector of control variables, α is a constant term, u_j is the provider error term, and ε_{ij} is the error term specific to patient i at provider j .

Regression coefficients for the explanatory variables were developed using ordinary least squares (providing an unbiased estimation) but the t -tests of the significance of each coefficient were adjusted to take into account heteroscedasticity (a Breusch-Pagan test rejected the null hypothesis of homogeneity of variance, $p < 0.01$) in the data-set, so that the White-Huber covariance matrices were used to frame the correct t -tests. Normal Q-Q plots reveal a normality of the model residuals. This implements the GLS method.

EuroQol 5D-3L Model

Of the 3,192 patient records used in the follow-up analysis, two were removed due to invalid age. A further 253 records were deleted due to missing overall health (VAS) score in the building of the first model.

Model coefficients were estimated on the remaining data-set. To summarise:

	Estimate	Std. error	t value	Pr(> t)
(Intercept) α	0.11	0.03	3.47	<0.01
Q1	0.49	0.02	26.4	<0.01
Age	0.001	0.0002	4.35	<0.01
Sex (M)	-0.02	0.006	-2.72	<0.01
Walking ability	-0.02	0.001	-12.63	<0.01
ICD-10: G	0.11	0.028	4.03	<0.01
ICD-10: M	0.11	0.027	4.08	<0.01
ICD-10: 0	0.10	0.04	2.6	<0.01
ICD-10: R	0.091	0.03	3.14	<0.01
Overall health state	0.001	0.0002	6.75	<0.01

Clearly, all included variables are significant. In addition the (adjusted) R-squared equals 0.422 (the model explains 42% of the variation in the outcome measure). F-statistic: 239.3 on 9 and 2929 DF, p -value: < 0.001.

BPI Severity Model

54 observations were deleted due to 16 follow-up BPI severity scores and 38 pre-BPI severity scores missing.

Model coefficients were estimated on the remaining data-set. To summarise:

	Estimate	Std. error	t value	Pr(> t)
(Intercept) α	2.47	0.19	12.72	<0.01
Q2	0.59	0.02	27.71	<0.01
Age	-0.0009	0.002	-4.55	<0.01
Walking ability	0.08	0.012	7.07	<0.01
Overall health state	-0.006	0.002	-3.71	<0.01

For this model sex and ICD-10 codes grouped into the four categories described in the last section are not significant (p -value 0.05).

In addition the (adjusted) R-squared equals 0.3861; F-statistic: 457.3 on 4 and 2898 DF, p -value: <0.001.

BPI Interference Model

260 observations were deleted due to missing values, 253 records had missing pre-overall health scores and seven records had missing follow-up BPI-scores.

Model coefficients were estimated on the remaining data set. To summarise:

	Estimate	Std. error	t value	Pr(> t)
(Intercept) α	3.49	0.25	13.95	<0.01
Q2	0.56	0.03	19.0	<0.01
Age	-0.016	0.002	-6.68	<0.01
Walking ability	-0.10	0.02	5.33	<0.01
Overall health state	-0.01	0.002	-7.6	<0.01

As in the previous BPI model, sex and ICD-10 codes grouped into the four categories (described in the last section) are not significant (p -value 0.05).

In addition, the (adjusted) R-squared statistic equals 0.432. F-statistic: 557.3 on 4 and 2927 DF, p -value: <0.001.

Appendix 6

Admission rates to the audit per clinic. (For adjustments see Methods: data analysis)

