# The National Pain Audit Third Report

## FOCUS ON SAFETY AND OUTCOMES

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The British Pain Society

HQIP
Healthcare Quality
Improvement Partnership

# Foreword

Just over four years ago the British Pain Society made a successful bid to run an audit of specialised pain services throughout England and Wales — the first of its type in the UK. The audit systematically determined the current services available for patients in chronic pain, followed by the types of condition presenting and the impact that this had on their lives. The final part of this audit has determined the safety of services and patient outcome following specialist care in both the short and long term.

The audit has clearly illustrated the devastating impact that chronic pain has on the huge number of individuals with this condition. Specialised services are not available throughout the country and the quality of the service varies considerably.

It is essential that commissioners and NHS providers address this major shortfall by establishing appropriately trained multidisciplinary services in a timely fashion, to prevent the ongoing suffering of such a huge population. There is an urgent need for ongoing audit of services and patient outcome, to confirm that an effective service is being delivered, to confirm that the best care is delivered and that the best use is made of NHS resources.

This work could not have taken place without the dedicated input of Dr Cathy Price leading the clinical group and the support of the Dr Foster team.

**Dr William Campbell**
*President, British Pain society*
October 2013

# Introduction and background

Pain services were developed in response to the recognition in the 1960s that some people in pain may benefit from additional specialist care. Advances in the understanding, prevention and treatment of chronic pain have continued at a pace since then. Specialist pain services have provided a crucial leadership role in advancement of care for people with chronic pain.

The National Pain Audit was set up in response to findings from successive reports that specialist pain services were struggling to keep up with demand. There was clear variation in provision of service, a lack of visibility and no agreed standards of care.

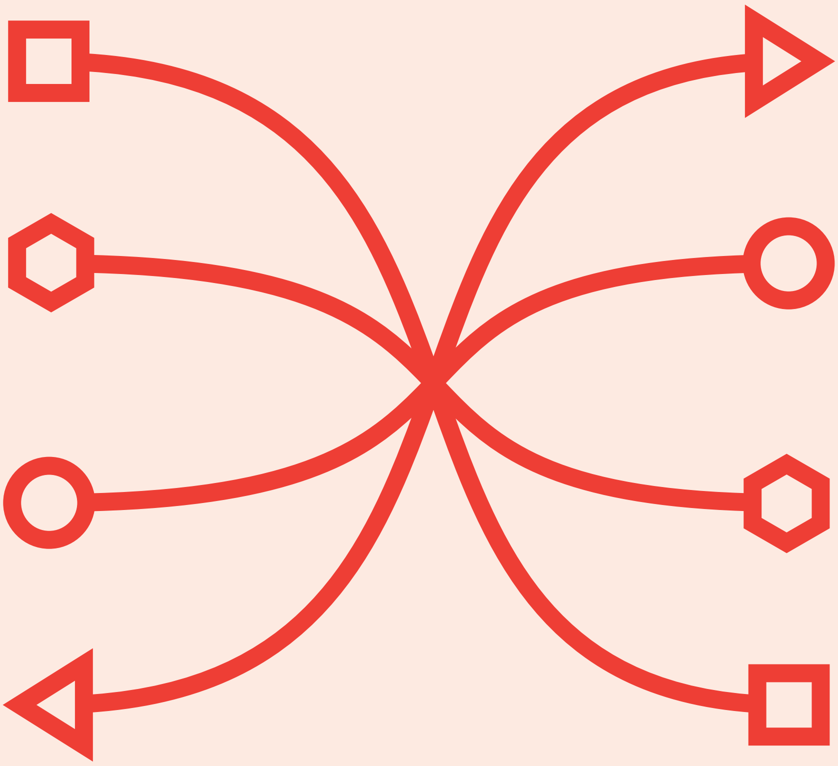
The National Pain Audit has explored the quality of specialist pain services provided to people with long-term pain, sought to evaluate them against known standards and, where necessary, to develop new standards in consultation with clinicians and patients. This audit was commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP). This is the fourth round of the audit.

**PREVIOUS AUDITS HAVE COVERED:**

- Round 1: Organisational arrangements of services audit
- Round 2: Case mix
- Round 3: Outcomes of care
- Rounds 2 and 3 were reported together in the Final Report

This fourth round, an extension of the audit, has examined one-year outcomes of pain service intervention, and sought to understand current models of care that exist and establish which safety procedures are in place to safeguard patients against unexpected sequelae of treatment.

As this was an extension, the audit has used existing methodology established in previous rounds with few additions or changes.



# Executive summary

The National Pain Audit has been an important exercise for the specialty. For the first time, clear standards have been developed and measured, changes recommended then re-audited.

**THE FOURTH ROUND OF THE NATIONAL PAIN AUDIT HAS FOUND:**

- There has been a substantial improvement in participation of services.
- Non-English speakers were poorly represented.
- Multidisciplinary provision appears to be increasing.
- Patients need multi-modal treatment.
- One case study on healthcare usage demonstrated reduced healthcare costs in outpatients but not inpatients.
- 8% of patients are very severely affected by their pain.
- There are some gaps in managing risk.
- There is wide variation in service delivery.

**SOME OF THE UNDERLYING ISSUES IDENTIFIED IN THIS AUDIT ARE:**

- Appropriately skilled staff to deliver treatment are frequently not available.
- Lack of understanding as to deliver highly specialised care is very small, meaning there are is no regional leadership structure in the specialty.
- The necessity of specialist pain services to be cross-cutting in nature and integrated with other services is poorly recognised, meaning access to specialist advice may be delayed.
- The work has not been done to assess the impact of improved pain management on other aspects of the healthcare system.
- Information on pain is not delivered in a way that many patients can grasp the essentials.
- There is no good understanding of optimal models and levels of service provision.

**ACTIONS NEEDED:**

- Competencies developed for non-medical practitioners in pain management.
- Differing levels of service provision that can match to need.
- Guidance on standards of care expected from services.
- A review of best practice in delivery of patient education in pain.
- Clear standards for risk management on assessment of people in pain.
- Better integrated working between services across the healthcare system.
- Subgroup analysis to identify whether some cohorts of patients respond better than others.
- Guidance on best interventions to return people in pain to work.
- An inpatient pain audit to improve quality of pain care in hospitals.

# Recommendations

## SERVICES

- A model service specification for specialist services (i.e. services commissioned by Clinical Commissioning Groups) is urgently needed. The service specification needs to be independent of setting and integrated with other specialties and providers, with clear treatment protocols in place. The Faculty of Pain Medicine is currently revising its recommendations and it would be helpful to include these.
- Safety protocols need to be reviewed in many services to ensure that mental health risk assessment and a full case review of missed diagnoses are included and that training is given to identify and manage those at risk. This requires discussion with the National Health Service Special Commissioning Board as patient safety now falls within its remit.
- As pain occurs across many if not all branches of medicine, multispecialty clinics and specialist non-anaesthetist led activity requires application of the treatment function code 191 while retaining background specialty. Guidance is needed from the Health & Social Care Information Centre on this.
- Specialised pain services need to work in an integrated fashion across a wide geographical area as virtually no single provider has the capability to manage patients at the severe and highly specialised end of the spectrum such as those patients presenting with highly complex needs. Options to achieve this are currently being scoped by the Specialised Pain Services Clinical Reference Group.
- There needs to be clearer linkage of level of services to patient need. A classification of services, such as that described for neuro-rehabilitation services, may be useful.
- Clinics need to audit patients’ understanding of persistent pain and of treatment options. This could be included in the Royal College of Anaesthetists Audit Recipe Book.
- Services should link with vocational rehabilitation experts and occupational health physicians to develop new ways of working that would return people to work. The Chronic Pain Policy Coalition is currently developing this, subsequent to the first English National Pain Summit.

## STANDARDS

- Standards that have been demonstrated as feasible to collect and measure data that are meaningful should be reviewed and considered for more formal adoption by bodies with responsibility for quality improvement e.g. NICE, Royal Colleges.
- Non-medical healthcare professions such as Physiotherapy, Nursing and Psychology should develop National Occupational Competencies with Skills for Health. The British Pain Society could usefully co-ordinate this development.

## FUTURE AUDITS

- Should build upon the extensive learning from this audit with regards to clinical engagement, governance, methodology, recruitment and sampling.
- Need to improve the case-mix adjustment to allow meaningful comparisons between providers.
- Need to improve diagnosis coding.
- Should include comorbidity to improve case-mix adjustment.
- Should assess if appropriately skilled staff are available to deal with complex pain problems.
- Need to have permission to use NHS numbers to allow data linkage, to identify and track patient across service, capture comorbidity and healthcare resource use.
- Should investigate the contribution of specialties other than Anaesthetics to pain medicine.

# Patient summary

The audit is all about the people that the service looks after and about what happens to them in the service, with the goal of learning how to provide pain relief and to help individuals live with their pain. This audit has shown that many parts of the country have poor provision for people living with pain.

The audit does show that multi-component treatments are better but these need to fit the patient's needs rather than to be provided in a single format. Some patients need regular attendance at a specialist service to manage their pain effectively. Some are very severely affected by their pain and it is not clear how their needs are being met. Most have a very poor quality of life with work most affected.

In contrast, staffing levels that can deliver multidisciplinary treatment are inadequate in many clinics and cannot be ignored. The number of clinics setup for specialised care is too low, meaning there is no regional leadership. Worryingly low numbers of non-English people are accessing pain services.

Patients need information about a service to be able to ask for it and need good information at a rate that is right for them. The audit found that many people do get the right information and it was helpful; however a substantial minority do not. This needs more work.

Developing a cycle of continuous audit, evaluation, consultation, implementation and audit again takes courage and leadership, as does making changes that are indicated by the findings. It also takes humility to evaluate something you have developed over time and to pull it apart (gently) to examine how it works and if it can be improved. The participation rates of services in this audit were excellent; the will to be under the microscope was admirable.

Patients can now look up how their clinic is doing on the *Find a Clinic* pages and work out if a clinic near them is in a position to help them in the way they choose. This is a significant step forward.

> *"Most patients think the NHS is the same all over. The National Pain Audit is proof that this is not true and has highlighted the poor quality of life that people living with pain experience"*

# Finding of the previous National Pain Audit rounds

In total, 161 pain clinics were located in the audit. Some PCTs had multiple providers within the same locality, but 28 PCTs did not appear to have any pain services. Just 91 clinics (56% of those identified) returned information in Round 2 on 9,588 patients who completed the questionnaires about themselves and the impact of pain on their lives. In Round 3, 4,414 patients returned follow-up questionnaires six months after their initial assessment; 3,192 of these were complete and provided a good understanding of what is happening to patients in 80 of these services.

*The key findings of the previous audit Rounds 2 and 3 were:*

- **Quality of life among patients attending specialist pain services is poor and is improved by these services:** The overall mean quality of life score (EQ5D-3L) of 0.4 represents severe impairment, and is lower than many individual long term conditions. This low score might be attributed to the collective impact of the comorbidities present in these complex cases. In total, 56% of providers reported post-treatment improvement in EQ5D-3L score, and 76% reported improvement specifically in pain-related quality of life.
- **Healthcare resource utilisation is high:** 16% of respondents reported visiting A&E to seek help in the six months prior to clinic attendance, despite having seen their GPs. By contrast, only 9% of respondents reported visiting A&E for pain-related events in the six months after attending their pain clinic.
- **There is wide variation in staffing and skills mix of services:** only 81 out of 204 English pain clinics (40%) were able to fulfil the criteria for a fully multidisciplinary pain service, as defined by the presence of a physician, physiotherapist and psychologist. In Wales, six out of the ten pain clinics were fully multidisciplinary. Wales has a clear pain strategy and implementation plan in the form of directives.

