Chronic Pain Services in Scotland: Where are we now?

April 2014
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Correction

Please note, following publication of this report in April 2014, an error in the data relating to the waiting time for pain psychology services in Forth Valley was identified. As of September 2013, NHS Forth Valley’s mean (and range) waiting time should read 78 (0–124) weeks and not 36 (30–64) weeks as originally published. We have now corrected the data on pages 10 and 38.
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Chronic Pain Services in Scotland: Where are we now?

Foreword

Dr Denise Coia, Chair, Healthcare Improvement Scotland

We know that chronic pain has a considerable impact on the quality of life for many people in Scotland. Approximately 800,000 people across Scotland are affected by chronic pain to varying degrees and it can result in significant suffering for both those directly affected and those close to them.

The scale of the challenge in improving the care for all affected is therefore significant. At Healthcare Improvement Scotland, our focus is to drive improvements in healthcare services. And our starting point has been understanding and analysing the current care provision in Scotland. In making that analysis, we have been able to make recommendations for a way forward which harnesses the commitment and desire to accelerating improvements to services we know already exists.

We look forward to the report’s information and recommendations being used by NHS boards, in conjunction with their third sector partners and patients, to help implement an improved model of care that patients suffering from chronic pain will benefit from for years to come.

Susan Scott, Chronic Pain Patient

Eighteen years ago my life changed overnight. I injured my spine which unfortunately has left me in constant pain ever since. Chronic pain is a complicated disease, the disabling effect on the body, both physically and mentally, should not be underestimated. It leaves sufferers feeling isolated and alone, as well as having to come to terms with the limitations it places on their lives. I am a dentist and at times have really struggled with work. If it hadn’t been for the fabulous support and understanding of my employer, work wouldn’t have been an option for me and the impact of my chronic pain even greater. It can’t be cured, but with the right help, management and ongoing support, the quality of life can be greatly improved.

But finding that help can be difficult and all too often at the moment patients are left to cope without adequate support or knowing how to access the help available. That is why I feel that patients should be closely involved in changes to the service and that their views are listened to. Who better to tell the clinicians what works and what doesn’t? I feel at the moment we have a unique opportunity to come together, to work together to provide high quality services that make a real improvement to the treatment and management of chronic pain in Scotland and welcome the development of Service Improvement Groups to lead this.
Dr Steve Gilbert: National Lead Clinician for Chronic Pain

Over the last 20 years, there have been a number of reports about the management of chronic pain in Scotland. The GRIPS report of 2008 noted the frustration with the lack of progress. From the information that we have collected for this latest report, we can see that some things have improved, but that much remains to be done.

Given that pain is one of the commonest reasons for people to seek healthcare advice, I am really glad to see more primary and community care involvement, as well as the inclusion of chronic pain as a priority by the Royal College of General Practitioners. I hope this will lead to more being done in primary care.

Chronic pain management, however, is still mostly seen as a specialty, to be managed in secondary/hospital pain clinics. To bring about real improvements, chronic pain needs to be recognised as a common condition and to involve the wider healthcare team and not just rely on treatment with medication. I believe that the Service Improvement Groups will be effective in involving colleagues in the voluntary sector and in primary care.

We need to make sure that the understanding of what to do at an early stage, when pain becomes chronic or persistent, becomes much more widely known by the public and healthcare professionals such as pharmacists, GPs and physiotherapists. We are working on consolidating pain management educational resources to make this a standard part of healthcare education and there are also local initiatives. Having high quality resources for patients, carers, healthcare professionals available on the www.chronicpainscotland.org website will also help with raising awareness and knowledge.

I believe that the future development of the Scottish Service Model for Chronic Pain (SSMCP) will help those with chronic pain to know what to do and where to find and get the best assistance in managing their pain towards better wellbeing and less suffering.
Our organisations work with the public, with those with chronic pain and their families and with healthcare professionals. We are all keen to make sure that services for those who need them are the best they can be and we look forward to hearing about how NHS boards progress the key recommendations.

The publication of this data report establishing the nature and scope of chronic pain services across Scotland is both welcome and timely. People who experience chronic pain have long called for more data to be available about the provision of services across Scotland to drive improvements in treatment and support for a condition which can have a profound impact on their daily lives. The collation of data, amongst other things, allows us to consider the level to which self-management approaches have been adopted across the country and consider strategies for their future embedding into practice.

We know that people with chronic pain have an interest in the development of services and service improvements and will want to have an opportunity to contribute to service developments. People need clear information about pain and where and when to get the right help. Knowing about what to do, what’s on offer and how to get it at the right time we know does impact on quality of life. We also know that across Scotland access to pain services has been patchy and inequitable, and reliable information is scarce. The type of information in this report is of real interest now, but vital going forward in order to capture whether the changes that are needed are being achieved on the ground and where further improvement is needed.
Executive summary

We know that chronic pain has a considerable impact on quality of life and results in significant suffering and disability for those affected and those close to them. We also know that in Scotland, there is wide variation in service provision, clinical practice and resources for the 800,000 people who are affected by chronic pain to varying degrees.

In 2013, the Scottish Government and specifically the Cabinet Secretary for Health and Wellbeing, Mr Alex Neil, announced the need to accelerate improvement across all levels of care and the intention to monitor progress through the NHS board Annual Review Process (29 May 2013).

This was welcomed by Service Improvement Groups established or in the process of being established within all NHS boards in Scotland to drive improvements in the management of chronic pain. The NHS boards also formally signed up to implementing the Scottish Service Model for Chronic Pain and committed to its implementation.

The model consists of four levels of care:

- **Level 1**: supported self-management
- **Level 2**: General Practitioner (GP) and Allied Health Professionals (AHP) primary care services
- **Level 3**: specialist multidisciplinary pain management teams
- **Level 4**: highly specialist services including specialist interventions and intensive residential services
The Scottish Government is committed to establishing a specialist residential chronic pain service in Scotland. This service is currently provided by the Bath Centre for Pain Services in England.

The recent public consultation showed a clear preference for the development of the service at a single location. The Scottish Government’s response to the consultation will be published in spring 2014.

To support NHS boards with their overall planning and to gain a national view of chronic pain service provision across the country, a data collection exercise was undertaken between September and November 2013.

Data were collated at two levels:

- organisation/service level which provided key information about the type of, approach to and current service provision across all levels of care (1-4), and
- individual patient level focusing on specialist (hospital-based) chronic pain services only (Level 3 and 4), nine data items including a patient reported quality of life outcome measure (EQ-5D-5L) and patient reported experience measure were collated.

As well as building an accurate picture of chronic pain service provision across the whole patient pathway and country, Level 3 specialist service patient data were provided by all NHS boards (although NHS Orkney, NHS Shetland and NHS Western Isles did not provide complete Level 3 patient data). This related to 799 new patients (794>16 years) over a snapshot four-week period. Additionally, over 1,800 new and return visit patients provided direct feedback about their experience.

Five NHS boards (NHS Fife, NHS Grampian, NHS Greater Glasgow and Clyde, NHS Lothian and NHS Tayside) also provided information about the pain services they offered specifically for children.
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Key findings about the organisation and provision of chronic pain service Levels 1-4

• Chronic pain services varied considerably across the country and particularly so in relation to ease of access, type of and scope of service provision across all levels of care (1–4).

• NHS boards were at different stages in terms of developing their Service Improvement Groups and improvement plans. One area, NHS Greater Glasgow and Clyde had established a Managed Clinical Network (MCN) with responsibility for chronic pain management since 2009. All others had established their Service Improvement Groups within the last 12 months and with financial pump priming support from Scottish Government.

• Considerable efforts were being put into producing local patient information and advice resources aimed at supporting self-management. This represents a degree of duplication across the country and the potential for inconsistent messages. However, it does present the opportunity to use the best of these and develop a national approach.

• Little evidence of any direct involvement of, or integration with, primary care GPs and/or Allied Health Professionals other than in three NHS boards at the time of data collection, but most NHS boards reported this as a priority going forward.

• Varying and mainly low levels of interaction with service users and the third sector in determining how services were organised and delivered locally. However, Service Improvement Groups reported that they were starting to address this.

• Few NHS boards were able to demonstrate coherent chronic pain pathways or evidence of joined-up services between primary and secondary care. The exception to this was NHS Fife which does offer a triage service to the appropriate level of care.
Key findings about Levels 3 and 4 specialist pain management services

- A national mean referral rate of 3.2 per 1000 of the population (3.2/1000) to Level 3 services ranging from 1.77–4.7/1000 with the lowest rates in NHS Grampian and highest in NHS Forth Valley.

- A mean waiting time to Level 3 services of 10 weeks (1–31) with NHS Grampian the longest (31 weeks). Two NHS boards, NHS Borders and NHS Western Isles reported mean waiting times of 7 weeks or less and the remainder between 8–16 weeks.

- The multidisciplinary teams within NHS boards differed considerably in terms of the disciplines involved and the number of whole time equivalents or being truly multidisciplinary. Five NHS boards (NHS Dumfries & Galloway, NHS Tayside and the three island boards) reported not having the full complement advocated (medical, nursing, physiotherapy, psychology with pharmacy and occupational therapy input). The highest proportion per 1000 of the local population of medical consultants was found in NHS Shetland (0.017/1000) and lowest in NHS Lanarkshire (0.0017/1000). The highest proportion of nurses was in NHS Tayside (0.014/1000) and lowest in NHS Forth Valley (0.0016/1000). Physiotherapy also varied, with NHS Fife the highest (0.0095/1000) and NHS Grampian the lowest (0.0005/1000) although four NHS boards had no dedicated provision. Psychology provision was highest in NHS Borders (0.003/1000) and lowest in NHS Grampian (0.0005/1000).

- Pain psychology service waiting times ranged from 9–84 weeks with a mean of 31.8 weeks. The shortest was found in NHS Tayside, with mean waits of over 36 weeks reported by NHS Greater Glasgow and Clyde (36 weeks), NHS Ayrshire and Arran (63 weeks), NHS Forth Valley (78 weeks) and NHS Borders (84 weeks).

- Although five NHS boards reported providing services to children, (NHS Fife, NHS Grampian, NHS Greater Glasgow and Clyde, NHS Lothian and NHS Tayside) only two had dedicated funding for these services (NHS Greater Glasgow and Clyde and NHS Lothian). In addition to some medical time, NHS Lothian had specialist nurse time (0.75 WTE). No NHS boards had any other staff with a recognised remit for children’s chronic pain services.