Provider	PCT	Observed 3 months	Total pop.	Crude rate per 100,000	SAR per 100,000
Manchester and Salford Pain Centre	5F5	165	243,115	67.87	66.22
West Sussex Community Trust	5P6	91	825,235	11.03	9.69
Birmingham East and North Community Trust	5PG	148	446,984	33.11	32.70
Mid Essex Community Pain Service	5PX	86	378,521	22.72	20.23
Chronic Pain Service Isle of Wight NHS PCT	5QT	48	141,256	33.98	29.93
Royal Surrey County Hospital NHS Foundation Trust	5P5	115	1,164,600	9.87	8.15
Bristol Adult Pain Management Service	5QJ	124	464,143	26.72	26.18
Paediatric Chronic Pain Clinic, Bristol Royal Hospital for Children	5QJ	3	464,143	0.65	0.81
Torbay Hospital Pain Clinic	TAL	47	145,796	32.24	25.52
Bradford Royal Infirmary	5NY	14	547,506	2.56	2.62
Royal Free Hampstead NHS Trust	5K7	10	247,907	4.03	4.58
Royal National Orthopaedic Hospital NHS Trust, Stanmore	5K6	84	236,871	35.46	34.71
Pain Clinic, Hillingdon Hospital	5AT	304	273,328	111.22	107.95
Kingston Hospital NHS Trust	5A5	205	188,676	108.65	104.83
Bath Centre for Pain Services, Royal National Hospital for Rheumatic Diseases	5FL	3	194,429	1.54	1.52
Luton and Dunstable NHS Foundation Trust Hospital	5GC	20	210,642	9.49	10.01
York Hospitals NHS foundation Trust	5NV	137	799,796	17.13	65.00
Sheffield Children's Hospital	5N4	31	564,816	5.49	6.63
The Queen Elizabeth Hospital, King's Lynn NHS Trust	5PQ	31	752,745	4.12	3.45
Poole Hospital NHS Foundation Trust	5QN	35	365,426	9.58	8.72
Basildon and Thurrock University Hospitals NHS Foundation Trust	5PY	122	419,493	29.08	27.05
Colchester General Hospital	5PW	115	324,139	35.48	31.51
Royal Bournemouth and Christchurch Hospital	5QN	93	365,426	25.45	21.47
Cornwall and Isles of Scilly PCT	5QP	313	550,074	56.90	51.15
The Walton Centre for Neurology and Neurosurgery NHS Foundation Trust / Pain Clinic	5NL	94	484,742	19.39	17.94
The Ipswich Hospital NHS Trust	5PT	144	617,746	23.31	20.44
Department of Pain Medicine Ipswich	5PT	48	617,746	7.77	6.66
Department of Pain Medicine, Addenbrooke's Hospital	5PP	131	620,686	21.11	19.72
Sheffield Teaching Hospitals NHS Foundation Trust / Pain Management Unit	5N4	8	564,816	1.42	1.31
St Mary's Hospital Portsmouth, Chronic Pain Clinic	5FE	120	212,965	56.35	55.62
Guy's and St Thomas' NHS Foundation Trust / Pain Management Centre	5LE	45	318,948	14.11	16.25
Warwick Hospital	5PM	25	550,196	4.54	3.90

Provider	PCT	Observed 3 months	Total pop.	Crude rate per 100,000	SAR per 100,000
Countess of Chester Hospital NHS Foundation Trust	5NN	13	259,571	5.01	4.19
Sherwood Forest Hospital NHS Foundation Trust / Pain Clinic	5N8	131	666,798	19.65	16.83
Derriford Hospital Pain Clinic	5F1	138	271,319	50.86	46.93
University Hospital Pain Clinic	5MD	131	358,752	36.52	35.65
Sunderland Royal Hospital	5KL	151	284,002	53.17	47.27
George Eliot Hospital NHS Trust	5PM	105	550,196	19.08	16.32
Norfolk and Norwich Pain Management Centre	5PQ	222	752,745	29.49	25.78
University Hospital of South Manchester NHS Foundation Trust	5NT	25	547,395	4.57	5.39
Trafford General Hospital	5NR	23	229,099	10.04	8.52
Tameside Hospital NHS Foundation Trust	5LH	110	239,598	45.91	42.02
Great Western Hospital Pain Management Service	5K3	80	215,647	37.10	35.27
Basingstoke and North Hampshire NHS Foundation Trust	5QC	36	1,320,755	2.73	2.46
Russells Hall Hospital, Dudley	5PE	126	315,100	39.99	35.95
North Cumbria University Hospitals Trust	5NE	124	517,266	23.97	21.60
Northampton General Hospital	5PD	50	705,355	7.09	6.69
Salisbury Foundation Hospital Pain Management Clinic	5QK	41	461,098	8.89	7.38
Barnsley Pain Management Unit	5N5	148	308,194	48.02	44.24
Barnsley Hospital	5N5	33	308,194	10.71	9.53
Heart of Birmingham Pain Management Unit	5MX	165	321,540	51.32	62.80
Queen Elizabeth Hospital	5KF	17	205,161	8.29	7.39
UCL Paediatric Pain Research Centre, Great Ormond Street Hospital for Children	5K7	17	247,907	6.86	8.63
Gloucestershire Pain Management Service	5QH	75	611,406	12.27	10.60
Wansbeck General Hospital	5D8	12	215,001	5.58	5.11
North Tyneside General Hospital	5D8	17	215,001	7.91	6.24
Ponteland Medical Centre	5D8	1	215,001	0.47	0.42
Hexham General Hospital	5D8	3	215,001	1.40	0.89
Pain Relief Unit, Oxford Radcliffe Hospitals	5QE	56	668,920	8.37	7.72
Ashford and St Peter's Hospital Trust	5P5	90	1,164,600	7.73	6.97
The James Cook University Hospital	5KM	102	152,879	66.72	63.15
Friarage Hospital	5KM	32	152,879	20.93	19.88
Sutton Hospital	5M7	138	393,325	35.09	33.13
University of Hartlepool	5D9	130	94,349	137.78	123.27
Royal Oldham Hospital	5J5	150	238,459	62.90	58.93
Fairfield Hospital	5J5	67	238,459	28.10	25.90
North Manchester General Hospital	5J5	224	238,459	93.94	89.69
Lincoln County Hospital	5N9	119	745,532	15.96	14.30
Grantham and District Hospital	5N9	37	745,532	4.96	4.04
University Hospitals of Leicester	5PC	36	356,968	10.08	9.98
St Albans City Hospital	5QV	28	1,175,371	2.38	1.99
Multidisciplinary Pain Clinic St Albans	5QV	26	1,175,371	2.21	2.11
Nottingham University University NHS Trust Pain Management	5EM	31	337,020	9.20	8.69
Eastbourne District General Hospital	5P8	132	183,307	72.01	62.08
Conquest Hospital	5P8	80	183,307	43.64	40.09
Pontefract Hospital	5N3	98	350,955	27.92	24.49
Dewsbury and District Hospital	5N3	89	350,955	25.36	22.59
City Hospital, Sandwell and West Birmingham Hospitals NHS Trust	5MX	252	321,540	78.37	97.09
Lancashire Teaching Hospitals NHS Foundation Trust	5NG	205	468,282	43.78	39.62