Recommendations from the audit in the second report were diverse and included improvements in coding, diversity of skills available, the information gathered and advice being more accessible to patients and healthcare planners. Though while the audit was published less than a year ago, some progress has been made in key areas. These include development of local joint strategic needs assessments based upon the data from this and the Health Survey for England, clear links on service outcomes on the NHS Choices website and submissions of topic suggestions to the National Institute for Health Research's health service and delivery programme on models of care for people in pain.

# Why and what?

## *Why was a re-audit of services needed?*

Rounds 2 and 3 of the audit showed that the quality of life of people referred to pain clinics is very poor. Most patients have more than one health problem. Clarity was needed as to whether pain services had processes in place to deal with such a disabled population including accuracy of diagnosis and assessment of suicide risk. Organisational data was displayed on the National Pain Audit website www.nationalpainaudit.org and visible to patients. These have been linked to other sources of information on pain services such as NHS Choices www.nhs.uk and the British Pain Society website www.britishpainsociety.org. However, due to the fact that most people had not completed their pain treatment, more time was needed before publishing outcomes.

The NHS has changed considerably between the original data collection and now. Many trusts have merged and some services were commissioned to provide a county-wide service, e.g. Somerset and Gloucestershire.

During the first audit round it became clear that some services were very unstable with some providers reporting extreme difficulty or no longer in existence. The characteristics and capability of specialist out-of-hospital pain services was poorly understood. The emergence of independent Any Qualified Providers introduced an element of competition and it was unclear whether such services truly existed and whether they could be accurately described as specialist pain services.

Clinical Commissioning Groups were introduced in 2011–12 and their impact on pain service provision needs to be understood. A national Service Specification for specialised pain management has since been published for contracting with specialised pain management centres/services. NHS England now has direct commissioning responsibility for specialised pain management services from a small number of tertiary pain management providers in England. The specification was developed by the clinical reference group for pain management during 2012/13 and is to be adopted formally from the 1st October 2013. **Importantly, it is still unclear whether current services meet patient needs and the landscape of how services are provided across the tiers of pain management provision**

## *What further information is needed from patients?*

During Round 3 of the audit it became evident that treatment was often incomplete at six months, so an understanding of the full impact of services on people in pain required further follow-up. Additionally, ethnicity data had not been collected from patients and it was agreed that it was needed.

Round 4 of the audit has had to introduce new methods to answer those questions that proved difficult to answer with the methods originally proposed. For example, to understand the relationship between hospital emergency admissions and services, a case study has been performed. This should provide better information to plan future audits.

### *Further information*

→ *Organisational data is available on the National Pain Audit website www.nationalpainaudit.org*

# Methods

## *Round 4 of the audit consisted of two audits*

1. 12-month patient follow-up from those who responded to the six-month follow-up, a subsample of those who provided data at the baseline.
2. Resampling of the organisational audit with the aims of:
    - **a.** Gaining as complete as possible representation of clinics, to include community clinics, treatment centres, and those under Any Qualified Provider.
    - **b.** Reviewing clinical governance processes to include:
        - **i.** Protocols to manage serious untoward events.
        - **ii.** Treatment fidelity, i.e. appropriate skills and processes in place to carry out treatments offered.
        - **iii.** Clarification of accountability, e.g. if a community clinic was in place, was this an outreach service from the acute trust, standalone, or did it have some other form of accountability?

*Note*

⇢ *This audit round focused on safety and long-term outcomes*

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## A: 12-month follow-up patient data

The questionnaire administered to patients was similar to that administered at six months, with some minor revisions in the light of the six month follow-up responses. For example, poorer response rates were noted where a response was contingent on a previous response.

**THE OVERALL RECOMMENDATIONS WERE:**

- Questions should be unconnected.
- Expected answers should be as simple as possible, preferably represented by a sliding scale or range.
- Groups of questions that followed a single conceptual theme and response format (BPI, EuroQol) seemed to perform well, so questions should aim to be consistent with these as far as possible.
- Some questions that were missed were possibly not relevant to all respondents. Where possible, questions were worded more generally, or where necessary, specific application should be clearly signalled (though that risks creating complexities of its own).

These recommendations were reflected in the design of the 12-month patient questionnaire.

Only those patients who replied at six months were sampled. Some patients had died by the first follow-up period; given the poor health of many in Round 2, there was some risk of sending questionnaires to people who had died in the intervening 12 months.

There was a deeper analysis of previous rounds to focus on healthcare use, since a key finding had been high use of emergency care, which decreased significantly following treatment in a pain service. The audit's scientific advisors felt it would be of value to examine whether this decrease was sustained.

Ethnicity was also included in this questionnaire as it was felt this was an important omission from previous questionnaires.

⇢ *Appendix 1 shows the final 12-month follow-up patient questionnaire*

## B: Provider questionnaire

Round 1 of the audit focused on identification and characteristics of specialist pain services. A re-sampling of these data was important for a number of reasons:

- A number of services had been reconfigured.
- Identification of providers had been incomplete, especially where provision was in the community.
- Providers were being encouraged to devolve services out of the acute hospital setting.
- Increasingly safety is an issue, with an emphasis on staff levels.

Rounds 2 and 3 demonstrated the complexity of case mix in those attending specialist pain services. In the time that the audit has been undertaken, guidelines have been introduced for pathways of care (for example, the British Pain Society's Map of Medicine persistent pain pathways). The audit therefore examined whether the services have governance processes in place to deal with the challenges of a complex case mix.

This audit round has also examined whether the staffing and skills are in place to deliver treatment according to guidelines.

A list of all potential NHS providers was extracted from the NHS Choices website. Each hospital, independent NHS provider and community trust website was searched for pain services offered, and respondents matched to these providers. To ensure that no services were missed and that all responses were complete, participation was maximised as follows:

- The audit was included in the *How Safe is Your Hospital?* survey run annually by Dr Foster with a high response rate.
- The British Pain Society Primary and Community Care Special Interest Group reviewed the questionnaire to ensure it was appropriate to non-hospital services.
- The British Pain Society Pain Management Programmes Special Interest Group reviewed the items to ensure that these types of rehabilitation services were able to respond.
- The audit was posted on the bulletin board for UK pain consultants and reminders sent through the group painconsultantsgooglegroup.
- The British Pain Society emailed all members and included reminders in its newsletter.

Clinical leads for services of non-responders were independently contacted, with support offered to complete the audit, and reminders sent.

→ *Data items for the provider questionnaire are fully downloadable from www.nationalpainaudit.org*

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## *Data analysis*

Detailed audit standards are outlined in Appendix 3. Data were analysed against each of these standards and reported per item.

## Key audit standards

### A: PATIENT QUESTIONNAIRE

- Advice and guidance on managing pain
- Quality of advice given
- Additional support provided
- Involvement in planning care

### *Patient outcomes*

→ *Advice rated: good/excellent*

→ *Support: good/excellent*

### QUALITY OF LIFE QUESTIONNAIRES

Two items were considered important to report: average pain and mean general activity interference. These were displayed graphically. Other data items are reported in chart form.

Robust evidence on clinically significant change in chronic pain for either the EuroQol or Brief Pain Inventory Questionnaire pain severity scores does not exist and thus was not included.

Case-mix adjustment methods were described in Round 3 of the audit. Given that the audit returns per provider were too small for comparisons to be reliable and the model used was over-dispersed when it came to benchmarking, case-mix adjusted scores are not reported.

### B: PROVIDER QUESTIONNAIRRE

- Number of sites that the provider was operating
- Waiting time for treatment
- Number of patients receiving multidisciplinary care
- Type of service:

**a.** We looked at this using standard definitions used by the International Association for the Study of Pain (IASP) services criteria. However, as all specialist pain services might reasonably be expected to be multidisciplinary in nature, we described clinics by:
   **i.** Level 1: able to deliver CBT-based treatments for less complex cases and review medication. Required minimum staffing of psychologist, physical therapist and physician.
   **ii.** Level 2: able to deliver pain services according to Faculty of Pain Medicine of the Royal College Of Anaesthetists' guidelines on comprehensive pain services that takes into account level of disability and the need to have a wide range of skills available including at bare minimum psychologist, physical therapist, physician and one other.
   **iii.** Level 3: services offering multispecialty clinics i.e. cross-cutting services.

- Protocols in place for review of missed serious pathology and assessment of suicide risk.
- Supporting professional activities time; engagement in routine audit.
- Governance on treatment;
  **a.** Prescribing guidance on opioids agreed.
  **b.** CBT carried out by appropriately qualified practitioner(s).
  **c.** Interventional pain medicine adverse events reporting protocol.
  **d.** Multidisciplinary team meetings.

Sites were displayed by geographical location. In a previous audit, the density of clinic provision was reported per head of population. As clinics served a number of commissioning groups, site and clusters of clinics was thought to be more meaningful.

Information on services was displayed on a *Find a Clinic* function on the National Pain Audit website and links created to the British Pain Society website and NHS Choices.

## *Note*

*→ Key standard for organisational levels of service*

*→ All services to be multi-disciplinary with skills specified*

*→ Graded at three levels to match patient needs*

## Case-mix adjustment single centre study

Case-mix adjustment has proved problematic. The population appears to be extremely heterogeneous and items that might contribute, such as socio-economic data and comorbidities, have not been routinely collected. HES data on outpatients does not include comorbidity and so it was not possible to link data, as had been originally intended, to understand these factors. Therefore, for this round, case-mix was not adjusted.

Further analysis of healthcare usage needed to be better understood through linkage to HES data. In order to test the assumptions on healthcare resource used to make recommendations for future audits, a case study was carried out on data from one centre where comorbidity and other items had been routinely collected at individual patient level.

These data were amalgamated with data from the audit and included emergency admissions.

We tested:
- A&E attendances six months/12 months prior to attendance.
- Admissions six months/12 months prior to attendance.
- A&E six months/12 months post attendance.
- Ward Admissions six months/12 months post-attendance.
- Outpatient attendances in various specialties.

Permission to link data had been sought at the outset of the PROMS data collection. If consent was not given to share data then they were not included.

# Results

## *Providers' organisational questionnaire results*

*Responding organisations are listed in Appendix 3*

Of these, 121 submitted data in sufficient time to be included in the analysis (66%). The other 35 were uploaded to the Find a Clinic function on the National Pain Audit website and can be viewed individually. 127 acute trusts with adult services in England submitted a return, nine reported they had no pain clinic, and 21 failed to reply a total of 156 acute trusts.

Three mental health trusts submitted a return, one failed to reply and 47 reported no pain clinic (total 51).

Six community providers submitted a return with four failing to reply and 14 with no pain clinic (total 24). One independent sector treatment centre responded, one failed to reply and four were reported as having no service.

