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Introduction

To support NHS boards with their overall planning for driving improvement in local services 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 (Levels 1-4) including children’s services in five NHS boards (NHS Fife, NHS Grampian, NHS Greater Glasgow and Clyde and NHS Tayside), 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.

This document includes all the materials that supported the approach to data collection:

- 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.
Proposed Core Measures /Data Set

**Definition:** This dataset relates to users of Level 3 and 4 chronic pain services in NHSScotland.

**Exclusion:** In Patients, Domiciliary, Non NHS funded, Palliative Care

**Inclusion:** Adult and Paediatric with Chronic Pain

What is proposed below is a National Core Dataset for Chronic Pain. For the purposes of the 2013 data collection exercise, NHS boards will be required to provide data that relates to **Essential Measures only**. Those data items contained within the ‘Desirables’ column denote data that has been recognised as being of potential benefit to local services and can be supplemented/replaced with any others of local interest.

<table>
<thead>
<tr>
<th>Essential Measures (for national use)</th>
<th>Desirable Measures (for local use)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Measure</strong></td>
<td><strong>Definition</strong></td>
</tr>
<tr>
<td></td>
<td>Female</td>
</tr>
<tr>
<td></td>
<td>Other</td>
</tr>
<tr>
<td>Age</td>
<td>Mean and range</td>
</tr>
<tr>
<td>Employment</td>
<td>See appendix 1</td>
</tr>
<tr>
<td>Source of Referral</td>
<td>See appendix 1</td>
</tr>
<tr>
<td>Body part affected</td>
<td>See appendix 1</td>
</tr>
<tr>
<td>Duration of symptoms</td>
<td>In weeks</td>
</tr>
<tr>
<td>Patient experience</td>
<td><a href="http://www.care-experiences.com">www.care-experiences.com</a></td>
</tr>
<tr>
<td>EQ-5D</td>
<td>See appendix 1</td>
</tr>
<tr>
<td></td>
<td>receipt of referral and first</td>
</tr>
<tr>
<td></td>
<td>clinical contact, face to face,</td>
</tr>
<tr>
<td></td>
<td>telephone or video (In working</td>
</tr>
<tr>
<td></td>
<td>days)</td>
</tr>
<tr>
<td>Waiting time to follow up</td>
<td>This includes: Phone review, GP;</td>
</tr>
<tr>
<td></td>
<td>Physiotherapy, Occupational Therapy,</td>
</tr>
<tr>
<td></td>
<td>Assessment for MDT Pain Management</td>
</tr>
<tr>
<td>WTE staff</td>
<td>Number of WTE by professional</td>
</tr>
<tr>
<td></td>
<td>grouping</td>
</tr>
</tbody>
</table>
## Appendix 1

### Body Part Affected

**Definition:** The region of the body affected by chronic pain OR where the pain originates (if pain in leg originates from low back pain – select low back pain).

### Values

<table>
<thead>
<tr>
<th>Part</th>
<th>Relates to:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low Back</td>
<td>Lumbar Spine, Lumbosacral, Sacral, Sacroiliac Joint, Sacrococcygeal</td>
</tr>
<tr>
<td>Hip</td>
<td>Hip Joint, Buttock, Thigh, Femur, Pelvis, Groin</td>
</tr>
<tr>
<td>Knee</td>
<td>Knee Joint, Patello-femoral, Fibula, Tibia, Lower Leg</td>
</tr>
<tr>
<td>Foot/ankle</td>
<td>Ankle Joint, Other Foot Joints, Metatarsus, Tarsus, Toes</td>
</tr>
<tr>
<td>Shoulder</td>
<td>Shoulder, Humerus, Clavicle, Scapula</td>
</tr>
<tr>
<td>Elbow/wrist/hand</td>
<td>Elbow Joint, Forearm, Radius, Ulna, Wrist Joint, Carpus, Fingers, Metacarpus, Hand Joints</td>
</tr>
<tr>
<td>Head &amp; Neck (Non spinal related)</td>
<td>Head and/or neck but none of the above</td>
</tr>
<tr>
<td>Pelvic</td>
<td>Including gynaecological</td>
</tr>
<tr>
<td>Abdominal</td>
<td>Non spinal/pelvic</td>
</tr>
<tr>
<td>Thoracic</td>
<td>Non spinal related</td>
</tr>
<tr>
<td>Multiple</td>
<td>More than one of the above</td>
</tr>
<tr>
<td>Other</td>
<td>Please state</td>
</tr>
</tbody>
</table>