Appendix 7

Patients who reported receiving advice on managing their pain, by clinic

HES provider code	Centre	Total replied	Yes
5F5	Manchester and Salford Pain Centre	72	92%
5FE	Portsmouth City Community Chronic Pain Service	17	88%
5NK	Wirral Hospital Pain Management Services	67	85%
5P6	West Sussex Community Service	56	84%
5PG	Birmingham and East North Community Service	53	91%
5PX	Mid Essex Community Pain Service	46	72%
5QT	Chronic Pain Service, Isle of Wight NHS PCT	21	90%
BCUHB	Pain Management Services, Wrexham Maelor Hospital	20	90%
CVUHB	Chronic Pain Management Service, Velindre NHS Trust	9	89%
HDHB	Pain Clinic, Withybush General Hospital	21	95%
RA2	Royal Surrey County Hospital NHS Foundation Trust	62	77%
RA7	Bristol Pain Management Service	52	96%
RA7	Paediatric Chronic Pain Clinic, Bristol Royal Hospital for Children	3	67%
RA9	Torbay Hospital Pain Clinic	25	76%
RAE	Bradford Royal Infirmary	9	89%
RAL	Royal Free Hampstead NHS Trust	6	83%
RAN	Royal National Orthopaedic Hospital NHS Trust	36	78%
RAS	Pain Clinic, Hillingdon Hospital	110	71%
RAX	Kingston Hospital NHS Trust	92	86%
RBB	Bath Centre for Pain Services, Royal National Hospital for Rheumatic Diseases	3	67%
RC9	Luton and Dunstable NHS Foundation Trust Hospital	6	83%
RCB	York Hospitals NHS foundation Trust	79	94%
RCU	Sheffield Children's Hospital Pain Clinic	9	100%
RCX	The Queen Elizabeth Hospital, King's Lynn NHS Trust	70	90%
RD1	Royal United Hospital Bath	20	90%
RD3	Pain Clinic, Poole Hospital NHS Foundation Trust	19	100%
RDD	Basildon and Thurrock University Hospitals NHS Foundation Trust	48	83%
RDE	Colchester General Hospital	58	91%
RDU	Frimley Park Hospital	1	100%
RDZ	Royal Bournemouth and Christchurch Hospital	55	87%
REF	Royal Cornwall Hospitals NHS Trust Pain Clinic	140	90%
RET	The Walton Centre for Neurology and Neurosurgery NHS Foundation Trust / Pain Clinic	19	79%
RFS	Chesterfield Royal Hospital NHS Foundation Trust	58	84%
RGQ	The Ipswich Hospital NHS Trust	74	89%
RGR	Department of Pain Medicine	30	97%