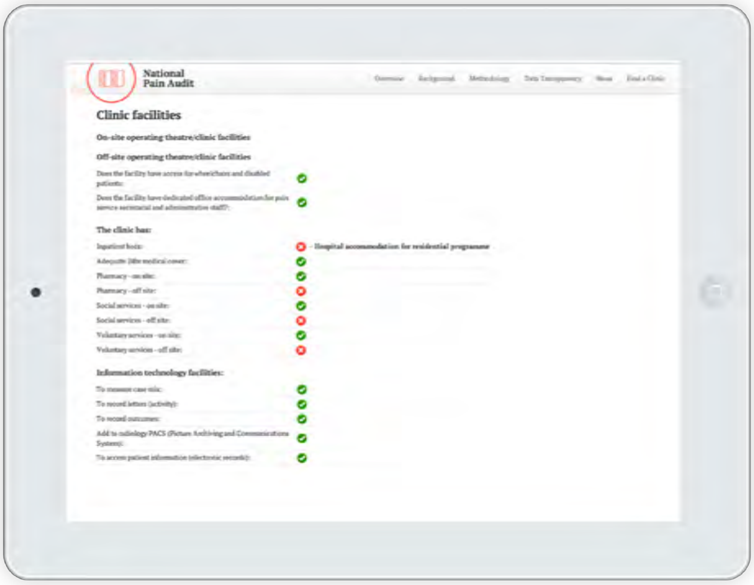
Two Welsh Health Boards submitted data, with the others responding too late to be formally included, though all services have now responded.

Three Any Qualified Providers submitted data. Six specialised children's pain services submitted data. Thus out of the total identified providers, 146 out of 182 responded in time for the data analysis, representing a response rate of 80%. In all, 20 providers who were identified as having a pain service did not submit a return. This is a substantial improvement from previous rounds.

An example of the *Find a Clinic* audit pages is shown below. The ticks represent standards met, the crosses where they were not. There are four themes to the pages; general information as shown below, facilities, staffing and patient safety. A further screenshot is being developed for clinical effectiveness and patient experience together with benchmarking data. Any patient, commissioner or healthcare professional can access this information.

### *Note*

- *221 clinics representing 121 providers submitted complete data sets for analysis*
- *Six specialised children's pain services submitted data*
- *20 providers failed to respond*



Clinic facilities

On-site operating theatre/clinic facilities

Off-site operating theatre/clinic facilities

Does the facility have access for wheelchairs and disabled patients: ✓

Does the facility have dedicated office accommodation for pain service secretarial and administrative staff?: ✓

The clinic has:

Inpatient beds: ✗ - Hospital accommodation for residential programme
Adequate 24hr medical cover: ✓
Pharmacy - on site: ✓
Pharmacy - off site: ✗
Social services - on site: ✓
Social services - off site: ✗
Voluntary services - on site: ✓
Voluntary services - off site: ✗

Information technology facilities:

To measure case mix: ✓
To record letters (activity): ✓
To record outcomes: ✓
Add to radiology PACS (Picture Archiving and Communications System): ✓
To access patient information (electronic records): ✓

**Above:** Find a Clinic audit page example

In total, 221 different sites were reported by the 121 services. These varied hugely from subspecialty clinics within a single hospital to county-wide services over a large geographical area. This made it difficult to establish what skills and treatments were available to the patient. Services were thus analysed both by provider and by site.

→ *Results are reported by individual standards as in Appendix 2 with different forms of service described in Appendix 3*

**NUMBERS OF SITES PROVIDERS OPERATING:**

| No. of sites | No. of providers | Type of provider |
|---|---|---|
| 1 | 76 | Mixed |
| 2 | 16 | Acute |
| 3 | 16 | Acute & 1 AQP |
| 4 | 5 | Acute |
| 5 | 3 | Acute |
| 6 | 0 | |
| 7 | 1 | Acute |
| 8 | 1 | Acute |

Types of clinics according to IASP classification (by clinic rather than provider)

| Type of clinic | Number |
|---|---|
| Single modality clinic | 5 |
| Pain clinic | 27 |
| Multidisciplinary pain clinic | 111 |
| Multidisciplinary pain centre | 34 |

## Note

→ *During the process of gathering data, many staff fed back that services felt fragmented with no clear sense of direction*

→ *Many reported that they did not have a clear service specification, and were uncertain as to where accountability lay for care*

## Multidisciplinary standard

| | Met by clinic | Not met by clinic | Met by provider | Not met by provider |
|---|---|---|---|---|
| Type 1: non-complex service | 106 | 115 | 81 | 40 |
| Type 2: FPM standard service | 30 | 191 | 28 | 93 |
| Type 3: multispeciality clinics | 17 | 204 | 15 | 106 |
| Multidisciplinary meetings | 180 | 41 | 108 | 13 |

## Levels of provision

→ *One-third of providers failed to provide even the most basic multidisciplinary care*

→ *Two-thirds of clinics did not fulfil the Faculty of Pain Medicine standards for Chronic Pain Services*

→ *14% of providers offered cross-cutting multispecialty clinics*

→ *34% of providers offered an inpatient service*

## Inpatient service for complex cases

Fifty-three clinics out of 220 (24%) clinics provided an inpatient service for complex cases with 41 out of 121 (34%) at an overall provider organisational level.

### PROTOCOLS FOR ASSESSING RISK AND REPORTING UNTOWARD EVENTS

These are reported at organisational level only (i.e. 121 providers submitted returns in time for analysis) as it is assumed they will be implemented across all sites.

- 53 (44%) had a suicide risk assessment protocol.
- 53 (44%) had a clear process for acting on misdiagnosis: in all of these providers they were reported as serious untoward events. Many ticked not applicable although all reported that their organisation had a serious untoward event reporting mechanism.
- 114 (94%) had a process for recording drug errors.
- 104 (86%) had pain prescribing guidance with 94 (77%) having opioid prescribing guidance for non-cancer pain.
- 88% of those providing interventional pain therapy had a process in place for managing accidental misplacement of an injection, with 92% having a process in place to manage adverse events with interventional pain therapy.

### SPECIFIC TREATMENT PROTOCOLS

- 47 (39%) graded referrals according to IASP guidance for immediate, urgent and routine referrals. It was unclear how patients were prioritised otherwise.
- 84 (69%) reported that cognitive behavioural therapy for pain was delivered by someone trained in CBT; none ticked not applicable. It appears the remaining 31% received CBT delivered by non-qualified individuals, which is of some concern.

### APPROPRIATE INFRASTRUCTURE IN PLACE TO DELIVER CARE

In total, 114 out of 121 (94%) of providers had sufficient administrative support. All had wheelchair access. All had sufficient access to IT support to allow electronic letters; 106 (88%) had sufficient access to carry out audit and all these reported carrying out regular audit.

**All multidisciplinary pain centres carried out audit and research.**

### *Note*

- *Less than half of services had a suicide risk assessment protocol or a process for acting on misdiagnosis*
- *Most had a process for recording drug errors*
- *The majority had pain prescribing guidance, including opioid prescribing guidance*
- *Most had a process in place for managing accidental misplacement of an injection and adverse events*

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## Results of the patient questionnaire at 12-month follow-up

1,799 patients replied to the follow-up questionnaire at 12 months; this represents 38% of those were who sent the questionnaire. Overall this represents 17% of those who returned a questionnaire at baseline, i.e. Round 2. Of the 1,799 who responded, 1,626 (92.9%) continued to have pain. Their mean age was 59.4 with a standard deviation of 14.4, a minimum of 15 and maximum of 96 years.

Responder analysis revealed that the average age of the 12-month responders was 59 years (standard deviation 15); range from 6 to 96 years with women accounting for 65% of patients. 70% had been referred by their GPs. 17% had neuropathic pain only, and the rest was a very mixed picture. In terms of site of pain, 77% had spinal pain including low back, neck pain and sciatica. Only 38% had been discharged by one year. This may be realistic in the sense that many patients are reluctant to be discharged, hence the fairly wide use (17%) of phone contact if necessary.

This responder cohort is in comparison with average age of the total cohort entered into Round 2 audit of 53 years (range 1 to 98 years). Women account for 64% of patients and 22% had neuropathic pain alone. Therefore the average age of responders was slightly older than the original cohort.

Ethnicity was collected for the first time in this audit round. The overwhelming ethnicity of respondents was white, reported at 92.9%. This may be a reflection either of the engagement in the audit at 12 months by a predominantly white population or of poorer access to pain clinics for non-white patients.

## *Patient quality of life and pain questionnaires*

The full comparison of 12-month follow up data with zero and six month data can be found in Appendix 5. Outcomes are reported as a whole. Case-mix adjustment and by-site reporting is not reported for the reasons outlined in Methods (p13).

### BRIEF PAIN INVENTORY

#### BPI PAIN

| | Pain average | Pain worst | Pain least | Pain now |
|---|---|---|---|---|
| Minimum | 0 | 0 | 0 | 0 |
| 1st quartile | 5 | 6 | 2 | 4 |
| Mean (s.d.) | 5.85 (2.19) | 7.27 (2.29) | 4.48 (2.63) | 5.86 (2.77) |
| Median | 6 | 8 | 4 | 6 |
| 3rd quartile | 7 | 9 | 6 | 8 |
| Maximum | 10 | 10 | 10 | 10 |

(N = 1712)

#### BPI INTERFERENCE

| | Total interference | General activiy | Mood | Walking ability | Normal work | Relationships | Sleep | Enjoyment of life |
|---|---|---|---|---|---|---|---|---|
| Minimum | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| 1st quartile | 4.29 | 5 | 3 | 4 | 5 | 2 | 4 | 4 |
| Mean | 6.13 | 6.51 | 5.76 | 6.33 | 6.67 | 4.78 | 6.12 | 6.46 |
| (s.d.) | (2.58) | (2.87) | (3.07) | (3.12) | (2.97) | (3.27) | (3.17) | (3.03) |
| Median | 6 | 7 | 6 | 7 | 7.5 | 5 | 7 | 7 |
| 3rd quartile | 8.29 | 9 | 8 | 9 | 9 | 8 | 9 | 9 |
| Maximum | 10 | 10 | 10 | 10 | 10 | 10 | 10 | 10 |

(N = 1712)

#### EQ-5D AT 12 MONTHS

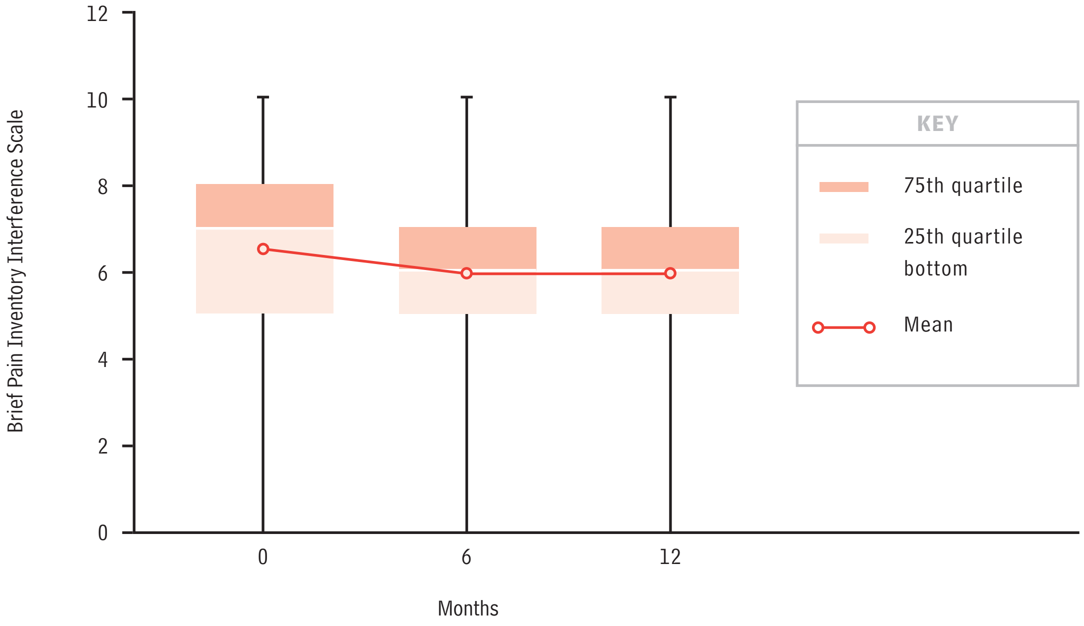
| | Overall health state (0.100) | Overall EQ-5D |
|---|---|---|
| Minimum | 0 | -0.07 |
| 1st quartile | 30 | 0.20 |
| Mean (s.d.) | 50.99 (23.12) | 0.43 (0.23) |
| Median | 50 | 0.43 |
| 3rd quartile | 70 | 0.66 |
| Maximum | 100 | 0.85 |