4
**Employment Status**

**Definition:** This term is used to describe an individual’s state of employment.

More than one item can be selected

**Values:**
1. Employed
2. Unemployed
3. Houseperson
4. Student
5. Retired
6. Registered Disabled

**Related items:** Work Status Assessment; Period of Absence.

---

**Work Status Assessment**

**Definition:** Identifies an employed person’s ability to remain in the workforce during a health related problem

**Inclusions:** Self-employed, employed

**Exclusions:** All others.

**Values:**
1. Absent from work due to the health problem
2. Remains at work
3. Remains at work with difficulty
4. other

**Related items:** Employment Status; Period of Absence.

---

**Period of Absence**

**Definition:** The time period the person has been absent from work.

**Values:** Less than 2 weeks
Between 2-4 weeks
Between 4-6 weeks
Over 6 weeks.

**Related items:** Employment Status; Work Status Assessment.
### Referral Source

**Definition:** Who made the referral to the chronic pain service

**Values:**
1. GP
2. Hospital doctor
3. AHP
4. Nurse
5. Self
6. Other

**Related items:** Duration of symptoms, waiting time

### EQ-5D

**Source:** (European Quality of Life 5 dimensions)

#### a) Mobility

**Definition:** The level of ability to walk about from the patient’s perspective.

**Values:**
0  No Problem  
1  Slight Problem  
2  Moderate Problem  
3  Severe Problem  
4  Unable

#### b) Self Care

**Definition:** The level of ability to wash & dress from the patient’s perspective.

**Values:**
0  No Problem  
1  Slight Problem  
2  Moderate Problem  
3  Severe Problem  
4  Unable

#### c) Usual Activities

**Definition:** The level of ability to carry out usual activities (work, study, housework, leisure, family etc) from the patient’s perspective.

**Values:**
0  No Problem  
1  Slight Problem  
2  Moderate Problem  
3  Severe Problem  
4  Unable
### d) Pain/Discomfort
**Definition:** The level of pain or discomfort reported from the patient’s perspective.

**Values:**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>None</td>
</tr>
<tr>
<td>1</td>
<td>Slight</td>
</tr>
<tr>
<td>2</td>
<td>Moderate</td>
</tr>
<tr>
<td>3</td>
<td>Severe</td>
</tr>
<tr>
<td>4</td>
<td>Extreme</td>
</tr>
</tbody>
</table>

### e) Anxiety/Depression
**Definition:** The level of anxiety/depression from the patient’s perspective.

**Values:**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>None</td>
</tr>
<tr>
<td>1</td>
<td>Slight</td>
</tr>
<tr>
<td>2</td>
<td>Moderate</td>
</tr>
<tr>
<td>3</td>
<td>Severe</td>
</tr>
<tr>
<td>4</td>
<td>Extreme</td>
</tr>
</tbody>
</table>
### Organisation/service and Level 3 patient data item details

<table>
<thead>
<tr>
<th>Organisation/service level</th>
<th>Included?</th>
<th>Collected via?</th>
<th>Collected when?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Organisation/service Level</td>
<td>Service model description</td>
<td>Data collected by national chronic pain facilitators:</td>
<td>Between September-October 2013</td>
</tr>
<tr>
<td></td>
<td>Staffing complement</td>
<td>• Semi-structured interview with local chronic pain clinical and administrative leads</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Waiting time to local AHP musculoskeletal services</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Number of referrals received</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Waiting times to first and onward/ follow-up appointment</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Information about the local approach to and where they were with regard to establishing a local improvement group</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Top three priorities for the forthcoming year</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Top three challenges for the forthcoming year</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Patient level</th>
<th>Patient level information relating to:</th>
<th>Data collated by local staff and patients:</th>
<th>Four-week period during October-November 2013</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Age</td>
<td>Mixed paper and electronic methods including:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sex</td>
<td>• Survey Monkey</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Employment status</td>
<td>• Excel spreadsheet</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Body part affected</td>
<td>• Patient experience website</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Duration of symptoms</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Semi-structured interview proforma