- Pain management programmes were operational in less than half of NHS boards (6 – NHS Fife, NHS Grampian, NHS Greater Glasgow and Clyde, NHS Highland, NHS Lanarkshire and NHS Lothian).

- Level 4 referral numbers considerably lower than NICE guidance would have predicted in relation to Scotland’s spinal cord stimulation population.
Key findings about the users of Level 3 specialist pain management services

- High levels of work absence (42%) and of more than 6 weeks (63.3%) in the third of those who were in employment (33.2%), with 34% reporting difficulties with remaining in work.
- For over one year, 89% had chronic pain problems.
- A demographic profile of 65.3% female and a mean age of 56 years.
- Multiple body areas were affected in 43.5%, with 20.2% affected by low back pain.
- A lower median quality of life than the population norm (0.3181 vs. 0.80) and particularly so in NHS Lanarkshire.
- Patient experience of Level 3 services varied by NHS board, but was generally positive. However, overall, 95% rated the actual care they received as either good or excellent. There was much praise for staff skills and attitudes, with patient concerns focusing on waiting times and a perception of staff shortages.
Recommendations

The main purpose of this report is to provide local NHS boards with key information about their services to help them plan and drive improvements. Based on the findings of the data collection exercise, key recommendations are made for NHS boards and Service Improvement Groups, for each level of the Scottish Service Model for Chronic Pain, the Scottish Government and for the National Chronic Pain Steering Group to be achieved by 2016.

NHS board and Service Improvement Group recommendations

- NHS boards take cognisance of the NHSScotland 2020 Local Delivery Plan (which requires NHS boards to prepare and implement a service delivery plan covering all aspects of chronic pain services from April 2014).
- NHS boards use the pump priming funding provided by the Scottish Government to establish a robust infrastructure that supports the implementation of the Scottish Service Model for Chronic Pain across all levels (1–4).
- NHS boards provide specific support to allow local Service Improvement Groups to achieve their aims and drive improvement in outcome and experience and, that service users, carers and the third sector are an integral part of the whole process.
- Service Improvement Groups should review the results of this national data collection exercise.
- Timescaled action plans are transparently and widely shared on the new chronic pain website (www.chronicpainscotland.org) and monitored by the Scottish Government.
- Local Service Improvement Groups should explore how those with chronic pain and absent from or struggling to stay in work can gain access to the available Health Works services scheme and improve working lives across all levels.
Level 1 recommendation: information and support

- Service Improvement Groups should create closer relationships with a range of third sector providers of supportive self-management information and support groups and make them more accessible at all levels and particularly, in community and primary care settings.

Level 2 recommendations: GP and other healthcare professionals

- Bring about a greater awareness, understanding and ability to manage chronic pain in the healthcare professionals who work in primary and community settings as outlined in SIGN 136 Management of Chronic Pain.
- Pathways of care are developed locally with a key focus on the early identification/stratification and management in primary and community care settings in line with SIGN 136 which includes access to pain management programmes.

Level 3 recommendations: specialist pain management services

- NHS boards should ensure access to the range of Level 3 specialist services recommended by the Scottish Service Model for Chronic Pain and that:
  - robust referral pathways are in place and widely shared,
  - multidisciplinary teams are in place, which includes as a minimum - specialist doctors, nurses, physiotherapists, psychologists, occupational therapists,
  - that the Level 3 service is integrated with primary and community care, and
  - all efforts are made to address the reported shortfalls and vacancies.
- Access to key services within NHS boards, and particularly to pain psychology services is improved.
- In those centres who do manage children with chronic pain, the current approach and staffing complement should be reviewed.

Level 4 recommendation: access and referral

- Referral criteria, access to and the provision of all Level 4 services (except the specialist residential chronic pain service which is being progressed separately) should be reviewed and endorsed by the National Chronic Pain Steering Group.
Scottish Government

- The Scottish Government provides the National Chronic Pain Steering Group with the support and resources to allow the Group to implement the recommendations below. This should be in the form of direct participation, dedicated co-ordination and clinical leadership.

National recommendations (to be overseen by the National Chronic Pain Steering Group)

- A national network for local Service Improvement Groups is established to share and learn from best practice overseen by the National Chronic Pain Steering Group.
- National, quality-assured advice, information and resources should be enhanced and made easily accessible to the public, service users and providers through a range of formats, predominantly web enabled and without necessarily requiring a healthcare professional referral.
- The range of learning and development resources for healthcare staff are developed further and widely shared to increase awareness of and skills for improved chronic pain management and particularly so for pharmacists, GPs, nurses and Allied Health Professionals.
- A mechanism is developed for use in primary care to identify those affected by chronic pain. This will allow better management and measurement of outcomes.
- The National Chronic Pain Steering Group should ensure that referral criteria for the specialist residential chronic pain services, once agreed, are shared across NHS boards.
- The national chronic pain dataset should be reviewed by the National Chronic Pain Steering Group in light of the 2013 exercise, refined as required and endorsed for national use.
- A further national data collection exercise should be undertaken by 2016 to quantify the extent to which services have improved from the baseline provided within this report.
Patient summary

This report is about the services that people with chronic pain were experiencing across Scotland in the autumn of 2013. Chronic pain is pain that has been present for more than 12 weeks despite medication or treatment. We were keen to understand this because chronic pain services everywhere had signed up to what is known as the Scottish Service Model for Chronic Pain.

The model sets out:
• what people need to help them live with their pain
• the information and advice they need, and
• when they need the help of healthcare professionals including GPs, physiotherapists, psychologists and the most specialist pain teams.

The Scottish Government has also recognised the need to improve chronic pain services and has directed NHS boards to do this and report these improvements directly to them. Local services needed to understand what they were providing, including what users of specialists services thought about them to be able to plan for and introduce the changes needed. They also value sharing with and learning from others.

The report has shown that in many parts of the country there are considerable improvements to be made and teams of healthcare professionals committed and keen to do this. Some patients were able to attend training programmes and self-management support groups run by both third sector organisations and healthcare services. However, not everyone has this opportunity. There is also a need for more training for pharmacists, GPs and physiotherapists in how to best manage chronic pain so people can get the right information and help at the right time. Patients seen by the specialist pain teams commonly had a poorer quality of life than the Scottish population, with many having a problem with being able to stay in work.

Getting access to pain services and pain psychology services in particular was difficult in some areas of the country.

All NHS boards in Scotland took part in this work and, at the time of collecting the information, all were formally signed up to improving services and had developed or were revising their improvement plans. This is reassuring and shows that healthcare services are serious about improving the care they provide and supporting the healthcare professionals to do this. This is good news for the people of Scotland. The fact that the Scottish Government will be monitoring how local services are doing and providing support for them to do this is also good news. People across Scotland will look forward to being able to report the progress made.

Most people think the NHS is the same all over Scotland. The chronic pain report shows this is not true and has highlighted the need for the right care at the right time and in the right place to improve the quality of life of people living with chronic pain.
Introduction

Chronic pain has a considerable impact on quality of life, resulting in significant suffering and disability for those affected and those close to them\textsuperscript{1-5}. Chronic pain is pain that has been present for more than 12 weeks despite medication or treatment\textsuperscript{6}.

It is also a major clinical challenge, with approximately 18\% of the population experiencing chronic pain at any time, of whom 6\% have severe pain\textsuperscript{7}. Although for many, a cure is often not possible, appropriate care and support can greatly reduce suffering and its detrimental effect. The majority of people with chronic pain are managed in primary and/or community care settings, by GPs and Allied Health Professionals with a small proportion requiring access to specialist hospital-based services (Level 3). The majority also have chronic pain that is musculoskeletal in origin with neuropathic pain associated with nerve damage experienced by 10\%, although it is also associated with other conditions\textsuperscript{7}.

The most common pathway experienced by people with chronic pain within the NHS (see Figure 1) can involve contact with pharmacists, GPs, Allied Health Professionals, especially physiotherapists, and occasionally, hospital-based specialist doctors before a referral to Level 3 pain specialist services is considered. It is suggested that between 5-10\% of those with chronic pain go on to be referred to secondary specialist chronic pain services\textsuperscript{7}.

In Scotland, it is recognised that in relation to chronic pain, there is wide variation in service provision, clinical practice and resources\textsuperscript{8,9}, but over the last five years, considerable efforts have been made by a wide range of statutory and non-statutory bodies including the third sector to address this problem.

Figure 1: Chronic pain pathway
The position in Scotland in 2013

By late 2013, the overall national picture included the following.

- A clear expectation set out by the Scottish Government that improvement across all four levels of chronic pain care was required and the intention to monitor progress through the NHS board Annual Review Process.
- A commitment from the Scottish Government to establishing a Scottish residential chronic pain service. The 2013 public consultation showed a clear preference for the development of the service at a single location. The Scottish Government’s response to the consultation will be published in spring 2014.
- A National Chronic Pain Steering Group with a revised role, remit and membership to reflect the evolving local arrangements. A group which recognised the need for a proactive national network to support local efforts with increased service user and third sector involvement to ensure a stronger patient voice.
- Service Improvement Groups established or being established in all NHS boards in Scotland.
- Two years funding provided by the Scottish Government to support NHS boards continue to develop their local Service Improvement Groups and drive forward improvements (£100,000 for each mainland territorial NHS board over two years, £70,000 for island boards).
- A revised Scottish Service Model for Chronic Pain (Figure 2) which recognised that everyone needs easy access to high quality, consistent advice, information and resources to help them and that:
  - most people affected by chronic pain primarily manage their day to day lives themselves and need the best advice and information resources to help them to do so (Level 1).
  - some may need the help of community and/or primary care healthcare professionals who are skilled and knowledgable about how best to manage and support those with chronic pain and also know when it is appropriate to refer to more specialist care (Level 2)
  - a smaller number will require more specialist help from chronic pain multidisciplinary teams who work together and with patients to identify and provide the best treatment and support options (Level 3), and
  - an even smaller number will require the very most specialist and/or intensive help and interventions (Level 4).
- All NHS boards formally signed up to both the principle and implementation of the model within their own area which remains a key aim of the current improvement programme.
• The publication of SIGN Guideline 136, Management of Chronic Pain. This sets out the evidence for the assessment and treatment of chronic pain in primary care and community settings.