(N = 1712)

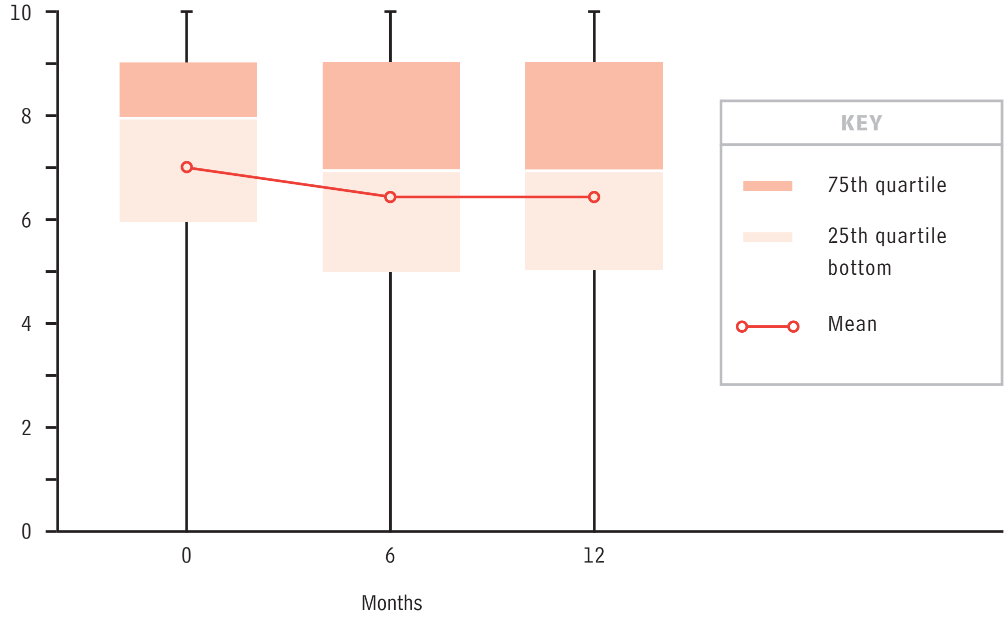
| | Mobility | | Self-care | | Usual activities | | Pain | | Anxiety/depression | |
|---|---|---|---|---|---|---|---|---|---|---|
| EQ-5D | N | % | N | % | N | % | N | % | N | % |
| No problems | 340 | 18.9 | 874 | 48.6 | 211 | 11.7 | 85 | 4.7 | 614 | 34.1 |
| Some impact | 1,372 | 76.3 | 803 | 44.6 | 1,214 | 67.5 | 920 | 51.1 | 881 | 48.9 |
| Severe impact | 37 | 21 | 70 | 3.9 | 326 | 18.1 | 723 | 40.2 | 250 | 13.9 |
| Invalid responses | 50 | 2.8 | 52 | 2.9 | 48 | 2.7 | 71 | 3.9 | 55 | 3.1 |
| **Total** | 1,799 | 100 | 1,799 | 100 | 1,799 | 100 | 1,799 | 100 | 1,799 | 100 |

## *Change in average pain of the 12 month responders at zero, six, and 12 months (Brief Pain Inventory)*

### CHANGE IN ACTIVITY INTERFERENCE ITEM AT ZERO, SIX, AND 12 MONTHS (BRIEF PAIN INVENTORY INTERFERENCE SCALE)



### OVERALL BOTH PAIN AND QUALITY OF LIFE IMPROVED AS A COHORT OVER THE 12 MONTH PERIOD



## INFORMATION ABOUT PAIN

**1.** Did you want information from your NHS service about your pain?
**2.** Were you given information about your pain from your NHS service?
**3.** If you were given information about your pain, how helpful was it?

Of those who wanted information, 70.4% got it. Of those who got information, whether they had wanted it or not, 86.7% rated it fairly or very helpful

| Did you want information about your pain? | Yes | No | Invalid |
|---|---|---|---|
| | 1,090 | 447 | 69 |
| Were you given information? | | | |
| Yes | 767 | 341 | |
| No | 129 | 45 | |
| Do not recall | 185 | 61 | |
| Invalid | 6 | - | |

| Review of information received | | |
|---|---|---|
| | Yes | No |
| Very helpful | 223 | 117 |
| Fairly helpful | 431 | 175 |
| Not at all helpful | 108 | 45 |
| Do not recall | 5 | 4 |

**4.** Which of these forms of information were you given, if any?

| | Total receiving this form of information | % of 1,111 respondents | Only form of information given |
|---|---|---|---|
| Verbal information from your clinician | 1,091 | 98.2 | 613 |
| Information leaflets | 575 | 51.8 | 137 |
| Self-help guide | 230 | 20.7 | 38 |
| How to access online resources | 42 | 3.8 | 4 |
| Other | 102 | 9.2 | 43 |
| I did not receive any information | 277 | 24.9 | 277 |
| No response | 173 | - | 173 |
| **Total** | - | - | 1,284 |

## ADVICE ABOUT MANAGING PAIN

**5.** Did you want advice from your NHS service about managing your pain?
**6.** Were you given advice from your NHS service about managing your pain?
**7.** If you were given advice about managing your pain, how helpful was it?

| Did you want advice about managing your pain? | Yes | No | Invalid |
|---|---|---|---|
| | 1,278 | 411 | 58 |
| Did you get information? | | | |
| Yes | 842 | 270 | |
| No | 185 | 55 | |
| Do not recall | 166 | 55 | |
| Invalid | 6 | - | |

| Review of information received | | |
|---|---|---|
| | Yes | No |
| Very helpful | 195 | 65 |
| Fairly helpful | 496 | 154 |
| Not at all helpful | 140 | 42 |
| Do not recall | 11 | 9 |

**8.** Which of these forms of information were you given, if any?

| | Total | % of 1,060 respondents | Only form of advice |
|---|---|---|---|
| Verbal information from your clinician | 1,061 | 95.8 | 488 |
| Referral to another clinical or service for advice | 407 | 38.5 | 134 |
| Advice leaflet | 459 | 43.4 | 71 |
| Self-help guide | 188 | 17.7 | 26 |
| How to access online resources | 41 | 3.9 | 6 |
| Other | 162 | 15.3 | 42 |
| **Subtotal** | | | 767 |
| I did not receive any advice on how to manage my pain | 299 | 28.2 | 299 |
| No response | 170 | - | 170 |
| **Total*** | 3,042 | - | 1,230 |

## TREATMENTS AND TREATMENT EFFECTS

**9.** What treatments did you receive from your NHS pain service?
**10.** Did you find these treatments helped to reduce your pain?

| Treatment | Total N | As only treatment | Very helpful | Moderate help | Little help | No help |
|---|---|---|---|---|---|---|
| Injections | 1,034 | 247 | 68 | 65 | 64 | 46 |
| Advice on medication | 713 | 118 | - | 41 | 54 | - |
| Physiotherapy | 779 | 72 | - | - | - | 24 |
| Pain Management Programme | 518 | 54 | - | - | - | - |
| Neurostimulation e.g. TENS | 496 | 29 | - | - | - | - |
| Psychology | 123 | 12 | - | - | - | - |
| Complementary therapies | 194 | 3 | - | - | - | - |
| Injections, physiotherapy | 100 | - | - | 29 | 33 | 25 |
| Injections, advice on medication | 60 | - | - | 24 | - | - |
| Injections, advice on medication, physiotherapy | 50 | - | - | 20 | 21 | - |
| Other | 880 | 49 | - | - | - | - |

(N = 1158)

Most treatments were given in combination, as can be seen by the difference between the total number of patients who said they had each particular treatment and the number who had only that treatment. The most common combinations are represented, but there were many more reported by fewer than 20 respondents. Unfortunately, the 'other' category was provided on the questionnaire without a request for further information, so it is unknown what respondents included in this category.

Helpfulness is only reported where 20 or more respondents endorsed the answer. Many gave several answers, not only when they had received more than one treatment but even within a single treatment, such as injections.

### TOTAL RESPONSES TO HELPFULNESS OF TREATMENT QUESTIONS

| | N | % of 1,672 respondents |
|---|---|---|
| Very good help | 263 | 15.7 |
| Moderate help | 486 | 29.1 |
| Little help | 576 | 34.4 |
| No help | 347 | 20.8 |
| No response | 115 | - |
| **Total*** | 1,787 | - |

**11.** Did you need more than one type of treatment to gain pain reduction?

| | N | % of 1,652 respondents |
|---|---|---|
| Yes | 1,317 | 79.7 |
| No | 184 | 11.1 |
| I do not recall | 151 | 9.1 |
| No response | 147 | - |
| **Total** | 1,787 | - |

## TREATMENT DELIVERY

**12.** Do you feel that you were given adequate information about the risks of the treatments offered?
**13.** Do you feel that you were given adequate information about the benefits of the treatments offered?

| Risks | N | % of 1,691 respondents |
|---|---|---|
| Yes | 1,118 | 66.1 |
| No | 319 | 18.9 |
| I do not recall | 253 | 15.0 |
| No response | 108 | - |
| **Total** | 1,799 | - |

| Benefits | N | % of 1,682 respondents |
|---|---|---|
| Yes | 1,124 | 66.8 |
| No | 299 | 17.8 |
| I do not recall | 257 | 15.2 |
| No response | 117 | - |
| **Total** | 1,799 | - |

Two-thirds of patients felt they had enough information about the risks and benefits of treatment. There is room for a substantial improvement in this

**14.** How satisfied were you with your involvement in planning your treatment?

| | N | % of 1,702 respondents |
|---|---|---|
| Very satisfied | 459 | 27.0 |
| Fairly satisfied | 743 | 43.7 |
| Not satisfied | 247 | 14.5 |
| Not satisfied: I was not involved | 5 | 0.3 |
| I was not involved in planning my treatment | 248 | 14.6 |
| No response | 93 | - |
| **Total** | 1,795 | - |

**15.** Were you given enough time to discuss your condition and treatment?

| | N | % of 1,705 respondents |
|---|---|---|
| Yes | 1,142 | 67.0 |
| No | 329 | 19.3 |
| I do not recall | 227 | 13.3 |
| I did not want to discuss my condition and treatment | 7 | 0.4 |
| No response | 89 | - |
| **Total** | 1,794 | - |

**16.** Were you offered a point of contact if you needed more information after the consultation?

| | N | % of 1,721 respondents |
|---|---|---|
| Yes | 807 | 46.9 |
| No | 600 | 34.9 |
| I do not recall | 314 | 18.2 |
| No response | 78 | - |
| **Total** | 1,799 | - |

The number who reported a positive consultation and support afterwards was approximately to two-thirds of patients. It is unclear what patient expectations of care were. Variation between clinics was relatively small

**17.** Have you been admitted to hospital in the past six months due to your pain condition?

| | N | % of 1,728 respondents |
|---|---|---|
| Yes | 279 | 16.1 |
| No | 1,429 | 83.0 |
| I do not recall | 20 | 1.2 |
| No response | 71 | - |
| **Total** | 1,799 | - |

16% of patients had been admitted to hospital due to their pain condition. Given the overall cohort this is unsurprising. However, not all hospitals have a specialist inpatient service to cater for their needs

**18.** Have you been discharged completely from the pain service?

| | N | % of 1,476 respondents |
|---|---|---|
| No | 615 | 41.7 |
| Yes | 605 | 41.0 |
| Yes but I can contact the pain service for help e.g. by phone | 256 | 17.3 |
| No response | 108 | - |
| **Total*** | 1,584 | - |

A substantial minority (40%) had not yet been discharged from care

**19.** Does your pain prevent you from working or seeking work?

| | N | % of 1,714 respondents |
|---|---|---|
| No | 387 | 22.6 |
| Yes | 566 | 33.0 |
| Not applicable | 761 | 44.4 |
| No response | 85 | - |
| **Total** | 1,799 | - |

**20.** If you are in work, have you had to reduce your hours due to your pain?

| | N | % |
|---|---|---|
| No | 247 | 56.0 of those in work |
| Yes | 194 | 44.0 of those in work |
| Subtotal to whom applicable | 441 | |
| Not applicable | 1,122 | 71.8 of respondents |
| No response | 229 | - |
| **Total*** | 1,792 | - |

As with previous audits the ability to work is severely impacted by pain

## *Most severely affected patients*

To try to make some clinical sense of the case mix, we decided to extract the numbers of patients who scored in the 'severe' range (7–10) of both pain severity and pain interference on the BPI, and those who scored a total EQ-5D in the lowest quartile (< 0.151). This produced 768 patients (8%), with a median age of 53.