HES provider code	Centre	Total replied	Yes
RGT	Department of Pain Medicine, Addenbrooke's Hospital	65	95%
RHQ	Sheffield Teaching Hospitals NHS Foundation Trust / Pain Management Unit	33	76%
RHU	St Mary's Hospital Portsmouth Chronic Pain Clinic	66	83%
RJ1	Guy's and St Thomas' NHS Foundation Trust / Pain Management Centre	16	88%
RJC	Warwick Hospital	10	90%
RJL	Pain Management Service Scunthorpe	25	76%
RJR	Countess of Chester Hospital NHS Foundation Trust	7	71%
RK5	Sherwood Forest Hospital NHS Foundation Trust / Pain Clinic	54	80%
RK9	Derriford Hospital Pain Clinic	64	98%
RKB	University Hospital Pain Clinic	64	77%
RLN	Sunderland Royal Hospital	71	87%
RLT	George Eliot Hospital NHS Trust	68	82%
RM1	Pain Management Centre	125	85%
RM2	University Hospital of South Manchester NHS Foundation Trust	10	100%
RM4	Trafford General Hospital	17	82%
RMP	Tameside Hospital NHS Foundation Trust	54	87%
RN1	Winchester and Eastleigh Healthcare NHS Trust	22	73%
RN3	Great Western Hospital Pain Management Service	29	93%
RN5	Basingstoke and North Hampshire NHS Foundation Trust	10	100%
RNA	Dudley Group of Hospitals NHS Foundation Trust	69	83%
RNL	North Cumbria University Hospitals Trust	56	82%
RNQ	Kettering General Hospital NHS Foundation Trust	6	67%
RNS	Northampton General Hospital	20	85%
RNZ	Salisbury Foundation Hospital Pain Management Clinic	23	87%
RP5	Doncaster and Bassetlaw Hospitals Foundation Trust	72	82%
RR1	Heart of England Foundation Trust	66	86%
RR7	Queen Elizabeth Hospital	10	100%
RR8	Leeds Pain and Neuromodulation Centre	40	68%
RRF	Wrightington Wigan and Leigh NHS Foundation Trust	58	86%
RRV	UCL Pain Management Centre	93	89%
RRV	UCL Paediatric Pain Research Centre, Great Ormond Street Hospital for Children	1	0%
RTD	Newcastle Upon Tyne Hospitals NHS Foundation Trust	29	79%
RTE	Gloucestershire Hospitals Foundation Trust	28	89%
RTF	Northumbria Healthcare NHS Foundation Trust	23	100%
RTH	Pain Relief Unit, Oxford Radcliffe Hospitals	29	86%
RTK	Ashford and St Peter's Hospital Trust	39	85%
RTR	South Tees Hospitals Foundation Trust	54	90%
RVJ	North Bristol Trust Pain Clinic	1	100%
RVR	Sutton Hospital Cheam	59	83%
RVV	Kent Centre for Pain Medicine	3	100%
RVW	University of Hartlepool Hospitals	68	84%
RW3	Royal Manchester Children's Hospital Pain Clinic	6	100%
RW6	Pennine Acute Hospitals NHS Trust	213	86%
RWD	United Lincolnshire Hospitals NHS Trust County Hospital	86	86%
RWE	University Hospitals of Leicester	13	85%
RWG	West Hertfordshire Hospitals NHS Trust	32	94%
RWP	Worcester Acute Hospitals NHS Trust	86	91%
RX1	Nottingham University University NHS Trust Pain Management	51	82%

HES provider code	Centre	Total replied	Yes
RXC	Eastbourne District General Hospital	70	87%
RXC	Conquest Hospital	35	94%
RXF	Pontefract Hospital	65	95%
RXF	Dewsbury and District Hospital	47	96%
RXH	Brighton and Sussex University Hospitals NHS Trust	12	83%
RXK	City Hospital, Sandwell and West Birmingham Hospitals NHS Trust	135	90%
RXN	Lancashire Teaching Hospitals NHS Foundation Trust	97	91%
RY6	Leeds Community Healthcare Trust	10	100%
RYQ	South London Healthcare Trust	88	89%

Appendix 8

Adjusted average health gain scores (PROMS case mix adjustment methodology) for the scores: EuroQol 5D, BPI severity and BPI interference

*A negative score on the EQ5D/Brief Pain Inventory represents improvement (the higher the score the worse the health state) on the adjusted health gain model.