• Since 2009, Healthcare Improvement Scotland has provided project support to the overall Chronic Pain Improvement Programme. However, earlier in 2013, Healthcare Improvement Scotland reviewed and revised the overall action plan in partnership with the National Chronic Pain Steering Group. Eight key actions were identified for 2013-2014 (Table 1) including one that specifically called for the need to develop and undertake a national data collection exercise (Action number 5).

Figure 2: Scottish Service Model for Chronic Pain

Most people get back to normal after pain that might come on after an injury or operation or for no apparent reason. Sometimes the pain carries on for longer than 12 weeks despite medication or treatment – this is called chronic or persistent pain.
Table 1: Healthcare Improvement Scotland: Chronic Pain Key Action Plan 2013-2014

1. Support national sign up to the use of the Scottish Service Model for Chronic Pain (SSMCP)

2. Support all NHS boards to establish and develop Service Improvement Groups

3. Produce information, advice and guidance for Service Improvement Groups to support their development and implement the SSMCP

4. Identify future SIG support requirements for 2014 going forward and convey to Scottish Government

5. Develop and undertake a national data collection exercise

6. Produce high quality advice and guidance and information resources for the public and those with chronic pain

7. Produce high quality educational/learning guidance and materials for healthcare professionals

8. Publish a SIGN Guideline for the primary care management of chronic pain
The need for a national data collection exercise

Up-to-date information was seen as critical for a number of reasons and audiences. If variation in service provision is to be reduced and equity increased across Scotland improving service user outcomes and experience, a better understanding of services is needed. Current information was needed about:

- how services are currently organised,
- what they provide,
- what service users think of them, and
- where there were gaps in provision.

Previous reports of chronic pain provision in Scotland were available, but none could fully describe the latest position and therefore credibly inform next steps. The information provided within this report aims to build on previous reports and be of current value to local services and service users as well as national organisations and the National Chronic Pain Service Improvement Network. It primarily aims to:

- help staff better understand the wider aspects of all levels of care and particularly Level 3 and 4 services, including their impact and what users think about them
- support the enhancement of local timescaled action plans, and
- provide a baseline from which any improvements can be measured in the future.

However, important secondary aims were to:

- produce a coherent picture of chronic pain management across Scotland, and
- identify examples of good practice for wider sharing and learning through a national chronic pain network.

As well as supporting local service improvement as outlined above, NHS boards are now required to report their position and performance directly to the Scottish Government as part of the NHSScotland 2020 Local Delivery Plan [www.scotland.gov.uk/Resource/0043/00439375.pdf](http://www.scotland.gov.uk/Resource/0043/00439375.pdf).

It states that NHS boards will set out planned levels of improvement and the approach being taken to prioritising improvement areas specifically in relation to chronic pain and Allied Health Professionals musculoskeletal services. The national data collection exercise will help the National Chronic Pain Steering Group to support this requirement.
The approach to data collection

Guiding principles

Rather than seeing this as a ‘one-off’ exercise, the intention was to create and test an approach to measurement that supports service improvement within chronic pain services and could be mainstreamed into routine practice including the tools and resources required.

With the full support of the National Chronic Pain Steering Group, the approach taken was guided by certain key principles. The exercise was designed to be:

• inclusive and transparent
• comprehensive and proportionate
• relevant, meaningful to and valued by local and national stakeholders including service users
• achievable, straightforward to undertake for services and service users, and
• reproducible and underpinned by validated, national core measures wherever possible.

All materials that supported the data collection exercise can be found in ‘Our Approach to Data Collection’. This document is available on www.healthcareimprovementscotland.org/chronic_pain.aspx and includes:

• Chronic Pain Measurement Framework (including Core Dataset)
• organisation/service and Level 3 patient data item details
• semi-structured interview proforma
• Level 3 and 4: Guidance Notes for Service Improvement Groups
• Level 3 and 4: Data Collection Sheet
• ‘Must do with me’ Patient Experience of Level 3 and 4 Chronic Pain Services
• EQ-5D-5L guidance, and
• the patient consent form.

Chronic Pain Measurement Framework

The Chronic Pain Measurement Framework was developed and endorsed by the National Chronic Pain Steering Group in July 2013. It was designed to support data collection undertaken at both organisational and individual patient levels. It consisted of a mixed methods approach which included both qualitative and quantitative data.

The core dataset

A chronic pain core dataset with supporting definitions and values relating to the individual Level 3 service user was determined and agreed. It consisted of 11 essential and eight desirable data items. Wherever possible, validated, national definitions were used. The dataset included a person reported outcome measure (PROM) and a person reported experience measure (PREM).
Person reported outcome measure

The PROM used was the EQ-5D-5L, a simple quality of life measure that can be used to demonstrate the quality and effectiveness of services and provide data for use in economic evaluations. It is used widely throughout the UK and globally to provide information at the individual person, service and/or population level of use for service users, services and policy makers. The EQ-5D-5L is also the PROM of choice within the Scottish National Musculoskeletal Redesign Programme with an established licence for its use in situ. It has a number of attractive features including:

- simple and quick to use; it takes less than two minutes to complete
- ideally suited for use in postal surveys, over the telephone or in face to face interviews
- robustly developed with a strong academic basis
- providing simple and relevant data within and across conditions and services, and
- potentially useful for economic analysis / cost-effectiveness.

Service users complete the EQ-5D-5L by scoring each of the five dimensions (see Figure 3) using a scale of 1-5 where 1 represents ‘no problem’, and 5 the ‘most severe’. Individual service user data relating to the five dimensions is then collated into a single weighted score. The weighted score, the EQ-5D-5L index score, lies between 0–1 where 1 equates to ‘full health’ and 0 to the quality of life equating to death.

Collecting the same information at discharge generates a second single index score and it is the difference in these scores that generates the change in the quality of life of:

- mobility
- selfcare
- usual activities
- pain/discomfort, and
- anxiety/depression.
Patient reported experience measure

The PREM used was the approach and tool developed by the ‘Better Together’ national patient experience programme. The programme has developed a web-based approach to collating the healthcare experience of patients (www.care-experiences.com). It has an extensive ‘library’ of robustly developed and validated questions. A set consisting of five specific and one general satisfaction questions was developed for use with chronic pain Level 3 service users and tested by the patient experience team.

The questions related to the person’s views about:
- how involved they felt in the discussion about their care
- whether they were given the information they needed
- whether they were listened to
- whether they got the care they needed
- whether staff took account of the people that mattered to the service user and involved them accordingly, and
- how they rated their overall care.

There was also the opportunity to provide additional comments. Each NHS board was assigned a unique code that their patients used to gain access to the system and record their views.
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Organisation/service level

How chronic pain services were organised and provided was known to vary by NHS board. This was due to the fact that in some places these services had evolved often through the specific clinical interest of local clinicians and not through active service planning. The British Pain Society and SIGN, had both produced guidance in relation to pain management provided, in both specialist and non-specialist (primary and community care) settings. These evidence-based frameworks set out how people with chronic or persistent pain can best be helped and also empowered to help themselves. Both publications strongly advocate for a bio-psychosocial approach to the assessment and management of pain irrespective of where care takes place. For those who need more specialist care (Level 3), the guidance is also clear that this should be provided by a multidisciplinary team (doctors, nurses, occupational therapists, physiotherapists, psychologists) who work together with those with chronic pain to achieve optimal pain management. Both guidelines also recognise the important contribution voluntary organisations and the third sector have to make in supporting people to achieve the best outcomes.

In Scotland, the most highly specialist care services (Level 4) are provided by the major centres in Aberdeen, Dundee, Edinburgh and Glasgow, staffed by healthcare practitioners with highly advanced knowledge and skills in pain management.

Although the guidance is clear about the approach needed for optimal care, they do not contain any information about the actual staffing levels required at population level to deliver these services. Responsibility for ensuring services are adequately staffed remains with individual NHS boards to determine. NHS boards should also take into account the wider context of service provision locally, for example, the extent and accessibility of Level 1 services such as Pain Association Scotland, the skills and knowledge of GPs and ease of access to Allied Health Professionals musculoskeletal services.

Due to the known variation across Scotland, information about how services were organised and provided was therefore gathered through semi-structured interviews. This included collating information from NHS Fife, NHS Grampian, NHS Greater Glasgow and Clyde, NHS Lothian and NHS Tayside about their specific children’s pain services.

The overall timeline for the data collection exercise can be found in Figure 4.
Figure 4: Data collection exercise timeline

<table>
<thead>
<tr>
<th>Date Range</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>April – September 2013</td>
<td>Measurement and monitoring tools and guidance developed</td>
</tr>
<tr>
<td>September – October 2013</td>
<td>Semi-structured interviews with Service Improvement Groups</td>
</tr>
<tr>
<td>October 2013</td>
<td>Four-week snapshot of Level 3 patient profile, activity and outcomes</td>
</tr>
<tr>
<td>December 2013</td>
<td>Data collated and shared with National Chronic Pain Steering Group</td>
</tr>
<tr>
<td>January – March 2014</td>
<td>Report compiled</td>
</tr>
<tr>
<td>March 2014</td>
<td>Service Improvement Groups reviewing their service improvement plans</td>
</tr>
<tr>
<td></td>
<td>Key issues shared at national share and learn event</td>
</tr>
</tbody>
</table>

The semi-structured interview

Drawing on the most recent 12 months’ activity, the national chronic pain facilitators conducted semi-structured interviews with NHS board chronic pain clinical leads between September-October 2013. Using a proforma, they collated information about:

- how local services were organised and what they provided
- how developed the local service improvement group was
- any particular challenges or issues they were experiencing, and
- their key priorities for the next two years.

Waiting times

One part of the interview was concerned with finding out the waiting times to Level 3 specialist services as this had been commonly cited as being of particular concern in some NHS board areas. Waiting times, the mean and range to first and return appointments with specialist chronic pain teams (Level 3) were collated. This included waiting times to follow-up referral appointments with individual disciplines including pain psychology services which had already been identified as particularly long in many areas. Please note that this refers specifically to pain psychology services and not to routine or mental health psychology services.
Allied Health Professionals musculoskeletal services

The waiting time to Allied Health Professionals musculoskeletal services (AHP MSK) in each NHS board was also included due to the direct relevance these services can have on specialist chronic pain services and the overall management of people with pain. Up to 80% of chronic pain is musculoskeletal in origin. Most people with MSK problems who are eventually referred to Level 3 and Level 4 chronic pain services have either been referred to and/or previously experienced AHP MSK services. There is compelling evidence that prompt and easy access to AHP MSK services can reduce the risk of pain, chronicity and improve patient outcomes and experience.