A more conservative criterion for the EQ-5D required that patients scored <30/100 for overall health, had at least some problems in mobility and self-care, reported extreme pain, and moderate or extreme anxiety or depression, and inability to perform usual activities. These criteria were decided on by three clinician authors, and produced 344 patients with a median age of 52.

## *Single site analysis of healthcare resource use*

**(Heart of England Trust and Birmingham North and East Community Clinic)**

This service has both in-hospital and out-of-hospital specialist pain services. 232 patient data were used to analyse healthcare resource use before and after attendance at pain management services. The hospital clinic reported EQ-5D score of 0.34 in the hospital and 0.44 in the community clinic on arrival (i.e. below average), meaning their overall quality of life was very low.

Overall, the community clinic improved quality of life in terms of EQ-5D 0.01, BPI severity 0.63, 0.99 change in pain interference. The hospital clinic changed by 0.02 in EQ-5D, 0.33 in BPI severity and pain interference of 0.45, despite the severe case-mix.

## *Outpatient attendances*

|  | Mobility |  |  | Self-care |  |  |  |
|---|---|---|---|---|---|---|---|
| Code description | New | Fup | Total | New | Fup | Total | % reduction |
| Orthopaedics | 56 | 112 | 168 | 34 | 70 | 104 | 38% |
| Rheumatology | 10 | 73 | 83 | 6 | 28 | 34 | 59% |
| Total | 66 | 185 | 251 | 40 | 98 | 138 | 45% |

Outpatient attendances fell by 45% overall, with rheumatology showing the greatest overall reduction. Other conditions were too small in number to be meaningful

For A&E, pain-related attendances reduced from 56 to 50. Back pain and non-specific abdominal pain were the most common reason for attendance. Minor soft tissue injuries accounted for a significant number of attendances (39), perhaps a reflection of overall poor function.

Although numbers fell overall there was a small increase in hospital admissions and a decrease in non-admitted patients. These numbers were small and may be within normal fluctuations. Patients reported overall 21% attendances and 19% to A&E which correlates with Hospital Episode Statistics. Thus, despite heath gain being reported by patients, a substantial number are reliant on hospital services to manage their pain.

## *Discussion*

Pain services have learned a great deal from this and previous audit rounds. Understanding of what is important, acceptable and possible to collect has been established. We have established clear methodologies, we understand where there are gaps, and the data generated will serve as a useful resource to shed further light on pain services.

Engagement in this audit round was far greater than previous audits. Services also seem to have been able to broaden the skills mix available to treat patients i.e. have become true multidisciplinary clinics. However much could be done to ensure that services are well matched to patient need.

## *Services*

Our findings from this audit suggest wide variation in how services are provided. Many services told a story of mergers and splits, with staff having to shift across boundaries to remain as a cohesive team. A typical scenario is a consultant providing nerve blockade in a hospital setting with only fixed sessions, with the remainder of the team in the community, communication is limited, risking fragmented care for patients. It also entails serial referrals from one part of the service to another, rather than more effective and economical joint sessions.

Other providers cover huge geographical areas. The number of services that fall into the specialised services specification is very small at present based on staffing levels and provision of highly specialist interventions.

Darzi modelling of services was based on volume not on outcome, but we take the view that bigger clinics are not necessarily best.

The increase overall from 40% of providers to 67% being able to deliver multidisciplinary care represents a significant shift, though this may be a function of better data quality from this audit. Most treatments were given in combination; this is appropriate as most (almost 80%) of patients stated that they required more than one type of treatment to improve. This underlines the need for a multidisciplinary, multi-component approach.

However, many services continue to have a skills shortfall. Fewer than half were able to provide basic care at a clinic site through lack of sufficient skills, although a provider overall may deliver such treatments across a wider geographical area. This suggests that even the more straightforward patients will need to travel to receive treatment.

As pain management is multispecialty, a better understanding of who is involved in managing patients with severe pain would be useful. There is currently no training programme in pain for non-anaesthetists. Recent studies report undergraduate education in pain remains woefully poor with teaching confined to the classroom rather than out on the wards and in everyday practice. This deprives students of the opportunity to practise complex skills such as communication, problem solving and clinical decision making. It may also hinder staff recruitment as practise of more advanced skills is confined to those who have decided to commit to working in such clinics. The number of multispecialty clinics was small (14%) implying that pain as a cross-cutting issue is not prioritised.

## *Safety*

While nearly all centres have policies in place to manage the complications of treatment and methods of treatment, the majority have nothing in place to cover more fundamental issues such as review of misdiagnosis, and suicide risk. Both of these potentially carry a mortality risk and thus are important areas for guidance protocols for all staff. The lack of clear risk management protocols for suicide risk (44%) is concerning given the level of distress in this population. The lack of processes to learn from a missed serious pathology again questions the governance of some services. The fragmentation of services may exacerbate shortcomings in governance.

➡ *There were significant gaps in clinical governance in relation to dealing with mental health risks and missed serious pathology*

## *Responder analysis*

In terms of case mix we are aware that the sampling methods appear to have introduced bias against non-white ethnic groups. It is unlikely that lack of fluency in English, the language of the questionnaire, accounts for a large part of this. The ethnicity of patients attending UK pain clinics has not been previously recorded; the non-white population was previously reported as underrepresented in a Canadian study.[1] It would be useful to understand this better.

The current paper-based sampling was used in anticipation of the elderly population being substantially represented among respondents. Future audits need to utilise multiple sampling techniques, including web-based.

## *Health gain on EQ-5D and BPI*

Health gain on the questionnaires used was relatively modest overall. However, this may mask some patients who made substantial gains. The requirement to persist, as a recent review suggests, may mean that treatment may take a substantial period of time (beyond the time period of this audit).[2] Services which fall short of recommended provision are hoping that medical interventions will not only reduce pain but also reduce disability and distress, despite a large body of research showing that once pain has become chronic, it is unlikely that disability and distress will be so easily improved. Hence the need for physical and psychological therapy to coincide with or follow medical treatment. Services clearly see a wide variation in severity, i.e. they are attempting to cater for a wide variety of needs on very stretched resources.

A significant minority is being admitted with complications of chronic pain yet inpatient services for these patients barely exist. How much gain is possible is unknown for the general pain population. Very few get to pain rehabilitation programmes.

➡ *Health gain is modest. When patients have an extremely poor quality of life and pain severity is high, substantial improvements are hard to achieve*

## *Healthcare resource use single-site analysis*

The single-site analysis showed that attendance at A&E changed very little over a longer time period, at variance to the patient report as per the *Final Report 2012*. Of note is that significant numbers of patients continue to be admitted for pain. This number fell within the first six months but further falls in hospital admissions did not occur. Further work needs to be done to characterise this population and the importance of having inpatient provision needs to be highlighted when planning services. However, attendance at musculoskeletal outpatients, such as orthopaedics and rheumatology, was significantly reduced. This outcome would have a large impact on healthcare resource if the impact were the same throughout England and Wales.

> ⇢ *The single-site case study on healthcare resource use demonstrated a significant fall in outpatient attendances*

## *Case mix*

We now know more from other audits and from our own experience about what is important. In relation to comorbidity, the list of possible comorbidities can be made less daunting than a full set for patients to complete themselves. Very severely affected patients who might reasonably expect to require significantly enhanced levels of care accounted for 8% of the case mix. It was difficult to establish whether services are matched to need; this requires deeper analysis of the data.

Outcome data can be compared internally within clinics but not across clinics because we have not allowed, for instance, for the deprivation index and other possible sources of difference. Future audits urgently need to identify other factors that can account for variation in referral rates of particular groups.

> ⇢ *Very severely affected patients who might reasonably expect to require significantly enhanced levels of care accounted for 8% of the case mix*

## *General information on pain*

The information collected from patients on processes of care was invaluable and sheds a useful light on the value of advice and information in this cohort. Much of this was verbal alone (55%). Although the sample size was relatively small, the fact that the proportion of patients reporting whether advice and information was useful did not vary by clinic suggests that it is important to derive tailor-made solutions that fit with a patient's processing ability.

For those patients who wanted information, 85% found it helpful. This compares favourably with back pain booklet trials and the usefulness of information-giving on health in general. 90% of people reported that they had received advice on managing pain from a variety of sources.

Patients also seem to require far more information than is anticipated by services. Many people who attend a service are likely to struggle to maintain concentration. Further research is needed into how patients wish to receive information and in what form in a pain clinic setting that is appropriate to need. Some pain clinic advice (notably to try to remain active or to increase the level and range of activity) goes against 'common sense' advice from family and friends, and not infrequently from healthcare providers, to rest and wait for the pain to remit.[3]

Patients need to be able to process information, and this varies considerably between individuals. Pain reduces concentration and attention, making processing of information even more difficult. Information needs to be provided in a way that is meaningful and retrievable, and is consistent across healthcare staff. Some written/website information is available and of good quality (IASP, ARC, and others) and could be given to patients. However, this does not happen for multiple reasons. Usually it's nobody's job to restock information stands for patients, or on staff's desks, but also it takes time to establish what patients do and don't understand, and to try to make information relevant to their particular history, situation and level of comprehension.

## *Information on treatments*

Nearly 19% of patients reported that they were not given adequate information on the risks of treatment. Only 18% felt that they had insufficient information on the benefits of treatment. This suggests that there is still some way to go on fully informed choice. A majority (71%) were satisfied with being involved in planning treatment, although many reported wanting more time to go over options and further contact to discuss these. This suggests that decision aids[4] and the process of shared decision making, which is an NHS priority, could work well in this setting. Services need to evaluate the need for more information on treatment choices to improve outcomes.

45% reported treatment as being moderately or very helpful. Treatment helpfulness has been previously explored[5] and it is vital that centres understand which treatments patients attending their service are finding the most helpful.