<table>
<thead>
<tr>
<th>Facilitator Name</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>NHS board &amp; size of population covered</td>
<td></td>
</tr>
<tr>
<td>Date/s</td>
<td></td>
</tr>
<tr>
<td>Those present/discussed with</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Please describe the SSMCP within your board Level 1 – Information and Advice resources Level 2 – primary care Level 3 – chronic pain management service Level 4 – highly specialised interventions such as: - Spinal Cord Stimulation - Intrathecal - Spinal cord stimulator - Percutaneous cordotomy - Intensive Programme What disciplines are involved in Level 3 and Level 4 services? (include discipline WTE numbers etc) please provide information about long term vacancies / sickness etc</td>
<td></td>
</tr>
</tbody>
</table>
2. Where do your referrals come from for Level 3 services (i.e. GP, self, AHP, hospital doc)

2.1 Where do your referrals come from for Level 4 services (i.e. GP, self, AHP, hospital doc)

*These need to be supplied numerically and as a percentage of total referrals (n= x, x%)*

3. How many referrals a year are made to your Level 3 services? Rate expressed as 1000/board population

3.1 How many return patients a year attend your Level 3 services?

3.2 What is your new to return ratio for Level 3 services?

4. How many referrals a year are made to your Level 4 services? Rate expressed as 1000/board population

4.1 How many return patients a year attend your Level 4 services?

4.2 What is your new to return ratio for Level 4 services

5. What is the waiting time (mean and range) to first appointment within Level 3 services to reflect local access

5.1 What is the waiting time (mean and range) to second appointment. 2\textsuperscript{nd} appointment includes:

- 2\textsuperscript{nd} pain service appointment
- Psychology
- Physio
- OT
5.2 What is your waiting time (mean and range) to psychology services?

5.3 What is your (mean and range) waiting time to Level 4 services?

5.4 What is the current waiting time (mean and range) to AHP MSK services (Level 2)?

5.5 What is the current waiting time (mean and range) to psychology services?

6. Do you have an agreed action plan for the next 1-2 years?
   If yes, is it publically available and where?
   If not when?
   Are you willing to share local resources?

7. What are your top 3 priorities for the coming year?
   1. 
   2. 
   3. 

8. What do you see as your three key challenges?
   1. 
   2. 
   3.
<table>
<thead>
<tr>
<th></th>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>9</td>
<td>Have you formed a local steering group/executive?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Who is on that group?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Are there patients?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>When did funding for your SIG start?</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Have you accessed local support to help with developing your SIG? e.g. clinical effectiveness staff, improvement advisors, organisational development etc</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Description?</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Have you identified any specific support you feel you need to progress your actions that is not being met or able to be met locally?</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>What information do you signpost/provide to users of your services?</td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>Do you have a pain management programme in place?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Who runs it?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>What is the waiting time for this service?</td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>Do you have any thoughts about what a SIG network should deliver</td>
<td></td>
</tr>
<tr>
<td>15. Any other key issues to record?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Level 3 and 4: Guidance Notes for Service Improvement Groups

Chronic Pain Services Data Collection: Autumn 2013

Background

The Scottish Government is supporting the development of Chronic Pain services throughout Scotland and have made funding available to support this. Healthcare Improvement Scotland is actively working with boards and the emerging Service Improvement Groups to support this. As part of these developments, an up to date picture needs to be assimilated about SIG structure, progress and service provision. This information will be used by the government and wider stakeholders as a baseline from which to gauge ongoing improvement. It will also be useful for local services as they identify or hone their priorities over the next two years.

Data Collection Content and Arrangement

There are two parts to this;

1. Service level data collection, and
2. Patient level data collection

Service Level Data Collection

Q. When will this take place?

Towards the end of September, you will be visited by your designated national chronic pain facilitator. The purpose of this visit is to collect information about your service (details below) and also to take you through the patient level data collection process so all are clear about what is required and how they are going to undertake this. There are two separate parts to the data collection.
Q. What information will be collected?

This will be collected via a semi-structured interview undertaken with your chronic pain facilitator around the end of September. They will use a proforma which they will take you through and include questions such as:

Q. Where you are with your local arrangements for having a functioning SIG?

Q. What are the waiting times to local MSK services? These often have a knock on effect on waiting times/demand for chronic pain services – this is required for context

Q. The number of referrals you receive per annum - rate expressed as 1000/board population

Q. We will need a breakdown of where your patients are referred/come from – this needs to be supplied in both numerical and as a percentage of total referrals (n= x, x%)

Q. What is your staffing compliment by discipline for Level 3 and level 4 services given as WTE, we need information about

- Medical
- Nursing
- Physio
- OT
- Psychology
- Other?