It is recognised in Scotland that there is wide variation in waiting times for AHP MSK services, reported to be as much as 26 weeks in 2012. However, more recently, a national MSK redesign programme is bringing about a considerable reduction in waiting times across the country and aims to have a maximum waiting time of 4 weeks by 2015. This has a direct impact on chronic pain services, not only significantly influencing the number of patients referred to them, but also the degree of chronicity presented hence the reason for its inclusion.

Patient level data collection in Level 3 specialist pain management services

Patient level data were collated by local staff during a four-week period between October–November 2013. It related to all new adult patients (>16 years) seen, and five children 0-15 years, during the period. Prior to this, all NHS boards were provided with a range of tools to collect the required data and clear guidance in what, how and when to do this. The guidance was reinforced by the national facilitators during face to face meetings in the run up to the data collection period. Much of the information (9 of the 11 data items) was collated locally by staff and then shared electronically with Healthcare Improvement Scotland in a patient anonymised manner using Survey Monkey. However, PROM and PREM data were collated and shared differently, but still in an electronic format.
EQ-5D-5L data

Services were provided with a specifically designed Excel spreadsheet to collate the EQ-5D-5L data with embedded functions that automatically calculated the weighted scores. At the end of the data collection period, a non-patient identifiable summary sheet was generated which provided data per dimension per NHS board area, together with the mode and overall median weighted scores. Only data relating to new patients were collated due to the constraints of the four-week period and the nature of chronic pain management exceeding this time for the majority of patients. There were therefore no ‘pre and post’ scores for comparison. However, this baseline information provides a useful view of the profile of service users attending these services for each NHS board. Some NHS boards are continuing to use EQ-5D-5L which will allow them to undertake comparisons of pre and post scores to provide an indication of the extent of any change in patient status in the future. The summary sheet with all personal identifiers removed was then shared with Healthcare Improvement Scotland.

Patient reported experience measures

All and not just new patients seen during the four-week data collection period were encouraged to provide feedback about their care experience. The National Patient Experience Programme’s web-based system was used for inputting and collating these views (www.care-experiences.com). Each NHS board was provided with a unique code for their patients to use. However, as not everyone has access or chooses to use the internet, a number of other options were put in place to enable and encourage patients to provide feedback. The choice of method was locally determined, but included the following.

- Handing a specially printed business card to every patient seen which provided the web address and the unique code attributed to each NHS board. Patients were asked to complete the questionnaire online either at home or in a location of their choice.
- Making available an internet access point, usually a laptop or PC in the clinic area for patients to use to provide feedback after their appointment.
- Asking the patient to complete the survey on paper and either posting when back home or completing before they left the clinic. Paper responses were then entered manually by local staff directly into the web-based system.
Data verification and clinician feedback on exercise

All data were collated and prepared for publication by Healthcare Improvement Scotland. During January and February 2014, each NHS board was asked to review their data before its inclusion within this report and to provide formal verification of its accuracy. At the same time, clinical teams were asked for their views and thoughts on the data collection exercise.

Limitations

The patient level data collection exercise was conducted within Level 3 and Level 4 chronic pain services only. It had to be limited to these services despite there being a far greater number of individuals affected by chronic pain managed in community and primary care settings. This was because it was not possible to accurately and consistently identify people managed in non-hospital settings as they are not formally classified as having chronic pain, but rather by the diagnosis or condition that may or may not relate to it. Ways to address this are being explored by the National Chronic Pain Steering Group.

It also needs to be noted that the Level 3 patient data was a four-week snapshot only and therefore in the smaller NHS boards, the number of patients involved should be considered and the observations in this report, although helpful, should be viewed as such.
What we found

It needs to be noted that these results represent the position in NHS boards as of October 2013 and that it is known that even since that time, progress has been made across the country. This particularly relates to the Service Improvement Groups and their timescaled action plans which have now been developed, many informed by this data collection exercise, and submitted to the Scottish Government.

The information in this report therefore should be used to refresh these plans and seen as a reliable baseline from which to monitor progress in the future.

Most NHS boards were able to provide all required information from existing information systems or by collating prospectively. In a couple of NHS boards, and particularly NHS Greater Glasgow and Clyde and NHS Tayside, the clinical services experienced considerable difficulty in accessing some of the information. In light of this, NHS boards should ensure that chronic pain services are supported locally by robust information management systems.

As previously stated, the primary purpose of this report is to provide information to NHS boards and their Service Improvement Groups to help them better understand their service and to develop meaningful improvement action plans.

The results relating to all aspects of the data collection exercise, the semi-structured interviews (including information about children’s services), the Level 3 patient data collection, and the PROM and PREM are therefore presented by individual NHS board.

After verifying their own data in February 2014, NHS boards also outlined their top three priorities for the forthcoming year. Each NHS board’s detailed report can be found on www.healthcareimprovementscotland.org/chronic_pain.aspx

A further secondary aim was to produce a more coherent picture of chronic pain services across Scotland. To support this, the Level 3 patient data are also presented in different formats to support a national overview:

- combined national results
- a quick look-up table of all NHS boards, and
- pain services for children.

These national overview tables can be found on www.healthcareimprovementscotland.org/chronic_pain.aspx
**Summary findings**

**Level 1 services: Advice and information about pain and what to do about it. Anyone can access these services from home or community settings.**

In terms of providing advice, information and resources that support self-management, it would appear that there is no clear and consistent approach to the development and provision of Level 1 services across Scotland. There were a few examples of community-based Level 1 resources being available to people without a healthcare professional’s referral, for example, the information about chronic pain found on the NHS inform website (www.nhsinform.co.uk/MentalHealth/Wellbeing/Long-Term-Health-Conditions/Chronic-Pain-Management) and from community pharmacies. In some parts of some NHS boards, the public and those with chronic pain have easy access to local support groups whereas others do not. Pain Association Scotland were the main provider of support groups and/or self-management courses across Scotland and involved with most NHS boards (10/14). Other third sector organisations were reported to fulfil similar roles. However, it is known that not all areas within NHS boards are covered by these arrangements, for example, some boards cover large geographical areas with people having to travel considerable distances to access these groups and/or courses.

There was conflicting information about the content of these courses and their perceived local value by service users and staff with some appearing to meet local needs more than others. In areas where there are no formal or comprehensive arrangements in place, there is the opportunity for NHS boards to create closer relationships with a range of third sector organisations that are keen to co-produce resources to benefit those with chronic pain and provide more support activities nearer to everyone’s home.

A range of locally developed information resources were referred to and provided as part of the exercise, some of which were impressive. However, in some cases, the quality of their presentation could have been improved, an issue commented on by a service user in one area who suggested that a new photocopier was required. In some NHS board areas, services had an ad hoc approach and relied on information from organisations such as the British Pain Society. Regardless, what needs to be addressed is the duplication of effort being made across the country together with the variable quality of content and presentation of these resources. The value of having nationally developed and endorsed resources made available in a variety of formats, but especially in an electronic format, must be considered.
Level 2 services: When help from a GP or therapist is needed.

Level 2 services were the least developed, with no NHS board able to demonstrate a truly integrated service. This is unfortunate as it is well accepted that this approach has the potential to bring about the biggest improvement in outcome and experience of chronic pain. The most advanced were those provided by NHS Fife which included the RIVERS Programme where central triage directs patients to the appropriate level of care. There are also close links with primary care physiotherapy, orthopaedics, rheumatology, neurology and addiction services to ensure consistent information for patients.

In general, there was little evidence of system-wide engagement. However, there were examples of NHS boards developing local education programmes for up-skilling local GPs and Allied Health Professionals in advanced pain management and driven by Level 3 services. Better and more focused engagement with primary care and Allied Health Professionals services is required and should be addressed by Service Improvement Groups as a matter of urgency.

The inability to consistently identify those with chronic pain in primary care settings was also identified. This related to identifying, diagnosing and coding the presence of chronic pain in individuals and, at a population level.

There were examples of a minority of Level 2 services, predominantly physiotherapy services, that were using stratification tools such as STaRT Back to identify those with back pain most at risk of having persistent problems, but these are not being routinely used by GPs or Allied Health Professional services.

Being able to identify people with chronic pain in primary care and community settings is important for many reasons, but especially to be able to monitor management, progress and outcomes. As previously reported, the absence of a ‘code’ to specifically assign to chronic pain needs to be addressed nationally and should be progressed by the National Chronic Pain Steering Group. There are examples in some areas, NHS Fife for example, of aspects of chronic pain management being added to the local Quality Outcomes Framework for GPs in order to raise awareness and improve the quality and timeliness of specialist referrals. The Royal College of General Practitioners has also identified chronic pain as one of their four clinical priorities for 2011-2014.
Level 3 services: For those needing more specialist help from a chronic pain management service.

There was considerable variation across Scotland in how Level 3 services were organised and the approach they adopted to service delivery. There were examples of some NHS boards, for example NHS Greater Glasgow and Clyde, that had adopted an integrated approach supported by a Managed Clinical Network in place since 2009. Others appeared quite embryonic and removed from wider functions although many did report the desire to become more integrated. There were also examples of different services within one NHS board area that were organised and delivered separately to each other with little integration. It needs to be recognised that most services had developed over time based on a strong medical model and enthusiastic leadership. NHS Forth Valley, NHS Grampian, NHS Tayside are good examples and although there were other disciplines involved, these services could develop a much stronger multidisciplinary bio-psychosocial approach as advocated by national guidance. The quality of team relations and interactions across the country was generally perceived to be good. However, in a small number (2), it was felt that there was scope for better internal communications and more cohesive multidisciplinary team working.