→ *Many patients report needing more time to go over treatment options*

## *Work*

Patients report that work is severely affected by pain and this continues to be the case a year after treatment. Services should include specific vocational rehabilitation to either return people to new work or retain people in their employment. This has previously been trialled successfully and NICE guidance is available yet seems to be ignored by service planners.[6]

## *Learning for future audits*

This audit produced a much greater response than the initial audit. This has been seen in other national audits, where participation rates have grown as the outputs begin to have an impact. In terms of provider responses the multiplicity of pain service models is a challenge and requires greater understanding before determining how to contact each site in the future.

In terms of patients the response rate overall was better than expected. However, future audits should use multiple methods of engaging with patients, such as online tools and paper copies to cover more of the population.

Greater investment in clinical engagement and clinical input to future audits is needed. The need to engage with colleagues and a depth of understanding of potential idiosyncrasies would greatly improve the quality and quantity of data returns.

Thought needs to be given to this prior to future sampling in order to ensure case-mix adjustment is adequately covered. Factors such as comorbidity, ethnicity and socio-economic factors may be important.

The web-based *Find a Clinic* function has worked well and led to significant feedback from clinics. Linking to patient facing websites has also been useful.

A recent Improving Access to Psychological Therapies audit commented that routine data collection is crucial, and should be part of training and treatment protocols. We would support clinics developing collection systems and some of the standards developed can be useful to support audit within clinics. Clinics are often short of time, staff, and software to assess routinely and to analyse data, and this needs further discussion.

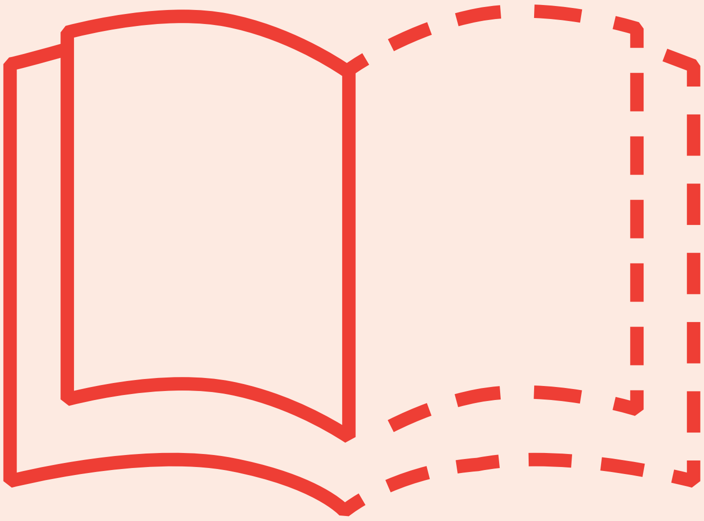
# Conclusions

Participation in the National Pain Audit has been generally good. The audit has demonstrated that it is possible to develop measures and apply clear standards of care to pain services. Many of these standards could now be adopted nationally. Case-mix adjustment is in its infancy for pain management; significant development is needed. The case study on healthcare resource use yielded interesting data but requires wider testing.

A significant proportion of patients are severely disabled and distressed and there needs to be clear provision for this cohort. Skills available to manage these patients still fall short of what is needed, though the increase in multidisciplinary care is encouraging. There are many levels of provision, and services go from very small to very large. Services can be frequently fragmented, leading to patients having to move between providers. As patients are highly disabled and struggle to maintain concentration, this fragmentation may be expensive for both the patient and commissioner. Whether services are matched to need requires greater attention. Pain has a major impact on work, yet there is little research on how health services can best help people in pain return to work or retain work.

Whilst safety protocols are apparent for treatment, governance in the area of clinical assessment is less robust. A great deal is now known about treatment of people with moderate to severe pain, but less is known about services where pain is part of another condition and specialist care is not accessed.

This audit has found where specialist services are for people in pain, characterised them and looked at the quality of care provided by them. Future audits should seek to understand in greater depth how patients are benefiting from this care and the impact of such services on NHS resources.



# Appendix 1

## *12-month follow-up questionnaire items*

### Brief Pain Inventory follow-up questionnaire (11 items)

### EuroQol 5D-3L (six items including thermometer)

### Ethnic Group (one of six items)

### Did you want information from your NHS service about your pain?

- Were you given information about your pain from your NHS service?
- If you were given information about your pain, how helpful was it?
- Which of these forms of information were you given, if any?

### Did you want advice from your NHS service about managing your pain?

- If you were given advice about managing your pain, how helpful was it?
- What forms of advice about managing your pain were you given?

### Treatments received from an NHS pain service

- Requiring more than one treatment to reduce pain
- Treatment helpfulness

### Involvement in treatment planning

- Do you feel that you were given adequate information about the risks of the treatments offered? (Y/N)
- Do you feel that you were given adequate information about the benefits of the treatments offered? (Y/N)
- How satisfied were you with your involvement in planning your treatment? (VRS four items)
- Were you given enough time to discuss your condition and treatment? (Y/N)
- Were you offered a point of contact if you needed more information after the consultation? (Y/N)

### Work-related questions

- Does your pain prevent you from working or seeking work? (Y/N)
- If you are in work, have you had to reduce your hours due to your pain? (Y/N)

# Appendix 2

## A: Patient Questionnaire

| Brief Pain Inventory | Clinically significant change = 1 point or half a SD on BPI interference subscale mean Both pre- and post-case-mix adjustment | % of patients attending facility who achieved clinically significant change |
|---|---|---|
| Number who wanted information on managing pain reporting it as helpful | Excellent/good | 80% reported receiving advice and guidance |
| Number who wanted advice on managing pain reporting it as helpful | Excellent/good | 80 % reported excellent/good |
| Additional support provided | Excellent/good | 80 % reported excellent/good |
| Help and advice | Excellent/good | 80 % reported excellent/good |
| Involvement in planning care | Excellent/good | 80 % reported excellent/good |

## B: Provider questionnaire

| Item | Audit standard | Demonstrated by |
|---|---|---|
| Identified service completed data return | Report overall number of providers who returned a questionnaire (internal audit standard) | % returned/total number of known providers |
| Data completeness | 100 % fields completed | % of questionnaire fully completed |
| Data correctness | 100% completed correctly - for location and treatments as inpatients reported | Cross tab with known data from HES, routine statistics under 191 code |
| Staffing: clinical | Level 1: multidisciplinary team of psychology, doctor and physio | 100% |
| Involvement in planning care | Level 2: enhanced multidisciplinary team: multidisciplinary team plus at least one of nursing, pharmacy or occupational therapists as per RCOA guidance | No standard applied, just report |
| | Level 3: multispecialty service: enhanced multidisciplinary team plus more than one medical specialty as per service specification | No standard report, numbers only |
| | Co-ordination of care: multidisciplinary team meeting to discuss patient care | 100% |
| | Presence of inpatient pain service for complex cases | 100% acute providers |
| Staffing inpatients with persistent pain (hospital-based services only) | 24/7 availability of staff | Report |
| For neuro-modulation and intrathecal pump insertion (spinal cord stimulation) services | Established risk assessment protocol for acting on potential suicide risk | 100% providers |

| Item | Audit standard | Demonstrated by |
|---|---|---|
| Mental health support | Established risk assessment protocol for acting on misdiagnosis | 100% providers |
| Missed diagnosis | Staff have easy access to the policy | 100% providers easy access |
| SUI policy access | Yes/No | 100% yes |
| Drug errors recording process | Yes/No | 100% yes |
| Organisational guidance on pain prescribing | Yes/No | 100% yes |
| Opioid prescribing guidance | Yes/No | 100% yes |
| CBT by CBT practitioner | Yes/No | 100% yes |
| CBT review after six sessions | Yes/No | 100% yes |
| Interventional treatments wrong placement policy | Yes/No | 100% yes |
| Interventional treatments adverse events protocol | Yes/No | 100% yes |
| Administrative support | Access to administrative support | 100% providers |
| Access to pharmacy support for medicine advice | 100% have access 2.1 GPAS | 100% providers |
| Administrative Support | Access to administrative support | 100% |
| Wheelchair access | Wheelchair access | 100% |
| IT support | Service has computerised access to notes and for audit purposes | 100% |
| Timely access to care | IASP standards on waiting times<br>< 1 week for emergency cases | Report figure |
|  | < 1 month for urgent cases | Report figure |
|  | < 1 month for urgent cases | Report figure |
|  | < 8 weeks for routine cases | Report figure |
|  | < 18 weeks for UK time to first treatment | Report figure |
| Carry out regular supporting professional activities | Teaching students - for those listed as multidisciplinary pain centre by region | 100% teach |
|  | Audit - all centres | 100% audit |
|  | Research – for those listed as multidisciplinary pain centre by region | 100% research |

# Appendix 3

## *Shape and form of participating providers*

| Provider | Type of provider | Number of services |
|---|---|---|
| Taunton FT | Acute | 8 |
| Dorset County | Acute | 2 |
| Bristol | Acute | 3 |
| St Helens and Knowsley Hospitals NHS Trust | Acute | 2 |
| Luton and Dunstable | Acute | 3 |
| Harrogate and District NHS Foundation Trust | Acute | 2 |
| Heatherwood and Wrexham Park Hospitals NHS Foundation Trust | Acute | 3 |
| Basildon and Thurrock University Hospitals NHS Foundation Trust | Acute | 2 |
| The Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust | Acute | 2 |
| Royal Cornwall Hospitals NHS Trust | Acute | 3 |
| Peterborough and Stamford Hospitals NHS Foundation Trust | Acute | 2 |
| Royal Berkshire NHS Foundation Trust | Acute | 2 |
| Northern Lincolnshire and Goole Hospitals NHS Foundation Trust | Acute | 3 |
| University Hospitals Coventry and Warwickshire NHS Trust | Acute | 2 |
| Bolton NHS Foundation Trust | Acute | 2 |
| Chelsea and Westminster Hospital NHS Foundation Trust | Acute | 2 |
| Homerton University Hospital NHS Foundation Trust | Acute | 2 |
| Heart of England NHS Foundation Trust | Acute | 3 |
| Gateshead Health NHS Foundation Trust | Acute | 5 |
| Leeds Teaching Hospitals NHS Trust | Acute | 3 |
| Wrightington, Wigan and Leigh NHS Foundation Trust | Acute | 3 |
| Royal Brompton Harefield NHS Foundation Trust | Acute | 3 |
| Northumbria Healthcare NHS Foundation Trust | Acute | 4 |
| South Tees Hospitals NHS Foundation Trust | Acute | 3 |
| University Hospitals of Morecambe Bay NHS Foundation Trust | Acute | 4 |
| East Kent Hospitals University NHS Foundation Trust | Acute | 4 |
| North Tees and Hartlepool NHS Foundation Trust | Acute | 3 |
| Southport and Ormskirk Hospital NHS Trust | Acute | 4 |
| Pennine Acute Hospitals NHS Trust | Acute | 4 |

| Provider | Type of provider | Number of services |
|---|---|---|
| United Lincolnshire Hospitals NHS Trust | Acute | 7 |
| University Hospitals of Leicester NHS Trust | Acute | 4 |
| Maidstone and Tunbridge Wells NHS Trust | Acute | 3 |
| East and North Hertfordshire NHS Trust | Acute | 3 |
| Nottingham University Hospitals NHS Trust | Acute | 3 |
| East Sussex Hospitals NHS Trust | Acute | 2 |
| Mid Yorkshire Hospitals NHS Trust | Acute | 2 |
| Brighton and Sussex University Hospitals NHS Trust | Acute | 2 |
| Sandwell and West Birmingham Hospitals NHS Trust | Acute | 2 |
| East Lancashire Hospitals NHS Trust | Acute | 3 |
| The Shrewsbury and Telford Hospital NHS Trust | Acute | 3 |
| Imperial College Healthcare NHS Trust | Acute | 2 |
| South London Healthcare NHS Trust | Acute | 5 |
| Western Sussex Hospitals NHS Trust | Acute | 3 |
| Pain Management Solutions | AQP | 3 |
| University Hospital of North Staffordshire NHS Trust | Acute | 3 |