Provider name	Clinic name	EuroQol 5D	BPI sev	BPI int
Salford Royal NHS Foundation Trust	Manchester and Salford Pain Centre	0.00	-0.48	-0.44
West Sussex PCT	Bognor War Memorial Hospital	0.06	-0.26	-0.48
Birmingham East And North PCT	Multidisciplinary Pain Service	0.01	-0.63	-0.99
Mid Essex PCT	Pain Consultant clinics	0.04	-1.03	-1.59
Isle of Wight NHS PCT	Chronic Pain Service Isle of Wight NHS PCT	0.03	-0.75	-0.77
Cardiff and Vale Health Board	Chronic Pain Management Service, Velindre NHS Trust	-0.04	-0.22	-1.04
Hywel Dda Health Board	Pain Clinic, Withybush General Hospital	-0.03	-0.57	-0.24
Royal Surrey County Hospital NHS Foundation Trust	Royal Surrey County Hospital NHS Foundation Trust	-0.01	0.04	-0.07
University Hospitals Bristol NHS Foundation Trust	Pain Management Service	0.00	-0.77	-0.67
University Hospitals Bristol NHS Foundation Trust	Paediatric Chronic Pain Clinic, Bristol Royal Hospital for Children	-0.08	-0.42	0.41
South Devon Healthcare NHS Foundation Trust	Torbay Hospital Pain Clinic	0.00	-0.60	-0.72
Bradford Teaching Hospitals NHS Foundation Trust	Bradford Royal Infirmary	0.27	-0.55	-1.51
Royal Free London NHS Foundation Trust	Royal Free Hampsstead NHS Trust	0.09	0.31	-0.48
Royal National Orthopaedic Hospital NHS Trust	Royal National Orthopaedic Hospital NHS Trust	-0.05	0.24	0.38
The Hillingdon Hospitals NHS Foundation Trust	Pain Clinic, Hillingdon Hospital	0.03	-0.38	-0.57
Kingston Hospital NHS Trust	Kingston Hospital NHS Trust	0.05	-0.92	-0.59
Royal National Hospital For Rheumatic Diseases NHS Foundation Trust	Bath Centre for Pain Services, Royal National Hospital for Rheumatic Diseases	-0.06	-0.53	0.31
Luton and Dunstable Hospital NHS Foundation Trust	Luton and Dunstable NHS Foundation Trust Hospital	-0.02	-0.33	0.11
York Teaching Hospital NHS Foundation Trust	York Hospitals NHS foundation Trust	0.08	-0.88	-0.39
Sheffield Children's NHS Foundation Trust	Sheffield Children's Hospital Pain Clinic	0.09	-1.09	-1.98
The Queen Elizabeth Hospital, King's Lynn, NHS Foundation Trust	The Queen Elizabeth Hospital, King's Lynn NHS Trust	0.00	-0.17	-0.69
Poole Hospital NHS Foundation Trust	Pain Clinic, Poole Hospital NHS Foundation Trust	0.05	-0.65	-0.51
Basildon and Thurrock University Hospitals NHS Foundation Trust	Basildon and Thurrock University Hospitals NHS Foundation Trust	0.02	0.51	0.04

Provider name	Clinic name	EuroQol 5D	BPI sev	BPI int
Colchester Hospital University NHS Foundation Trust	Colchester General Hospital	0.09	-0.80	-1.01
The Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust	Royal Bournemouth and Christchurch Hospital	0.04	0.19	-0.33
Royal Cornwall Hospitals NHS Trust	Pain Clinic	0.03	-0.26	-0.36
The Walton Centre NHS Foundation Trust	The Walton Centre for Neurology and Neurosurgery NHS Foundation Trust / Pain Clinic	-0.02	-0.32	0.38
Ipswich Hospital NHS Trust	The Ipswich Hospital NHS Trust	0.06	-1.10	-1.31
West Suffolk NHS Foundation Trust	Department of Pain Medicine	0.05	-0.68	-1.24
Cambridge University Hospitals NHS Foundation Trust	Department of Pain Medicine, Addenbrooke's Hospital	0.02	-0.81	-0.56
Sheffield Teaching Hospitals NHS Foundation Trust	Sheffield Teaching Hospitals NHS Foundation Trust / Pain Management Unit	0.10	-0.54	-0.81
Portsmouth Hospitals NHS Trust	St Mary's Hospital Portsmouth, Chronic Pain Clinic	0.02	-0.58	-0.68
Guy's and St Thomas' NHS Foundation Trust	Guy's and St Thomas' NHS Foundation Trust / Pain Management Centre	0.05	0.03	0.42
South Warwickshire NHS Foundation Trust	Warwick Hospital	0.04	-0.23	-0.13
Countess of Chester Hospital NHS Foundation Trust	Countess of Chester Hospital NHS Foundation Trust	-0.13	2.42	-0.16
Sherwood Forest Hospitals NHS Foundation Trust	Sherwood Forest Hospital NHS Foundation Trust / Pain Clinic	-0.06	1.24	1.22
Plymouth Hospitals NHS Trust	Derriford Hospital Pain Clinic	0.06	-0.49	-0.64
University Hospitals Coventry and Warwickshire NHS Trust	University Hospital Pain Clinic	-0.01	-0.43	-0.05
City Hospitals Sunderland NHS Foundation Trust	Sunderland Royal Hospital	-0.04	-0.13	-0.15
George Eliot Hospital NHS Trust	George Eliot Hospital NHS Trust	-0.02	-0.07	-0.15
Norfolk and Norwich University Hospitals NHS Foundation Trust	Pain Management Centre	0.04	-0.75	-0.61
University Hospital of South Manchester NHS Foundation Trust	University Hospital of South Manchester NHS Foundation Trust	-0.02	1.52	0.02
Trafford Healthcare NHS Trust	Trafford General Hospital	0.00	-0.24	-0.41
Tameside Hospital NHS Foundation Trust	Tameside Hospital NHS Foundation Trust	-0.02	0.23	-0.06
Great Western Hospitals NHS Foundation Trust	Great Western Hospital Pain Management Service	0.05	0.55	0.39
Hampshire Hospitals NHS Foundation Trust	Basingstoke and North Hampshire NHS Foundation Trust	0.07	-0.62	-0.72
The Dudley Group NHS Foundation Trust	Russells Hall Hospital	0.00	-0.23	-0.18
North Cumbria University Hospitals NHS Trust	North Cumbria University Hospitals Trust	0.03	-0.40	-0.19
Northampton General Hospital NHS Trust	Northampton General Hospital	0.13	-0.88	-0.84
Salisbury NHS Foundation Trust	Salisbury Foundation Hospital Pain Management Clinic	0.01	-0.26	-0.87
Doncaster and Bassetlaw Hospitals NHS Foundation Trust	Pain Management Unit	0.01	0.61	-0.21
Doncaster and Bassetlaw Hospitals NHS Foundation Trust	Barnsley Hospital	0.04	-0.37	-0.06
Heart of England NHS Foundation Trust	Pain Management Unit	0.02	-0.33	-0.45
Gateshead Health NHS Foundation Trust	Queen Elizabeth Hospital	-0.06	0.57	0.85
University College London Hospitals NHS Foundation Trust	UCL Paediatric Pain Research Centre, Great Ormond Street Hospital for Children	-0.07	0.33	0.73