Services for children with chronic pain were provided to differing degrees in five NHS board areas of Scotland: NHS Fife, NHS Grampian, NHS Greater Glasgow and Clyde, NHS Lothian and NHS Tayside. Only in NHS Greater Glasgow and Clyde and NHS Lothian were these provided by specifically funded pain consultants and, in NHS Lothian, with the addition of a specialist pain nurse. NHS Tayside reported being in the process of developing a children’s chronic pain services, ‘steps to better healthcare’.

What is clear is that the majority of chronic pain services had not been established or designed around the needs of children with most having to travel to the major cities (Glasgow and Edinburgh) to access care.

There were reports of difficulties with recruiting staff for Level 3 services in some NHS board areas, specifically medical and pain psychology staff, despite efforts to do so. This was particularly highlighted by NHS Grampian who also experienced the longest mean waiting time (31 weeks). In two of the island boards, NHS Orkney and NHS Western Isles, the service had been provided by single handed doctors both of whom were due to retire. At the time of writing, a replacement clinician has started in NHS Orkney, but nothing is yet confirmed for NHS Western Isles. There is a risk therefore that the service could experience some degree of disruption given the particular challenge of recruiting multidisciplinary specialists in remote and rural areas. Vacancies for other key multidisciplinary staff, psychologists and physiotherapists were also identified. The need for and value of a full multidisciplinary team was echoed in some of the patient feedback who appeared to be aware of the vacancies and the impact they had on service provision.

Staffing issues are not the only challenge for remote and rural areas. Patients often have to travel considerable distances to access Level 3 specialist services. Telehealth options should therefore be considered and it is known that this is currently being explored by research teams in Glasgow and Aberdeen.
Multidisciplinary Level 3 teams across the country

The whole time equivalent establishment of the dedicated disciplines within each NHS board’s multidisciplinary team was collated and can be found in detail within the individual NHS board reports. The variation in the disciplines involved (see Figure 5) and proportion per 1000 (see Table 2) of the local population is clear.

Figure 5: Whole Time Equivalent of Individual Professions within Level 3 Services by NHS board
Guidance indicates that Level 3 multidisciplinary specialist teams should have dedicated medical, nursing, physiotherapy, psychology with input from pharmacy and occupational therapy as well. It does not provide any advice as to the numbers required at population level. However, as can be seen in Figure 5, not all NHS boards had the full complement as advocated, particularly seen in the island boards. However, when the established whole time equivalents are expressed as a proportion per 1000 of their board population, the picture is somewhat different (see Table 2).

In terms of medical pain consultants, NHS Shetland had the highest proportion (0.017/1000) with the lowest seen in NHS Lanarkshire (0.0017/1000) and NHS Fife (0.002).

Physiotherapy input also varied considerably with four NHS boards having no dedicated service at all (NHS Dumfries & Galloway and the island NHS boards). The highest levels were seen in NHS Fife (0.0095/1000) and lowest in NHS Lanarkshire (0.0017/1000) and NHS Grampian (0.0005/1000).

Similarly, four NHS boards had no dedicated pain nurses within their team with the highest levels seen in NHS Tayside (0.014/1000) and NHS Borders (0.009/1000), and lowest in NHS Forth Valley (0.0016/1000) with NHS Grampian, NHS Lanarkshire and NHS Lothian in the lower values (0.002/1000).

Dedicated pain psychology services were not available in four NHS boards. Highest levels of input were seen in NHS Borders (0.003/1000) and NHS Lothian (0.0054), and lowest in NHS Grampian (0.0005/1000). It is interesting to observe the level in NHS Borders given that they reported the highest waiting times to these services, but explained by the fact that this post was vacant for most of 2013.

It would appear from this complex landscape that there is not a direct correlation between the establishment of Level 3 multidisciplinary teams and waiting times. More detailed examination of service provision and patient pathways would help to clarify this position.
Table 2: Individual discipline by proportion per 1000 of the local population

<table>
<thead>
<tr>
<th>NHS board</th>
<th>Pain consultant per 1000 population</th>
<th>Pain physiotherapist per 1000 population</th>
<th>Pain nurse per 1000 population</th>
<th>Pain psychologist per 1000 population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ayrshire &amp; Arran</td>
<td>0.003</td>
<td>0.003</td>
<td>0.0005</td>
<td>0.001</td>
</tr>
<tr>
<td>Borders</td>
<td>0.007</td>
<td>0.005</td>
<td>0.009</td>
<td>0.003</td>
</tr>
<tr>
<td>Dumfries &amp; Galloway</td>
<td>0.005</td>
<td>0</td>
<td>0</td>
<td>0.001</td>
</tr>
<tr>
<td>Fife</td>
<td>0.002</td>
<td>0.0095</td>
<td>0.003</td>
<td>0.0007</td>
</tr>
<tr>
<td>Forth Valley</td>
<td>0.008</td>
<td>0.001</td>
<td>0.0016</td>
<td>0.0007</td>
</tr>
<tr>
<td>Grampian</td>
<td>0.0035</td>
<td>0.0005</td>
<td>0.002</td>
<td>0.0005</td>
</tr>
<tr>
<td>Greater Glasgow and Clyde</td>
<td>0.0056</td>
<td>0.006</td>
<td>0.006</td>
<td>0.002</td>
</tr>
<tr>
<td>Highland</td>
<td>0.004</td>
<td>0.0034</td>
<td>0.005</td>
<td>0.0025</td>
</tr>
<tr>
<td>Lanarkshire</td>
<td>0.0017</td>
<td>0.0017</td>
<td>0.002</td>
<td>0.0017</td>
</tr>
<tr>
<td>Lothian</td>
<td>0.003</td>
<td>0.0035</td>
<td>0.002</td>
<td>0.0054</td>
</tr>
<tr>
<td>Orkney</td>
<td>0.0046</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Shetland</td>
<td>0.017</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Tayside</td>
<td>0.006</td>
<td>0.0024</td>
<td>0.014</td>
<td>0</td>
</tr>
<tr>
<td>Western Isles</td>
<td>0.0072</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>
Chronic Pain Services in Scotland: Where are we now?

Referral rates to Level 3 specialist chronic pain services

The number of patients referred to Level 3 services also varied across the country as might be expected (see Figure 6). As previously outlined, it is the wider context of how other levels and other services are organised and available, the awareness and skills of GP referrers and their referral behaviour together with the waiting times to Level 3 services that will contribute to this. Higher or lower numbers of referrals should not be seen as any indicator of quality, but only of demand. The national mean referral rate was 3.6 per 1000 of the population (/1000) and ranged from 1.77–4.7/1000. However, the lowest rate was reported by NHS Grampian who also had the longest mean waiting time (31 weeks) together with considerable recruitment issues.

![Figure 6: Number of referrals to Level 3 specialist services by NHS board per 1000 population](image)

<table>
<thead>
<tr>
<th>NHS board</th>
<th>Referral rate per 1000 of the population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ayrshire &amp; Arran</td>
<td>2.7</td>
</tr>
<tr>
<td>Borders</td>
<td>2.3</td>
</tr>
<tr>
<td>Dumfries &amp; Galloway</td>
<td>4.1</td>
</tr>
<tr>
<td>Fife</td>
<td>4.1</td>
</tr>
<tr>
<td>Forth Valley</td>
<td>4.7</td>
</tr>
<tr>
<td>Grampian</td>
<td>1.77</td>
</tr>
<tr>
<td>Greater Glasgow and Clyde</td>
<td>2.4</td>
</tr>
<tr>
<td>Highland</td>
<td>2.59</td>
</tr>
<tr>
<td>Lanarkshire</td>
<td>2.75</td>
</tr>
<tr>
<td>Lothian</td>
<td>2.5</td>
</tr>
<tr>
<td>Orkney</td>
<td>3.42</td>
</tr>
<tr>
<td>Shetland</td>
<td>4.1</td>
</tr>
<tr>
<td>Tayside</td>
<td>4.5</td>
</tr>
<tr>
<td>Western Isles</td>
<td>3</td>
</tr>
<tr>
<td>National mean</td>
<td>3.2</td>
</tr>
</tbody>
</table>
Waiting times to Level 3 specialist services

Most people referred to Level 3 chronic pain services have already been seen by other healthcare professionals usually including their GP and/or other Allied Health Professional or hospital-based consultants before being referred (see Figure 1, page 16). This complexity in terms of trying to assess the quality and appropriateness of their management makes it difficult to meaningfully draw conclusions from waiting times alone without considering the overall pathway, an exercise that needs to be undertaken locally.

For example, how speedily Allied Health Professional musculoskeletal services can be accessed and how skilled Allied Health Professional staff are in the management of pain has a direct relationship with patient outcome and further referral rates to Level 3 chronic pain services. What was apparent from these results was that access to Allied Health Professional musculoskeletal services as of October 2013 did vary across the country. The national mean waiting time to these services was 10.5 weeks (5-22), with some of the longest waits experienced in NHS Borders and NHS Ayrshire & Arran. We also know that there is a national target to reduce this to under four weeks by 2015.

Throughout Scotland, the time patients waited to be seen by Level 3 services ranged considerably (1-31 weeks), with a mean wait of 10 weeks (not specified in two NHS boards) (see Figure 7). The shortest waits were experienced in NHS Western Isles (1 week) followed by NHS Borders (5 weeks) and NHS Ayrshire & Arran (7 weeks). The longest were reported by NHS Lothian (15 weeks) and NHS Grampian (31 weeks). Most children’s services had waiting times of less than 4 weeks with the exception of NHS Lothian where the mean wait was 10 weeks.