Q. We also need to know what vacancies you may have or not and if these are dedicated for Level 3 and 4

Q. We will be asking about any challenges you currently have and your plans to overcome these

Q. We need to know the waiting time to first AND second Level 3 and 4 services – this can be expressed as a mean but please do include the range

Q. We will also be asking about the information you provide/signpost to patients, what type? Format? Views about? Please provide examples
Q. What preparation do I need to do before the Interview?

Please look at the information above and compile as soon as possible. Your facilitator will agree with you a date for this to be provided to us. You will need to provide data for the full year 1st September 2012 – 31st August 2013. We appreciate that some of this may require a little work to collate but all should be readily available to you.

Q. What else will happen at the interview?

You will have the opportunity to talk through any other issues you feel relevant to your own situation. Your facilitator will also take you through the patient level data collection process to ensure you are fully aware of the requirements and help identify any remedial actions needed.

**Patient Level Data**

You will be required to provide a **four consecutive week** snapshot of **ALL NEW** patients to Level 3 and Level 4 services seen during the data collection period.

Q. When will this take place?

You can choose when you start to collect your data, anytime between the 7th to the 21st October 2013. This is to avoid the main October holiday period which varies from place to place.

Q. Are there data protection issues I need to be aware of?

Yes, as with all data, the approach must comply with Data Protection legislation. Patients also need to consent to the use of their data for all purposes. We will not be using any patient identifiable data.

We will provide you with a suggested consent form that patients need to complete.

We advise that you check your current approach to see whether consent for all data (including this snapshot) could be combined.
Q. What information will be collected?

You will be asked to collect information about ALL NEW patients seen over the four weeks. Data being asked for includes:

- Age
- Gender
- Employment status / work absence
- Source of referral
- Body part affected
- Duration of symptoms
- Patient Reported Outcome Measure (PROM)
- Patient Experience Reported measure (PREM)

Q. How will I record this information?

- HIS will provide you with all the tools you will need to use
- This will be an initial paper exercise for all aspects except the PROM and PREM to collect at patient level – we advise that all clinicians complete as they go along for later data entry
- A paper proforma will be provided to use with every new patient which will basically be a tick box
- This will then need to be transferred into an online Survey Monkey database we have created specifically for this purpose: [https://www.surveymonkey.com/s/C6N8NTP](https://www.surveymonkey.com/s/C6N8NTP)
- We advise that completed proforma are inputted in batches for maximum efficiency (consider a once a week option) – each patient’s data takes approx 30-40 seconds to enter

**The Patient Reported Outcome Measure (PROM)**

Q. What PROM is being used?

The PROM being used is the EQ-5D-5L which is a well validated measure and ideal for this purpose. EQ-5D-5L allows for the rerecording of both pre and post treatment values (scores) identified by the patient relating issues such as pain, quality of life and levels of anxiety and depression. It also allows for economic analyses to be carried out. We have secured permission from Euroqol to use the tool.
Q. What will I be collecting?

- You will be asking **ALL NEW patients ONLY at their first visit to** complete the EQ-5D-5L on paper
- Although the calculator allows you to enter pre and post treatment scores and get a comparator value, an outcome measure, for the purposes of this data collection exercise, we are only collecting information at the FIRST visit
- This is because very few patients will be seen and discharged within the four week period
- We do feel however that this will produce very helpful information and a descriptor of your population
- We advise SIGs to start to use the EQ-5D-5L routinely to start to generate outcome measures.

Q. How do I collect this?

- We will provide this for you.
- This then has to be entered into the EQ-5D-5L calculator spread sheet (also provided to you) by one of your staff.
- We advice that this is done in batches and literally takes less than 20 seconds per patient.
- The calculator automatically provides you with a value and full guidance is also provided.

| The Patient Reported Experience Measure (PREM) |

Q. What is this?

We have been working with the National Person Centred Programme 'Must do with me' to develop a set of 7 questions that will collect patients’ views of their care. It covers things like how involved and listened to they felt, the information they were given and overall satisfaction. This is an internet based system.
Q. How do I collect this?