Provider name	Clinic name	EuroQoL 5D	BPI sev	BPI int
Gloucestershire Hospitals NHS Foundation Trust	Countywide summary sheet	0.06	-0.70	-1.54
Northumbria Healthcare NHS Foundation Trust	Wansbeck General Hospital	0.00	-0.41	-0.06
Northumbria Healthcare NHS Foundation Trust	North Tyneside General Hospital	0.01	0.00	0.03
Northumbria Healthcare NHS Foundation Trust	Ponteland Medical Centre	0.00	-0.74	-3.63
Northumbria Healthcare NHS Foundation Trust	Hexham General Hospital	-0.12	0.37	-0.46
Oxford University Hospitals NHS Trust	Pain Relief Unit, Oxford Radcliffe Hospitals	0.00	-0.06	-0.16
Ashford and St Peter's Hospitals NHS Foundation Trust	Ashford and St Peter's Hospital Trust	0.00	0.04	-0.37
South Tees Hospitals NHS Foundation Trust	The James Cook University Hospital	-0.04	0.02	-0.29
South Tees Hospitals NHS Foundation Trust	Friarage Hospital	-0.08	-0.93	-0.65
Epsom and St Helier University Hospitals NHS Trust	Sutton Hospital	0.02	-0.57	-0.70
North Tees and Hartlepool NHS Foundation Trust	University of Hartlepool	0.02	-0.53	-0.55
Pennine Acute Hospitals NHS Trust	Royal Oldham Hospital	0.00	-0.39	0.01
Pennine Acute Hospitals NHS Trust	Fairfield Hospital	-0.05	-0.08	0.64
Pennine Acute Hospitals NHS Trust	North Manchester General Hospital	-0.06	-0.02	0.52
United Lincolnshire Hospitals NHS Trust	Lincoln County Hospital	0.01	-0.24	-0.42
United Lincolnshire Hospitals NHS Trust	Grantham and District Hospital	-0.05	-0.92	-0.76
University Hospitals of Leicester NHS Trust	University Hospitals of leicester	0.00	0.14	0.05
West Hertfordshire Hospitals NHS Trust	St Albans City Hospital	0.03	-1.08	-0.95
West Hertfordshire Hospitals NHS Trust	Multidisciplinary Pain Clinic	-0.04	0.77	0.28
Worcestershire Acute Hospitals NHS Trust	Worcestershire acute trust	0.00	-0.56	-0.48
Nottingham University Hospitals NHS Trust	Nottingham University NHS Trust Pain Management	-0.01	0.54	0.36
East Sussex Healthcare NHS Trust	Eastbourne District General Hospital	0.01	-0.19	-0.18
East Sussex Healthcare NHS Trust	Conquest Hospital	0.00	0.78	-0.07
Mid Yorkshire Hospitals NHS Trust	Pontefract Hospital	0.02	-0.29	-0.42
Mid Yorkshire Hospitals NHS Trust	Dewsbury and District Hospital	0.08	-0.34	-0.36
Sandwell and West Birmingham Hospitals NHS Trust	City Hospital, Sandwell and West Birmingham Hospitals NHS Trust	0.02	-0.22	-0.06
Lancashire Teaching Hospitals NHS Foundation Trust	Lancashire Teaching Hospitals NHS Foundation Trust	0.00	0.11	-0.17
Leeds Community Healthcare NHS Trust	Nurse-led Pain Clinic	-0.05	-0.45	-0.47
South London Healthcare NHS Trust	South London Healthcare Trust / Bromley Hospitals Pain Relief Clinic	0.05	0.00	-0.27
South London Healthcare NHS Trust	Pain Management Clinic	-0.01	0.63	0.21