### SERVICES DESCRIBING DIFFERENT CLINICS OPERATING SEPARATELY ON ONE SITE

| Provider | Type of provider | Number of services |
|---|---|---|
| Salisbury NHS Foundation Trust | Acute | 3 |
| Royal Liverpool and Broadgreen University Hospitals NHS Trust | Acute | 5 |
| University Hospitals of Leicester NHS Trust | Acute | 2 (specialised separately) |
| Buckinghamshire Hospitals NHS Trust | Acute | 2 |

# Appendix 4

## *Providers who successfully submitted returns and were included in the analysis*

### Acute trusts

Ashford and St Peter's Hospitals NHS Foundation Trust
Barking, Havering and Redbridge University Hospitals NHS Trust
Basildon and Thurrock University Hospitals NHS Foundation Trust
Bedford Hospital NHS Trust
Bolton NHS Foundation Trust
Bradford Teaching Hospitals NHS Foundation Trust
Brighton and Sussex University Hospitals NHS Trust
Buckinghamshire Healthcare NHS Trust
Burton Hospitals NHS Foundation Trust
Calderdale and Huddersfield NHS Foundation Trust
Cambridge University Hospitals NHS Foundation Trust
Chelsea and Westminster Hospital NHS Foundation Trust
Chesterfield Royal Hospital NHS Foundation Trust
City Hospitals Sunderland NHS Foundation Trust
Colchester Hospital University NHS Foundation Trust
County Durham and Darlington NHS Foundation Trust
Dartford and Gravesham NHS Trust
Derby Hospitals NHS Foundation Trust
Dorset County Hospital NHS Foundation Trust
The Dudley Group NHS Foundation Trust
East and North Hertfordshire NHS Trust
East Cheshire NHS Trust
East Kent Hospitals University NHS Foundation Trust
East Lancashire Hospitals NHS Trust
East Sussex Healthcare NHS Trust
Epsom and St Helier University Hospitals NHS Trust
Frimley Park Hospital NHS Foundation Trust
Gateshead Health NHS Foundation Trust
George Eliot Hospital NHS Trust
Gloucestershire Hospitals NHS Foundation Trust
Great Western Hospitals NHS Foundation Trust
Guy's and St Thomas' NHS Foundation Trust
Hampshire Hospitals NHS Foundation Trust
Harrogate and District NHS Foundation Trust
Heart of England NHS Foundation Trust
Heatherwood and Wrexham Park Hospitals NHS Foundation Trust
Hinchingbrooke Health Care NHS Trust
Homerton University Hospital NHS Foundation Trust
Hull and East Yorkshire Hospitals NHS Trust
Imperial College Healthcare NHS Trust
Ipswich Hospital NHS Trust
Isle of Wight NHS Trust
James Paget University Hospitals NHS Foundation Trust
King's College Hospital NHS Foundation Trust
Lancashire Teaching Hospitals NHS Foundation Trust
Leeds Teaching Hospitals NHS Trust
Liverpool Women's NHS Foundation Trust
Luton and Dunstable Hospital NHS Foundation Trust
Maidstone and Tunbridge Wells NHS Trust
Medway NHS Foundation Trust
Mid Cheshire Hospitals NHS Foundation Trust
Mid Essex Hospital Services NHS Trust
Mid Staffordshire NHS Foundation Trust
Mid Yorkshire Hospitals NHS Trust
Milton Keynes Hospital NHS Foundation Trust
Norfolk and Norwich University Hospitals NHS Foundation Trust
North Bristol NHS Trust
North Cumbria University Hospitals NHS Trust
North Tees and Hartlepool NHS Foundation Trust
Northampton General Hospital NHS Trust
Northern Devon Healthcare NHS Trust
Northern Lincolnshire and Goole Hospitals NHS Foundation Trust
Northumbria Healthcare NHS Foundation Trust
Nottingham University Hospitals NHS Trust
Papworth Hospital NHS Foundation Trust
Pennine Acute Hospitals NHS Trust
Peterborough and Stamford Hospitals NHS Foundation Trust
Plymouth Hospitals NHS Trust
Poole Hospital NHS Foundation Trust
Portsmouth Hospitals NHS Trust

## Acute trusts

- Royal Berkshire NHS Foundation Trust
- Royal Brompton and Harefield NHS Foundation Trust
- Royal Cornwall Hospitals NHS Trust
- Royal Devon and Exeter NHS Foundation Trust
- Royal Liverpool and Broadgreen University Hospitals NHS Trust
- Royal National Orthopaedic Hospital NHS Trust
- Royal Surrey County NHS Foundation Trust
- Royal United Hospital Bath NHS Trust
- Salford Royal NHS Foundation Trust
- Salisbury NHS Foundation Trust
- Sandwell and West Birmingham Hospitals NHS Trust
- Sheffield Teaching Hospitals NHS Foundation Trust
- Sherwood Forest Hospitals NHS Foundation Trust
- Shrewsbury and Telford Hospital NHS Trust
- South Devon Healthcare NHS Foundation Trust
- South London Healthcare NHS Trust
- South Tees Hospitals NHS Foundation Trust
- South Warwickshire NHS Foundation Trust
- Southend University Hospital NHS Foundation Trust
- Southport and Ormskirk Hospital NHS Trust
- St George's Healthcare NHS Trust
- St Helens and Knowsley Hospitals NHS Trust
- Stockport NHS Foundation Trust
- Surrey and Sussex Healthcare NHS Trust
- Tameside Hospital NHS Foundation Trust
- Taunton and Somerset NHS Foundation Trust
- The Dudley Group NHS Foundation Trust
- The Hillingdon Hospitals NHS Foundation Trust
- The Lewisham Healthcare NHS Trust
- The Newcastle Upon Tyne Hospitals NHS Foundation Trust
- The Queen Elizabeth Hospital, King's Lynn. NHS Foundation Trust
- The Rotherham NHS Foundation Trust
- The Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust
- The Royal Marsden NHS Foundation Trust
- The Walton Centre NHS Foundation Trust
- United Lincolnshire Hospitals NHS Trust
- University College London Hospitals NHS Foundation Trust
- University Hospital Birmingham NHS Foundation Trust
- University Hospital of North Staffordshire NHS Trust
- University Hospital of South Manchester NHS Foundation Trust
- University Hospital Southampton NHS Foundation Trust
- University Hospitals Bristol NHS Foundation Trust
- University Hospitals Coventry and Warwickshire NHS Trust
- University Hospitals of Leicester NHS Trust
- University Hospitals of Morecambe Bay NHS Foundation Trust
- West Hertfordshire Hospitals NHS Trust
- West Middlesex University Hospital NHS Trust
- West Suffolk NHS Foundation Trust
- Western Sussex Hospitals NHS Trust
- Weston Area Health NHS Trust
- Wirral University Teaching Hospital NHS Foundation Trust
- Worcestershire Acute Hospitals NHS Trust
- Wrightington, Wigan and Leigh NHS Foundation Trust
- Wye Valley NHS Trust
- York Teaching Hospital NHS Foundation Trust

## Community trusts

- Central London Community Healthcare NHS Trust
- Derbyshire Community Health Services NHS Trust
- Dorset Healthcare University NHS Foundation Trust
- Leeds Community Healthcare NHS Trust
- Solent NHS Trust

## Independent sector treatment centres

- BMI Goring Hall

## Welsh providers

- Betsi Cadwaladr University Health Board
- Cardiff and Vale University Health Board

## Any qualified providers

- Dorking Healthcare LLP
- Angel and Bowden
- Pain Management Solutions

## Children's services

- Alder Hey Children's NHS Foundation Trust
- Great Ormond Street Hospital for Children NHS Foundation Trust
- Royal National Hospital for Rheumatic Diseases NHS Foundation Trust
- University Hospitals of Leicester NHS Trust
- Bristol Children's Hospital
- University Hospital Leeds
- Manchester Children's Hospital

## Community trusts

Bridgewater Community Healthcare NHS Trust
Cambridgeshire Community Services NHS Trust
Central and North West London NHS Foundation Trust
Hounslow and Richmond Community Healthcare NHS Trust
Lancashire Care NHS Foundation Trust
Lincolnshire Community Health Services NHS Trust
Liverpool Community Health NHS Trust
Norfolk Community Health and Care NHS Trust
Pennine Care NHS Foundation Trust
Shropshire Community Health NHS Trust
Torbay and Southern Devon Health and Care NHS Trust
Wirral Community NHS Trust
Worcestershire Health and Care NHS Trust

## Mental health trusts

Cheshire and Wirral Partnership NHS Foundation Trust
Cornwall Partnership NHS Foundation Trust
Coventry and Warwickshire Partnership NHS Trust
Cumbria Partnership NHS Foundation Trust
Devon Partnership NHS Trust
Dudley and Walsall Mental Health Partnership NHS Trust
East London NHS Foundation Trust
Greater Manchester West Mental Health NHS Foundation Trust
Hertfordshire Partnership NHS Foundation Trust
Kent and Medway NHS and Social Care Partnership Trust
Leicestershire Partnership NHS Trust
Lincolnshire Partnership NHS Foundation Trust
Manchester Mental Health and Social Care Trust
Mersey Care NHS Trust
Norfolk and Suffolk NHS Foundation Trust
North Essex Partnership NHS Foundation Trust
North Staffordshire Combined Healthcare NHS Trust
Northumberland, Tyne and Wear NHS Foundation Trust
Nottinghamshire Healthcare NHS Trust
Oxford Health NHS Foundation Trust
Oxfordshire Learning Disability NHS Trust
Oxleas NHS Foundation Trust
Rotherham, Doncaster and South Humber Mental Health NHS Foundation Trust
Somerset Partnership NHS Foundation Trust
South Essex Partnership University NHS Foundation Trust
South London and Maudsley NHS Foundation Trust
South Staffordshire and Shropshire Healthcare NHS Foundation Trust
South West London and St George's Mental Health NHS Trust
South West Yorkshire Partnership NHS Foundation Trust
Surrey and Borders Partnership NHS Foundation Trust
Sussex Partnership NHS Foundation Trust
Leeds and York Partnership NHS Foundation Trust