### Figure 7: Mean (range) waiting time to first appointment for Level 3 specialist services by NHS board

<table>
<thead>
<tr>
<th>NHS board</th>
<th>Mean (range) Waiting Time to Level 3 services in weeks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ayrshire &amp; Arran</td>
<td>7 (0-18)</td>
</tr>
<tr>
<td>Borders</td>
<td>5 (4-6)</td>
</tr>
<tr>
<td>Dumfries &amp; Galloway</td>
<td>9 (2-12)</td>
</tr>
<tr>
<td>Fife</td>
<td>8 (7-9)</td>
</tr>
<tr>
<td>Forth Valley</td>
<td>11 (max 18)</td>
</tr>
<tr>
<td>Grampian</td>
<td>31 (4-31)</td>
</tr>
<tr>
<td>Greater Glasgow and Clyde</td>
<td>9 (2-9)</td>
</tr>
<tr>
<td>Highland</td>
<td>8 (6-24)</td>
</tr>
<tr>
<td>Lanarkshire</td>
<td>11 (0-12)</td>
</tr>
<tr>
<td>Lothian</td>
<td>15 (0-37)</td>
</tr>
<tr>
<td>Orkney</td>
<td>7.6 (1-7.9)</td>
</tr>
<tr>
<td>Shetland</td>
<td>10 (1-34)</td>
</tr>
<tr>
<td>Tayside</td>
<td>8 (3.3 – 12.4)</td>
</tr>
<tr>
<td>Western Isles</td>
<td>1 (1-2)</td>
</tr>
<tr>
<td><strong>National mean</strong></td>
<td><strong>10.0</strong></td>
</tr>
</tbody>
</table>
Concern had been previously raised about the time that patients had to wait for a follow-up appointment. The majority of services reported that at first appointment, patients were assessed to determine their needs and then referred on to the type of service they required either within the chronic pain multidisciplinary team or local routine service. For example, if it was decided that the most appropriate management plan involved physiotherapy and psychology, arrangements would be made for these onward referrals and therefore the next appointment would actually be with the appropriate practitioner rather than a return appointment with a pain consultant. It also needs to be noted that in some cases and completely appropriately, patients are given a return appointment with the pain clinic consultant for many months into the future. These decisions are always based on clinical need and with the patient’s understanding of the reasons. However, for those requiring a medical intervention, most NHS boards reported a range in the time between appointments of between 1 to 9 weeks. As the models across NHS boards varied due to local circumstances, waiting times for onward referrals and return appointments varied within and between NHS boards. It is not possible therefore to make any comment on the values provided and this exercise should be undertaken locally with full appreciation of the whole context.

The most critical waits were reported for pain psychology services (Figure 8). The national mean wait was 31.8 weeks (unknown in two NHS boards), but it is the range that was most varied. The shortest mean wait was experienced in NHS Tayside (2 weeks - to Level 2 routine service as no dedicated Level 3 psychology services in place) compared to 36 weeks in NHS Greater Glasgow and Clyde, 63 weeks in NHS Ayrshire & Arran, 78 weeks in NHS Forth Valley and 84 weeks in NHS Borders.

**Figure 8: Mean (range) waiting time to appointment for Level 3 pain psychology services by NHS board in weeks**

<table>
<thead>
<tr>
<th>NHS board</th>
<th>Mean (range) waiting time to pain psychology in weeks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ayrshire &amp; Arran</td>
<td>Mean unknown (0-63)</td>
</tr>
<tr>
<td>Borders</td>
<td>84 (78-104)</td>
</tr>
<tr>
<td>Dumfries &amp; Galloway</td>
<td>No one in post</td>
</tr>
<tr>
<td>Fife</td>
<td>10 (83%&lt;18 weeks)</td>
</tr>
<tr>
<td>Forth Valley</td>
<td>78 (0-124)</td>
</tr>
<tr>
<td>Grampian</td>
<td>12 (10-13)</td>
</tr>
<tr>
<td>Greater Glasgow and Clyde</td>
<td>36 (30-64)</td>
</tr>
<tr>
<td>Highland</td>
<td>9 (8-10)</td>
</tr>
<tr>
<td>Lanarkshire</td>
<td>19 (13-25)</td>
</tr>
<tr>
<td>Lothian</td>
<td>36 (31-37) for first focused appointment and 0 (1-3) for second appointment</td>
</tr>
<tr>
<td>Orkney</td>
<td>Not provided</td>
</tr>
<tr>
<td>Shetland</td>
<td>Not provided</td>
</tr>
<tr>
<td>Tayside</td>
<td>2 (2-3)</td>
</tr>
<tr>
<td>Western Isles</td>
<td>Not provided</td>
</tr>
<tr>
<td><strong>National mean (range)</strong></td>
<td><strong>31.8 (0-104)</strong></td>
</tr>
<tr>
<td><strong>For 9 NHS boards only</strong></td>
<td></td>
</tr>
</tbody>
</table>
Patient profile of Level 3 specialist service users

Overall, the national demographic profile of those referred to Level 3 services in Scotland was 65.3% female (Figure 9) and an overall mean age of 56 years. This is similar to that found in the recent British Pain Society Audit Report\(^\text{15}\) which identified 65% of referrals were female with a mean age of 59.4 years. The largest group (43.5%) presented with chronic pain affecting multiple body areas followed by low back pain problems (20.2%). The fact that 89% had been affected by chronic pain for over one year with many reporting problems for much longer should also be noted. This would indicate that access to Level 3 services is protracted and not in the best interests of achieving good outcomes and experiences. However, it needs to be noted that for those reporting symptoms of over one year, it is unknown how long they had had pain or what other services they had accessed before being referred to Level 3 specialist services.

Employment considerations of Level 3 specialist service users

The health of Scotland’s working-age population has been recognised as key to the wellbeing of both individuals and communities, and to the future economic success of Scotland\(^\text{15}\). It is known that poor health costs the Scottish economy around £10 billion a year in lost productivity, lost tax revenues, lost spending and increased health and social care costs\(^\text{15}\). There are also implications for individuals, families and communities as a result of health barriers to working that cannot be costed. One third of those referred to Level 3 services were in employment (33.2%) (see Figure 10). Although there were multiple reasons in relation to work absence rates, 42% of those in employment were absent from work and 63.3% absent for more than 6 weeks (see Figure 11). A further 34% reported remaining at work with difficulty and 10.3% were registered as disabled. This has considerable implications for these people, their families and society. The Scottish Government wants as many people as possible to share in the rewards of work, because satisfying work is the best route for most people to a fulfilling life and to good health and wellbeing. It has introduced the Health Works strategy which provides active support to those absent or struggling with work [www.scotland.gov.uk/Topics/Health/Healthy-Living/Health-Work/Strategy](http://www.scotland.gov.uk/Topics/Health/Healthy-Living/Health-Work/Strategy). No evidence was found of local pain management services actively linked to these initiatives and therefore, local services should explore how chronic pain patients in this category can gain access to this helpful scheme and stay in work.

---

**Figure 9: Gender breakdown of Level 3 specialist service users by NHS board**

<table>
<thead>
<tr>
<th>Patient gender</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>33.8% (270)</td>
</tr>
<tr>
<td>Female</td>
<td>65.3% (522)</td>
</tr>
<tr>
<td>Other</td>
<td>0.1% (1)</td>
</tr>
<tr>
<td>Missing</td>
<td>0.8% (6)</td>
</tr>
</tbody>
</table>
Figure 10: Employment status of Level 3 specialist service users

<table>
<thead>
<tr>
<th>Employment status</th>
<th>Percentage (Number)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed</td>
<td>33.2% (265)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>21.1% (169)</td>
</tr>
<tr>
<td>Houseperson</td>
<td>8.3% (66)</td>
</tr>
<tr>
<td>Student</td>
<td>1.9% (15)</td>
</tr>
<tr>
<td>Retired</td>
<td>24.0% (192)</td>
</tr>
<tr>
<td>Registered disabled</td>
<td>10.5% (84)</td>
</tr>
<tr>
<td>Other</td>
<td>0.9% (7)</td>
</tr>
<tr>
<td>Missing</td>
<td>0.1% (1)</td>
</tr>
</tbody>
</table>

Pain management programmes

Best practice advocates that people with chronic pain who are comfortable in a group setting have access to pain management programmes\(^5,10\). A Pain Management Programme (PMP) is a psychologically-based rehabilitative course for people with chronic pain which remains unresolved by other treatments currently available. It is delivered in a group setting by a multidisciplinary team of experienced healthcare professionals working closely with patients\(^16\).

At the time of data collection, pain management programmes were reportedly in place in six NHS boards (NHS Fife, NHS Greater Glasgow and Clyde, NHS Grampian, NHS Highland, NHS Lanarkshire and NHS Lothian) with a mean waiting time of 9 weeks. Two further NHS boards had active plans and a date for their introduction in early 2014; a further three reported that these were ‘under development’. Although none of the three island boards had a Pain Management Programme in place, NHS Shetland and NHS Orkney did report plans to explore the possibility of a service level agreement with the Pain Management Programme recently established in NHS Grampian.

Interestingly, NHS Lothian reported having reduced waiting times from 26 to 16 weeks to their Pain Management Programme by introducing a pre-assessment introductory session that provides earlier access to information and advice.
**EQ-5D-5L results: quality of life status of Level 3 specialist services**

EQ-5D-5L index levels are presented by NHS boards and also nationally (see Figure 12). It was also decided to compare the data with what might be expected within the general population in order to better understand the burden of illness in the chronic pain Level 3 population. Within the UK, a large survey was undertaken to derive EQ-5D data norms and this information has been used in this exercise.\textsuperscript{17,18}

Although the chronic pain data were provided at an aggregate level and mean patient ages were not available for all NHS boards, it was possible to undertake some analysis and arrive at a working assumption. Using age distribution data from one NHS board whose overall age profile reflected the national picture, it was possible to ascertain that the mean age was 56 years. The mean EQ-5D-5L index value reported for the UK population aged 55-64 is 0.80. By comparison, the median index value in the NHS board samples ranged from 0.1749 to 0.53605 and the median value across all the NHS boards was 0.3181. While assumptions have had to be made to compare these data, they do suggest that patients attending chronic pain services in Scotland experience a significant detriment to their quality of life compared to a general population of a similar average age. This is also supported by a median EQ-5D-5L value within the British Pain Society’s 2013 Audit\textsuperscript{14} of 0.49 which suggests the Scottish chronic pain population reported a lower quality of life than those with similar problems in England and Wales.