Appendix 9

Main diagnostic codes finally used

Code	Description	Code	Description
B330	Epidemic myalgia	H571	Ocular pain
G440	Cluster headache syndrome	H920	Otalgia
G441	Vascular headache, not elsewhere classified	K146	Glossodynia
G442	Tension-type headache	M255	Pain in joint
G443	Chronic post-traumatic headache	M315	Giant cell arteritis with polymyalgia rheumatica
G444	Drug-induced headache, not elsewhere classified	M353	Polymyalgia rheumatica
G448	Other specified headache syndromes	M541	Radiculopathy
G500	Trigeminal neuralgia	M542	Cervicalgia
G501	Atypical facial pain	M543	Sciatica
G521	Disorders of glossopharyngeal nerve	M544	Lumbago with sciatica
G546	Phantom limb syndrome with pain	M545	Low back pain
G564	Causalgia	M548	Other dorsalgia
G570	Lesion of sciatic nerve	M549	Dorsalgia, unspecified
G571	Meralgia paraesthetica	M774	Metatarsalgia
G572	Lesion of femoral nerve	M791	Myalgia
G573	Lesion of lateral popliteal nerve	M792	Neuralgia and neuritis, unspecified
G574	Lesion of medial popliteal nerve	M796	Pain in limb
G575	Tarsal tunnel syndrome	M913	Pseudocoxalgia
G576	Lesion of plantar nerve	N644	Mastodynia
G578	Other mononeuropathies of lower limb	N940	Mittelschmerz
G579	Mononeuropathy of lower limb, unspecified	R070	Pain in throat
G580	Intercostal neuropathy	R071	Chest pain on breathing
G587	Mononeuritis multiplex	R072	Precordial pain
G588	Other specified mononeuropathies	R073	Other chest pain
G589	Mononeuropathy, unspecified	R074	Chest pain, unspecified
G600	Hereditary motor and sensory neuropathy	R101	Pain localised to upper abdomen
G601	Refsum's disease	R102	Pelvic and perineal pain
G602	Neuropathy in association with hereditary ataxia	R103	Pain localised to other parts of lower abdomen
G603	Idiopathic progressive neuropathy	R104	Other and unspecified abdominal pain
G608	Other hereditary and idiopathic neuropathies	R200	Anaesthesia of skin
G609	Hereditary and idiopathic neuropathy, unspecified	R201	Hypoaesthesia of skin
G610	Guillain-Barre syndrome	R202	Paraesthesia of skin
G611	Serum neuropathy	R203	Hyperaesthesia
G618	Other inflammatory polyneuropathies	R208	Other and unspecified disturbances of skin sensation
G619	Inflammatory polyneuropathy, unspecified	R300	Dysuria
G620	Drug-induced polyneuropathy	R309	Painful micturition, unspecified
G621	Alcoholic polyneuropathy	R51X	Headache
G622	Polyneuropathy due to other toxic agents	R520	Acute pain
G628	Other specified polyneuropathies	R521	Chronic intractable pain
G629	Polyneuropathy, unspecified	R522	Other chronic pain
G64X	Other disorders of peripheral nervous system	R529	Pain, unspecified

Appendix 10

Additional pain diagnoses not originally ascribed to pain codes

Code	Description
B022.9	Post-herpetic neuralgia
G893	Neoplasm-related pain
F454	Somatiform pain disorder
G571	Meralgia paraesthetica
G577	Lower limb causalgia
G564	Upper limb causalgia
G890	Central pain syndrome
G894	Chronic pain syndrome with significant psychosocial dysfunction
G577	Lower limb complex regional pain syndrome II
G564	Upper limb complex regional pain syndrome II
G905	Complex regional pain syndrome I
G933	Chronic fatigue syndrome
K628.9	Painful anal scar
M050	Rheumatoid polyneuropathy
M501	Cervical radiculopathy
M533	Sacrococcygeal disorders NEC
M774	Metatarsalgia
M791	Myalgia
M792	Neuralgia NOS
M796	Pain in limb, unspecified
M797	Fibromyalgia
M890	Complex regional pain syndrome I
M891	Complex regional pain syndrome I shoulder
M892	Complex regional pain syndrome I upper arm
M893	Complex regional pain syndrome I forearm
M894	Complex regional pain syndrome I hand
M895	Complex regional pain syndrome I thigh
M896	Complex regional pain syndrome I lower leg
M897	Complex regional pain syndrome I ankle and foot
M940	Tietze's syndrome
M961	Post laminectomy syndrome
R520	Pain unspecified
R100	Abdominal pain
R101	Upper abdominal pain
R102	Pelvic pain
R103	Lower abdominal pain
R203	Hyperaesthesia
R208	Disorder of skin sensation
S134	Whiplash

Appendix 11

Additional codes used but not included as pain codes.