## Acute trusts

Central Manchester University Hospitals NHS Foundation Trust
Ealing Hospital NHS Trust
Moorfields Eye Hospital NHS Foundation Trust
The Christie NHS Foundation Trust
The Clatterbridge Cancer Centre NHS Foundation Trust
The Princess Alexandra Hospital NHS Trust
Warrington and Halton Hospitals NHS Foundation Trust
Aintree University Hospital NHS Foundation Trust
Hertfordshire Partnership NHS Foundation Trust
Kent and Medway NHS and Social Care Partnership Trust
Leicestershire Partnership NHS Trust
Lincolnshire Partnership NHS Foundation Trust
Manchester Mental Health and Social Care Trust
Mersey Care NHS Trust
Norfolk and Suffolk NHS Foundation Trust
North Essex Partnership NHS Foundation Trust

| Providers who submitted late returns and thus were not included in the analysis but have been matched on the Find a Clinic function on www.nationalpainaudit.org |
|---|
| Barnet and Chase Farm Hospitals |
| Barts and the Royal London University Hospitals |
| Croydon University Hospitals FT |
| Oxford University Hospitals FT |
| Royal Free Hospital |
| Royal Hospital for Rheumatic Diseases |
| The Royal Wolverhampton NHS Trust |
| South Yorkshire and Bassetlaw Pain Management Service |
| Aneurin Bevan Health Board |
| Abertawe Bro Morgannwg University Health Board |
| Cwm Taf Health Board |
| Hywel Dda Health Board |
| Powys Teaching Health Board |
| Mersey Care NHS Trust |
| Norfolk and Suffolk NHS Foundation Trust |
| North Essex Partnership NHS Foundation Trust |

| Providers who were identified as having pain management services but did not submit a return |
|---|
| Birmingham Children's Hospital NHS Foundation Trust |
| Camden and Islington NHS Foundation Trust (CHECK) |
| Derbyshire Healthcare Foundation Trust (CHECK) |
| Countess of Chester Hospitals |
| Doncaster and Bassetlaw FT |
| Kent Community Health NHS Trust |
| Hertfordshire Community NHS Trust |
| Humber NHS Foundation Trust |
| Kettering General Hospital |
| Northamptonshire Healthcare NHS Foundation Trust |
| Liverpool Heart and Chest Hospital |
| North Middlesex University Hospital |
| Norfolk and Norwich Hospitals FT Children's Services |
| Oxford Children's Pain Services |
| Pennine MSK Services |
| Robert Jones and Agnes Hunt Hospital |
| Royal Hospital for Rheumatic diseases Children's Service |
| Southampton NHS Treatment Centre |
| The Whittingdon Hospital London |
| Walsall Healthcare NHS Trust |

| Providers who confirmed they did not have a pain service |
|---|
| Central Manchester Hospitals |
| The Christie NHS Foundation Trust |
| The Clatterbridge Cancer Centre NHS Foundation Trust |
| Ealing Hospital |
| Moorfields Eye Hospital |
| The Royal Orthopaedic Hospital NHS Foundation Trust |
| Warrington and Halton Hospitals NHS Foundation Trust |

# Appendix 5

## *Changes in pain severity, Pain interference and quality of life over the 12-month audit period*

| | Pain average 0m | Pain average 6m | Pain average 12m | Pain worst 0m | Pain worst 6m | Pain worst 12m |
|---|---|---|---|---|---|---|
| Minimum | 0 | 0 | 0 | 0 | 0 | 0 |
| 1st quartile | 5 | 5 | 5 | 7 | 6 | 6 |
| Mean (s.d.) | 6.49 (1.89) | 5.85 | 5.85 (2.19) | 7.86 (1.80) | 7.24 (2.21) | 7.27 (2.29) |
| Median | 7 | 6 | 6 | 8 | 8 | 8 |
| 3rd quartile | 8 | 7 | 7 | 9 | 9 | 9 |
| Maximum | 10 | 10 | 10 | 10 | 10 | 10 |

| | Pain least 0m | Pain least 6m | Pain least 12m | Pain now 0m | Pain now 6m | Pain now 12m |
|---|---|---|---|---|---|---|
| Minimum | 0 | 0 | 0 | 0 | 0 | 0 |
| 1st quartile | 3 | 2 | 4 | 7 | 4 | 4 |
| Mean (s.d.) | 4.84 (2.533) | 4.48 (2.63) | 5.85 (2.19) | 6.12 (2.5) | 5.77 | 5.86 (2.77) |
| Median | 5 | 4 | 6 | 7 | 6 | 6 |
| 3rd quartile | 7 | 6 | 7 | 8 | 8 | 8 |
| Maximum | 10 | 10 | 10 | 10 | 10 | 10 |

# Appendix 6

## *Changes in pain interface*

| | General activity 0m | General activity 6m | General activity 12m | Mood 0m | Mood 6m | Mood 12m |
|---|---|---|---|---|---|---|
| Minimum | 0 | 0 | 0 | 0 | 0 | 0 |
| 1st quartile | 6 | 5 | 5 | 5 | 4 | 3 |
| Mean (s.d.) | 7.12 (2.41) | 6.51 (2.82) | 6.51 (2.87) | 6.33 (2.72) | 5.91 (3.00) | 5.76 (3.07) |
| Median | 8 | 7 | 7 | 7 | 6 | 6 |
| 3rd quartile | 9 | 9 | 9 | 8 | 8 | 8 |
| Maximum | 10 | 10 | 10 | 10 | 10 | 10 |

| | Walking ability 0m | Walking ability 6m | Walking ability 12m | Normal work 0m | Normal work 6m | Normal work 12m |
|---|---|---|---|---|---|---|
| Minimum | 0 | 0 | 0 | 0 | 0 | 0 |
| 1st quartile | 5 | 4 | 4 | 6 | 5 | 4 |
| Mean (s.d.) | 6.70 (3.06) | 6.28 (3.23) | 6.33 (3.12) | 7.23 (2.54) | 6.67 (2.97) | 5.86 (2.77) |
| Median | 8 | 7 | 7 | 8 | 7.5 | 6 |
| 3rd quartile | 9 | 9 | 9 | 9 | 9 | 8 |
| Maximum | 10 | 10 | 10 | 10 | 10 | 10 |

| | Relationships 0m | Relationships 6m | Relationships 12m | Sleep 0m | Sleep 6m | Sleep 12m |
|---|---|---|---|---|---|---|
| Minimum | 0 | 0 | 0 | 0 | 0 | 0 |
| 1st quartile | 3 | 2 | 2 | 5 | 54 | 4 |
| Mean (s.d.) | 5.07 (3.14) | 4.81 (3.23) | 4.78 (3.27) | 6.64 (2.98) | 6.21 (3.17) | 6.12 (3.17) |
| Median | 6 | 5 | 5 | 7 | 7 | 7 |
| 3rd quartile | 8 | 8 | 8 | 9 | 9 | 9 |
| Maximum | 10 | 10 | 10 | 10 | 10 | 10 |

| | Enjoyment of life 0m | Enjoyment of life 0m | Enjoyment of life 0m |
|---|---|---|---|
| Minimum | 0 | 0 | 0 |
| 1st quartile | 5 | 5 | 4 |
| Mean (s.d.) | 7.06 (2.56) | 6.54 (2.9) | 6.46 (3.03) |
| Median | 8 | 7 | 7 |
| 3rd quartile | 9 | 9 | 9 |
| Maximum | 10 | 10 | 10 |

### CHANGES IN EQ5D-3L SCORES FROM BASELINE TO 12 MONTHS

| | Overall health state (0-100) 0m | Overall EQ-5D 0m | Overall health state (0-100) 6m | Overall EQ-5D 6m | Overall health state (0-100) 12m | Overall EQ-5D 12m |
|---|---|---|---|---|---|---|
| Minimum | 0 | -0.021 | 0 | -0.021 | 0 | -0.07 |
| 1st quartile | 30 | 0.238 | 32 | 0.2 | 30 | 0.2 |
| Mean (s.d.) | 51 | 0.49 (0.27) | 50.44 (22.97) | 0.4 (0.24) | 50.99 (23.12) | 0.43 (0.23) |
| Median | 50 | 0.534 | 50 | 0.37 | 50 | 0.43 |
| 3rd quartile | 70 | 0.73 | 70 | 0.6 | 70 | 0.66 |
| Maximum | 100 | 0.845 | 100 | 0.814 | 100 | 0.85 |

# Stakeholder feedback

## *Patient Liaison Group British Pain Society*

Many people may feel that the National Pain Audit is nothing to do with them — it's an audit of services that professionals look at to evaluate what is going on nationally. In fact it is all about the people that the service looks after, what happens to them in the service and to help individuals live their lives with their pain and maybe to relieve pain somewhat.

From the patient perspective you expect to be seen fast (really fast when in pain as every day can feel like a lifetime). You want a service that is safe, efficient and you don't even think that it would be any different anywhere else. Most patients think the NHS is the same all over — the National Pain Audit is proof that this is not true and has highlighted the poor quality of life that people living with pain experience.

The audit does show that multidisciplinary treatments are better but that it needs to be for a length of time that fits the patient's needs; it is not a one size fits all. Some patients need regular attendance to manage their pain effectively, and some are very severely affected by their pain. In contrast staffing levels that can deliver multidisciplinary treatment are a concern for too many clinics and cannot be ignored. The number of clinics setup for specialised care is too low, meaning there is no regional leadership, and worrying low numbers of non-English speakers are accessing pain services.

Patients need information about a service to be able to ask for it, it's a catch 22. How much information do you give patients and their families about your services?

Getting to the root of the problems in your local services and finding the solutions is not always easy. Developing a cycle of continuous audit, evaluation, consultation, implementation and audit again is not rocket science but it takes courage and leadership to make changes.

Pain services need to do this — follow the guidance — still do the day job and do it with compassion and empathy. In doing so more people living in pain will lead more fulfilling lives and perhaps return to work. The benefits don't just stop with the patient but extend to their family, friends and co-workers.

## *The Chronic Pain Policy Coalition*

Since its inception in 2006, the Chronic Pain Policy Coalition has been campaigning for improved pain management services in England. Crucial to achieving this goal has been the availability of robust information on availability and performance of pain management services. To this end, the National Pain Audit has been a crucial resource and we welcome this fourth stage report. We are particularly heartened by the rise in multidisciplinary pain services and the improved participation in the Audit. This report will be crucial in supporting the recommendations of the first English Pain Summit and will provide vital data to support the continued commissioning of high quality pain services.

The commissioning of Pain Management Services is currently under review and is in a state of flux with consideration of specialised tertiary and specialist secondary care pain management services and community and primary based services. This Audit has once again provided robust evidence of their importance and value in the management of patients with persistent pain.

## *Faculty of Pain Medicine*

The Faculty of Pain Medicine is the professional body responsible for the training, assessment, on-going practice and educational development of specialist medical practitioners dealing with pain issues in the United Kingdom. Its core mission is to serve the community by promoting professional excellence. Advancing high quality pain practice is thus fully integrated with optimising patient care.

The National Pain Audit has provided an impressively comprehensive survey of the provision of pain services. It has explored the organisational structure and processes as well as the fundamental requirement of evaluating patient outcomes. The feedback will inform the FPM, as a key stakeholder, of the current provision and limitations of services. It will thus help evolve improved standards in the clinical management, safety and efficiency of specialist pain services.

## *Royal College of General Practitioners (Placeholder)*

The authors of the fourth round of the continuing National Pain Audit (NPA) continue to give important insight into the complexities of pain services in England (and Wales).  Pain remains a Clinical Priority for the Royal College of General Practitioners, which has a specific responsibility following the National Pain Summit to produce guidance on the commissioning pain services. This version of the NPA gives important reflections on some of the changing dynamics in pain services that are happening due to the reorganization of the NHS. The commissioning support document for pain professionals is about to be published, and will hopefully address many of the inconsistencies in care that are demonstrated in this report. However the guidance will not have official prioritisation. As the NPA suggests, nationally agreed standards need to be agreed and adopted.

The report does not specifically address pain services in primary care, however the majority of chronic pain patients flow initially from primary care. Commissioning does not necessarily address what happens at the start of the treatment pathway. Thus the RCGP, along with the Faculty of Pain Medicine, intends to address core standards in pain services in Primary Care, with an emphasis on correct assessment and early treatment.

# National Pain Audit team

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Design by design to communicate

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### SPECIAL THANKS

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