### Figure 12: Median EQ-5D-5L scores of Level 3 specialist service users by NHS board and nationally

<table>
<thead>
<tr>
<th>NHS board</th>
<th>EQ-5D-5L Index score (median)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ayrshire &amp; Arran</td>
<td>0.2379</td>
</tr>
<tr>
<td>Borders</td>
<td>0.3204</td>
</tr>
<tr>
<td>Dumfries &amp; Galloway</td>
<td>0.2902</td>
</tr>
<tr>
<td>Fife</td>
<td>0.2257</td>
</tr>
<tr>
<td>Forth Valley</td>
<td>0.3257</td>
</tr>
<tr>
<td>Grampian</td>
<td>0.4075</td>
</tr>
<tr>
<td>Greater Glasgow and Clyde</td>
<td>0.2741</td>
</tr>
<tr>
<td>Highland</td>
<td>0.3181</td>
</tr>
<tr>
<td>Lanarkshire</td>
<td>0.1749</td>
</tr>
<tr>
<td>Lothian</td>
<td>0.3181</td>
</tr>
<tr>
<td>Orkney</td>
<td>Not provided</td>
</tr>
<tr>
<td>Shetland</td>
<td>0.3099</td>
</tr>
<tr>
<td>Tayside</td>
<td>0.3809</td>
</tr>
<tr>
<td>Western Isles</td>
<td>Not provided</td>
</tr>
<tr>
<td><strong>National median</strong></td>
<td><strong>0.3181</strong></td>
</tr>
</tbody>
</table>
Patient experience of Level 3 specialist services

Reported patient experience of Level 3 services by NHS board, together with any additional comments thematically grouped, are presented within the individual NHS board reports. All comments can be found in Appendix 1 of the compendium. Users from all NHS boards, with the exception of NHS Shetland, provided views about their experience (1824) and overall were generally positive. Rating their overall care as either ‘excellent’ or ‘good’ was reported by 75.3% and 19.4% (total 94.7%), with ‘poor’ or ‘very poor’ care reported by 1.8% (see fig 13). Being listened to also rated similarly. Uncertainty about receiving the information and support needed to make decisions was reported by 7.3%, with the majority being positive (92.7%). Most also reported getting the care they needed ‘most’ or ‘all the time’, although a smaller proportion (8.7%) did not agree. Having the opportunity to be involved in their care all of the time, was reported by 78.5% and for most of the time by 15.8%. However, the extent to which the people who mattered to the patient were involved was less positively reported with only 55.6% strongly agreeing with the statement. The fact that 13.2% did ‘not agree’ or ‘neither agreed or disagreed’, although low, does suggest that family/carer involvement was not perceived as a strong aspect of their care for some.
Level 4 services: Highly specialised help.

These are provided by a limited number of centres in Scotland with those requiring access to an intensive residential programme currently being referred to Bath Centre for Pain Services, England until the new Scottish service is available. All NHS boards reported having some arrangements in place with one of the designated centres for when advanced interventions such as spinal cord stimulation, intrathecal services, percutaneous cordotomy were indicated. However, what is obvious even from the limited details provided is the variation in referral rates for these advanced interventions across the country. For example and based on the modelling contained within the NICE Technology Appraisal Guidance, it could have been predicted that approximately 100 patients in Scotland would be referred for spinal cord stimulation each year, but in fact less than half of this number were actually referred. Whether this was related to clinician awareness and clinical practice or the constraints of inter NHS board contracting is unknown. NHS Lothian, for example, did not have a spinal cord stimulation service in place in 2013 and therefore had an agreement to refer five patients each year to NHS Greater Glasgow and Clyde for the procedure and during 2013, three patients were actually referred. It would be good to understand the referral pathway further. In 2013, the National Lead Clinician initiated a collaboration between the Aberdeen, Glasgow and Dundee services to improve awareness of patient criteria for referral to Level 4 services as well as assessment, treatment and onward referral arrangements. Further work needs to be undertaken to gain a better understanding of the anomalies highlighted above and also to build on the work already under way which could be something that the National Chronic Pain Steering Group could lead on.

Clinician views of the data exercise

During the data verification process, staff from all NHS boards were asked for their views about the data collection exercise and these are provided in Appendix 1. It was gratifying to hear that most (22/27) reported positively about the experience despite the effort required. There was good support for the need for, and value of, local and national information expressed by most NHS boards. However, some did feel that the exercise was an additional burden to them and one of the 27 respondents questioned the value of the exercise. Two of the largest territorial NHS boards highlighted the fact that they found it ‘difficult/impossible’ to get hold of some of the data requested which related to waiting times to other members of the multidisciplinary team. It should also be noted that the views of two NHS boards, NHS Shetland and NHS Western Isles remain unknown as no response was received. The need for chronic pain services to have access to mainstream information systems that will routinely collate a core dataset as a minimum requirement is needed to overcome this issue.
Moving forward and next steps

NHS boards were asked to provide information about what they saw as their top three key challenges and priorities for the forthcoming year. These can be viewed in the NHS board reports.

In terms of the key challenges, these were similar across NHS boards. Those most commonly cited were:

- achieving meaningful engagement with their own NHS board management to plan next steps as well as gaining access to the funding available from the Scottish Government
- establishing and/or developing the Service Improvement Groups, their infrastructure and their working practices
- overcoming recruitment difficulties particularly to medical and psychology positions, and
- enhancing integration of the multidisciplinary team across the whole system and particularly with primary care.

Priorities tended to mirror the challenges outlined by NHS boards. They focused on:

- the Service Improvement Groups, their relationships and working practices
- addressing waiting times, in particular to pain psychology services, and
- developing strategies to bring about greater integration across the whole pathway.
Conclusion

The primary purpose of this report was to provide NHS boards with key information about:

- how local chronic pain services were organised and provided
- patient level detail about those that used Level 3 services, and
- what these users thought about them.

It provides a good basis for NHS boards and their Service Improvement Groups to reflect on and use to revise their action plans to drive improvement locally.

As clearly outlined within the Scottish Service Model for Chronic Pain, having easy access to high quality information and resources for the public and service users about how chronic pain underpins everything, and is key to better management. Creating a ‘one stop shop’ for Scotland made available through the use of technology would considerably reduce the duplication of local effort and improve awareness, consistency of messages, self-confidence and self-management in people with chronic pain.

Level 2 primary care services also have a vital role to play in achieving better outcomes. Being able to identify those with chronic pain in primary and community settings will be critical to better outcomes and experiences and seamless pathways transcending all levels of the Scottish Service Model for Chronic Pain. The use of stratification tools and electronic coding will greatly assist with this. It is also clear that a major effort needs to be directed at increasing understanding and awareness as well as the skills to manage pain in primary care settings. Pharmacists, GPs and Allied Health Professionals also need to signpost people with chronic pain to high quality resources and refer timeously into local pathways as required.

The current national effort being made to reduce waits to Allied Health Professional musculoskeletal services to a maximum of four weeks is most welcome as more speedy and timely access will help to reduce chronicity and improve quality of life.

The variation in Level 3 chronic pain services across Scotland is evident, as is the challenge with creating a highly functioning multidisciplinary team, recruitment, waiting times, and especially to pain psychology services. There is little evidence of an organised whole system approach to the management of chronic pain nor of consistent onward referral to the most specialist Level 4 services. This suggests a lack of joined-up care between primary and specialist services and seen in the current referral pathways, the duration of symptoms and supported by the descriptions these services provided, something that local Service Improvement Groups are well placed to address.

The Scottish Service Model for Chronic Pain clearly sets out what should be provided at all levels. It also recognises the interdependencies that these services have with a range of others and the need to create more integrated and seamless care. Service Improvement Groups have the opportunity to address many of these issues and it is gratifying to hear that all NHS boards either have or are establishing these groups helped by support provided by the Scottish Government. It is also gratifying to see the formal commitment made by all NHS boards to implementing the Scottish Service Model for Chronic Pain and that progress will be monitored over the next two years by the Scottish Government.
Recommendations

It is therefore within this context that the following key recommendations are made for NHS boards and Service Improvement Groups, for each level of the Scottish Service Model for Chronic Pain, the Scottish Government and, for the National Chronic Pain Steering Group to be achieved by 2016.

NHS board and Service Improvement Group recommendations

• NHS boards take cognisance of the NHSScotland 2020 Local Delivery Plan (which requires NHS boards to prepare and implement a service delivery plan covering all aspects of chronic pain services from April 2014).

• NHS boards use the pump priming funding provided by the Scottish Government to establish a robust infrastructure that supports the implementation of the Scottish Service Model for Chronic Pain across all levels (1-4).

• NHS boards provide specific support to allow local Service Improvement Groups to achieve their aims and drive improvement in outcome and experience and, that service users, carers and the third sector are an integral part of the whole process.

• Service Improvement Groups should review the results of this national data collection exercise and use them to develop and/or revise their own timescaled action plans.

• Timescaled action plans are transparently and widely shared on the new chronic pain website (www.chronicpainscotland.org) and monitored by the Scottish Government.

• Local Service Improvement Groups should explore how those with chronic pain and absent from or struggling to stay in work can gain access to the available Health Works services scheme and improve their working lives across all levels.

Level 1 recommendation: information and support

• Service Improvement Groups should create closer relationships with a range of third sector providers of supportive self-management information and support groups and make them more accessible at all levels and particularly, in community and primary care settings.

Level 2 recommendations: GP and other healthcare professionals

• Bring about a greater awareness, understanding and ability to manage chronic pain in the healthcare professionals who work in primary and community settings as outlined in SIGN 136 Management of Chronic Pain.

• Pathways of care are developed locally with a key focus on the early identification/stratification and management in primary and community care settings in line with SIGN 136 which includes access to pain management programmes.
Level 3 recommendations: specialist pain management services

- NHS boards should ensure access to the range of Level 3 specialist services recommended by the Scottish Service Model for Chronic Pain and that:
  - robust referral pathways are in place and widely shared,
  - multidisciplinary teams are in place, which includes as a minimum - specialist doctors, nurses, physiotherapists, psychologists, occupational therapists,
  - that the Level 3 service is integrated with primary and community care, and
  - all efforts are made to address the reported shortfalls and vacancies.
- Access to key services within NHS boards, and particularly to pain psychology services is improved.
- In those centres who do manage children with chronic pain, the current approach and staffing complement should be reviewed.

Level 4 recommendation: access and referral

- Referral criteria, access to and the provision of all Level 4 services (except the specialist residential chronic pain service which is being progressed separately) should be reviewed and endorsed by the National Chronic Pain Steering Group.

Scottish Government

- The Scottish Government provides the National Chronic Pain Steering Group with the support and resources to allow the Group to implement the recommendations below. This should be in the form of direct participation, dedicated co-ordination and clinical leadership.