Code	Description
G03.9	Meningitis
G04.89	Craniotomy
G46.1	TIA
G56.0	Carpal tunnel syndrome
K85.0	Pancreatitis
M15.0	Osteoarthritis
M35.3	Polymyalgia rheumatica
M41.9	Scoliosis
M42.1	Osteochondrosis spine
M43.1	Spondylolisthesis
M45.4	Ankylosing spondylitis
M48.0	Spinal stenosis
M54.08	Panniculitis
M70.6	Trochanteric Bursitis
M79.8	Soft tissue disorders
M79.9	Soft tissue disorders, unspecified
M80.0	Osteoporosis with fracture
M80.08	Osteoporosis, vertebral fracture
M94.0	Pseudoarthrosis
N50.9	Disorder of male genitalia
R74.0	Abnormal enzyme levels

Appendix 12

Stakeholders' comments and feedback

MR ANTHONY CHUTER, BRITISH PAIN SOCIETY, PATIENT LIAISON GROUP CHAIR

“Chronic pain is one of those things which can dominate and suffocate people, taking them from living to just existing. This report goes a long way towards bringing to life the reality of living with chronic pain. The difference being that the reader will think about it for a while but those living in chronic pain sometimes never have the privilege of respite or the chance of a life without pain in their future. It can be as if all hope has been turned off.

“Pain services can help, people need them and they can make a huge difference to patients and their families. Without rapid referral to services delivering the best, evidence-based care, patients and their loved ones endure further misery.”

“Chronic pain is one of those things which can dominate and suffocate people, taking them from living to just existing.”

DR BEVERLEY COLLETT, CHRONIC PAIN POLICY COALITION CHAIR

“This audit highlights the detrimental effect that persistent pain has on quality of life and ability to work. It shows how the presence of pain increases the use of general healthcare resources, including emergency departments and GP visits.

“The variable provision of pain management services around the country and the lack of multidisciplinary staff in many services delivering a broad range of effective treatments again reveals a postcode lottery for care. The lack of psychologists and physiotherapists in clinics is surprising when consideration is given to the high prevalence of musculoskeletal conditions and the high rates of psychological co-morbidity seen in these patients.

“This report shows the benefit that can occur after visiting a pain management service in reducing GP visits. There is a clear need to improve the quality of pain services to ensure that people in pain obtain the treatment and support that they need.

“The report highlights that in today’s NHS, persistent pain is not viewed as a significant condition and resources are just not in place in many locations to deal with these patients with complex needs.”

PROFESSOR DAVID ROWBOTHAM, DEAN FACULTY OF PAIN MEDICINE

“The Faculty of Pain Medicine of the Royal College of Anaesthetists is the professional body responsible for the training, assessment, practice and continuing professional development of specialist medical practitioners in the management of pain in the UK. It supports a multidisciplinary approach to pain management, informed by evidence-based practice and research.

“The problem of chronic pain in the UK is well documented and many people experience a very low quality of life because of this. Many are unable to seek work and make a high demand on NHS services. The Faculty of Pain Medicine is committed to improving the training of specialists in pain medicine and other professions to ensure that complex chronic pain and its comorbidities are managed in the best possible way.

“The provision of specialised pain services in the UK has been shown in this audit to be patchy and contributes to the overall morbidity and burden of chronic pain to the individual, their carers, the NHS and the nation as a whole. Much work is needed to provide equity of access of these vital services if we are to make a significant impact.”

“Many [patients] are unable to seek work and make a high demand on NHS services.”

**DR MARTIN JOHNSON, RCGP, CLINICAL
CHAMPION FOR PAIN**

“Despite the fact that the NPA has concentrated on specialist care, the adequate treatment of pain has a significant impact on all forms of care, including primary care. Patients with persistent pain are shown to have high healthcare utilisation, but having attended pain clinics then attend A&E less frequently. Considering that individual practices are being held to account by their CCGs for their patients visits to A&E, this is highly significant.

“Primary care is, not surprisingly, shown to be the biggest source of referral to pain clinics, but we have to continue to develop systems that enable appropriate patients to be sent as early as possible to the appropriate service. Primary care needs to play its part and accurately assess patients with pain, for example using the BPS Assessment pathway and then coding them correctly. I welcome the findings of the NPA and welcome its further extension into community services.”

“Patients with persistent pain are shown to have high healthcare utilisation, but having attended pain clinics then attend A&E less frequently.”

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Design by design to communicate

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