National recommendations (to be overseen by the National Chronic Pain Steering Group)

- A national network for local Service Improvement Groups is established to share and learn from best practice overseen by the National Chronic Pain Steering Group.
- National, quality-assured advice, information and resources should be enhanced and made easily accessible to the public, service users and providers through a range of formats, predominantly web enabled and without necessarily requiring a healthcare professional referral.
- A range of learning and development resources for healthcare staff are developed and widely shared to increase awareness of and skills for improved chronic pain management and particularly so for pharmacists, GPs, nurses and Allied Health Professionals.
- A mechanism is developed for use in primary care to identify those affected by chronic pain. This will allow better management and measurement of outcomes.
- The National Chronic Pain Steering Group should ensure that referral criteria for the specialist residential chronic pain services, once agreed, are shared across NHS boards.
- The national chronic pain dataset should be reviewed by the National Chronic Pain Steering Group in light of the 2013 exercise, refined as required and endorsed for national use.
- A further national data collection exercise should be undertaken in 2016 to quantify the extent to which services have improved from the baseline provided within this report.
References


11. AHP Activity and Workload Project 2012: www.isdscotland.org/Products-and-Services/Data-Definitions-and-References/Allied-Health-Professionals-National-Dataset/


Appendix 1: Clinician feedback about the data collection process

- Collecting the data was seen as challenging by some but I think that the pilot month has reassured many that it is not so difficult and actually worthwhile - clinical lead.
- The data collection exercise was an easy task although some patients found it a bit annoying that they had more than the usual clinic forms to fill out. It was sometimes quite difficult to keep track of who had filled it out as the clinic I was working in was very busy at times. Other than that it was a good experience and a lot of patients were happy to help fill it out for me, apart from the odd one here and there! – administration assistant.
- Wasn’t as bad as I expected – consultant.
- Great to get national figures – physiotherapist.
- I thought it was going to take a lot of time but it didn’t – nurse.
- It’s important to have all staff on board – doctor.
- Will be great to see how all the services compare – nurse.
- The data collection didn’t take as much time as I thought – doctor.
- We need funding or a system for dedicated staff to repeat this exercise – manager.
- The team were happy to be involved and active in this process.
- Would be keen to be involved in future re-do of the process.
- Once a data collection system has been developed which integrates with our current hospital database (Trak), amongst other data of interest, we will begin collecting EQ5D data for the purposes of auditing our patients’ progress.
- We do hope that this will not be a one off event.
- The data collection exercise was a very worthwhile undertaking but was difficult to undertake without any additional resource. xxx is a large area and the work involved to set up the organisation, distribution, collection and inputting of data fell to staff that are already overstretched.
- Data collection went well.
- We appreciate the time spent by patients to complete their questionnaires, and are gratified by the positive feedback given regarding the secondary care pain clinics.
- The semi-structured interview with HIS Facilitator was an opportunity for Clinical leads to reflect on progress to date and clarify our key priorities and challenges for the future. We found this a useful exercise and appreciate the support provided by the Facilitator.
- The semi structured interview process was helpful and the patient experience results are very encouraging with regards to patient satisfaction with clinician consultations.
- This has stimulated action on ongoing collection of data to allow measurement of the impact of the secondary care pain service.
- The process has highlighted the lack of continuous monitoring of some areas of the secondary care pain service.
- Data collection exercise was time consuming for members of staff. Although this was manageable on this occasion because of SIG funding it would have a significant impact on service delivery if repeated unless additional funds were made available or the process considerably streamlined.
- Improving our data collection to inform and improve delivery of Chronic Pain Services will be ongoing. Gathering feedback via www.care-experiences.com was very simple and the most straightforward of the datasets to capture during the ‘data snapshot’. Consideration will be given to other methods of data gathering including EQ5D in future.
Less positive comments

- We were unable to access some of the required service level data as current systems are unable to provide this data.
- As our service uses a number of questionnaires with our patients, Clinicians did feel a little uncomfortable adding in yet another one, especially when under pressure for time.
- Patients lack enthusiasm about filling out these questionnaires. Benefits thought to be only for SG, as this process does not alter individual treatment plans. Spreadsheet methodology not fit for purpose, we request an appropriate database tool be constructed.
- We found the interviews a little confusing, we were also unsure as to how the data collected would improve anything for anyone apart from highlight the inequality of services across Scotland.
- Some of the data was problematic to retrieve as it had not previously been gathered; this involved data analyst assistance to set up the required searches. In addition, a staff member was seconded on a short term basis to carry out the collection of patient data due to workload capacity in the department and the timeframe involved. Much of the patient questionnaire duplicated what is already collected and patients found it confusing to be asked to provide the same information twice.
### Appendix 2: Glossary

<table>
<thead>
<tr>
<th>Term</th>
<th>Explanation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Allied Health Professional (AHP)</strong></td>
<td>The Allied Health Professions are a distinct group of healthcare professionals who apply their expertise to diagnose, treat and rehabilitate people of all ages and all specialties. AHPs are distinct from medicine, pharmacy and nursing and include professions such as physiotherapy, dietetics, speech and language therapy, occupational therapy, podiatry.</td>
</tr>
<tr>
<td><strong>The ALLIANCE</strong></td>
<td>The national third sector intermediary for a range of health and social care organisations.</td>
</tr>
<tr>
<td></td>
<td><a href="http://www.alliance-scotland.org.uk">www.alliance-scotland.org.uk</a></td>
</tr>
<tr>
<td><strong>chronic pain</strong></td>
<td>Pain that carries on for longer than 12 weeks despite medication or treatment – this is called chronic or persistent pain.</td>
</tr>
<tr>
<td><strong>cognitive behavioural therapy (CBT)</strong></td>
<td>A psychological therapy that addresses thoughts, feelings and behaviours, aiming to reduce disability and suffering associated with chronic pain.</td>
</tr>
<tr>
<td><strong>EQ-5D-5L</strong></td>
<td>A simple quality of life measure that can be used to demonstrate the quality and effectiveness of services and provide data for use in economic evaluations. It is a patient reported outcome measure (PROM), completed by the patient and can be collected either through the post, over the telephone or face to face. It is defined as a ‘standardised measure of health status to provide a simple generic measure of health for clinical and economic appraisal’ (EuroQol Group 2011, <a href="http://www.euroqol.org">www.euroqol.org</a>).</td>
</tr>
<tr>
<td><strong>GP</strong></td>
<td>General Practitioner</td>
</tr>
<tr>
<td><strong>healthcare professional</strong></td>
<td>An individual qualified in a health discipline, for example doctor, nurse, occupational therapist, pharmacist, physiotherapist, podiatrist, psychologist.</td>
</tr>
<tr>
<td><strong>interventions</strong></td>
<td>Specialised techniques such as injections of local anaesthetic &amp; steroid or using heat or cold to damage nerves in an attempt to reduce pain.</td>
</tr>
<tr>
<td><strong>intrathecal</strong></td>
<td>A technique to deliver pain killers into the spinal fluid, next to the spinal cord, sometimes helpful in cancer pain.</td>
</tr>
<tr>
<td><strong>IT</strong></td>
<td>Information Technology</td>
</tr>
<tr>
<td><strong>mean</strong></td>
<td>The average value, calculated by adding all the observations and dividing by the number of observations.</td>
</tr>
<tr>
<td><strong>median</strong></td>
<td>Middle value of a list. If you have numbers 2, 3, 4, 5, 6, 7, and 8, the median is 5. Medians are often used when data are skewed, meaning that the distribution is uneven. In that case, a few very high numbers could, for instance, change the mean, but they would not change the median.</td>
</tr>
<tr>
<td><strong>mode</strong></td>
<td>For lists, the mode is the most common (frequent) value.</td>
</tr>
<tr>
<td>Term</td>
<td>Explanation</td>
</tr>
<tr>
<td>-------------------------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>multidisciplinary team</td>
<td>Professions may vary and include doctors, nurses, physiotherapists, psychologists, occupational therapists, pharmacists – working together to help patients according to individual needs.</td>
</tr>
<tr>
<td>musculoskeletal (MSK)</td>
<td>Relating to muscular, bone or joint symptoms.</td>
</tr>
<tr>
<td></td>
<td><a href="http://www.nhsinform.co.uk/msk">www.nhsinform.co.uk/msk</a></td>
</tr>
<tr>
<td>N/a</td>
<td>Not applicable</td>
</tr>
<tr>
<td>Pain Management Programme (PMP)</td>
<td>A psychologically-based rehabilitation programme for people with chronic pain, which remains unresolved by other treatments currently available. It is delivered in a group setting by a multidisciplinary team of experienced healthcare professionals working closely with patients. The aim is to help patients with similar problems to understand more about pain, how best to cope with it and how to live a more active life.</td>
</tr>
<tr>
<td>percutaneous cordotomy</td>
<td>A technique using a needle to partially cut the spinal cord, sometimes useful in cancer pain, particularly mesothelioma.</td>
</tr>
<tr>
<td>pump priming</td>
<td>The Scottish Government awarded grants to NHS boards to set up Service Improvement Group. Territorial boards received £100,000 over 2 years (£50,000 each year for 2 years) and island boards received £70,000 over 2 years (£35,000 each year for 2 years).</td>
</tr>
<tr>
<td>RIVERS Programme</td>
<td>The primary care component of the Fife Integrated Pain Management Service – RIVERS stands for, Relieving Pain as we Inspire change, impart new values with exercise, relaxation and self management. This primary care pain management programme uses mainly physiotherapy and pharmacy assessment and treatment.</td>
</tr>
<tr>
<td>Service Improvement Group (SIG)</td>
<td>A formal group of clinical and support staff, patients and third sector representatives brought together to lead and deliver improvements in patient experience and outcome.</td>
</tr>
<tr>
<td>service level agreement (SLA)</td>
<td>An agreement between an organisation and an NHS board to provide services.</td>
</tr>
</tbody>
</table>
| SIGN                                      | Scottish Intercollegiate Guidelines Network  
[www.sign.ac.uk](http://www.sign.ac.uk)                                                                                   |
| spinal cord stimulation                   | Implantable electrodes in the spine, which can relieve some types of pain, usually in an arm or leg.                                                                 |
| SSMCP                                     | Scottish Service Model for Chronic Pain                                                                                                     |
| STarT Back                                | The Keele STarT Back Screening Tool (SBST) is a brief validated tool (Hill et al 2008), designed to screen primary care patients with low back pain for prognostic indicators that are relevant to initial decision-making. |