- You should direct all patients to the website www.care-experiences.com and encourage them to complete.
- We will provide you with business cards to give to patients with the necessary details. **Please note that you need to write your 6 digit NHS board code on the blank code space on each card, which will ensure the patient will be able to access the questionnaire. Please choose your board code from below:**

<table>
<thead>
<tr>
<th>NHS board</th>
<th>NHS board code</th>
<th>NHS board</th>
<th>NHS board code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ayrshire &amp; Arran</td>
<td>AACP01</td>
<td>Highland</td>
<td>HICP01</td>
</tr>
<tr>
<td>Borders</td>
<td>BOCP01</td>
<td>Lanarkshire</td>
<td>LACP01</td>
</tr>
<tr>
<td>Dumfries &amp; Galloway</td>
<td>DGCP01</td>
<td>Lothian</td>
<td>LOCP01</td>
</tr>
<tr>
<td>Fife</td>
<td>FICP01</td>
<td>Orkney</td>
<td>ORCP01</td>
</tr>
<tr>
<td>Forth Valley</td>
<td>FVCP01</td>
<td>Shetland</td>
<td>SHCP01</td>
</tr>
<tr>
<td>Grampian</td>
<td>GRCP01</td>
<td>Tayside</td>
<td>TACP01</td>
</tr>
<tr>
<td>Greater Glasgow &amp; Clyde</td>
<td>GGCP01</td>
<td>Western Isles/ Eileanan Siar</td>
<td>WICP01</td>
</tr>
</tbody>
</table>

We do understand that not all patients have access to the internet, although many will have, or that they may have literacy problems. You will need to think about how you can collect this information in these circumstances. Some SIGs have already identified ways to do this such as:

- Having a laptop in the clinic for patients to use themselves
- Getting a loan from their IT department of a kiosk or IT equipment to collect this data
- Having paper copies available which are then input later into the web system – please note that if you require any paper copies, these can be printed out from the blank questionnaire template.

You should start to think about this now and make arrangements locally

Q. When does the data collection process need to be completed (including PROM and PREM)

All data needs to be entered **before the 22nd November 2013**
Q. When will we get the results back?

We will be working on assimilating these results as soon as the data is in. We have agreed to present a high level view of the data to the Parliamentary Cross Party Group on the 17th December but will ensure that you have a copy of this presentation in advance of that date. We anticipate publishing a full report at the end of March 2014.

Q. When and how will I get hold of these data tools and detailed guidance?

Your facilitator will ensure that these are with you prior well in advance of the data collection period. This will allow you to familiarise yourselves well in advance and contact your facilitator with any outstanding queries.

Q. I have further questions, who can help?

Your dedicated facilitator is on hand to help with queries of any nature, please contact them for help.
Please confirm that you have discussed with the patient that information may be entered into a computer database and used to help plan and improve health services locally and nationally. Ensure that patients are told that they are at liberty to withhold consent to the use of their information and that all details identifying patients are removed from all information used for this purpose (Please tick the relevant box).

YES, patient agrees to the above ☐ NO, patient does not agree ☐  
Clinician Initials

Date w/c: ………………………

1. Your NHS Board  …………………

2. Patient Gender
☐ Male  ☐ Female  ☐ Other (please specify) …………………………………………………

3. Patient Date of Birth
…………………………………………………………………………………………………………………………

4. Employment Status (tick as applicable)
☐ Employed  ☐ Unemployed  ☐ Houseperson  ☐ Student  ☐ Retired  ☐ Registered Disabled

5. Working status (if applicable)
☐ Absent due to health problems  ☐ Remains at work  ☐ Remains at work with difficulty
☐ Not applicable  ☐ Other (please specify)
………………………………………………

6. Period of absence from work (if applicable)
☐ Less than 2 weeks  ☐ Between 2-4 weeks  ☐ Between 4-6 weeks  ☐ Over 6 weeks  ☐ Not applicable

7. Source of referral
☐ GP  ☐ AHP  ☐ Hospital Consultant  ☐ Nurse  ☐ Self
☐ Other (please specify) …………………………………………………
8. **Body part affected (tick all that apply) (also tick multiple sites if > 1)**

- [ ] Low back
- [ ] Other spine
- [ ] Hip
- [ ] Knee
- [ ] Foot/ankle
- [ ] Shoulder
- [ ] Elbow/wrist/hand
- [ ] Head & neck (non spinal)
- [ ] Pelvic
- [ ] Abdominal (non spinal)
- [ ] Thoracic (non spinal)
- [ ] Multiple sites
- [ ] Other

9. **Duration of symptoms**

- [ ] Less than 3 months
- [ ] 3-6 months
- [ ] 6-12 months
- [ ] Over 1 year
1. I felt that staff always took account of the people that matter to me, and how much I wanted them to be involved in my care or treatment
   - Strongly Agree
   - Agree
   - Neither
   - Disagree
   - Strongly Disagree

2. I felt that I always had all the information and support I needed to help me make decisions about my care or treatment
   - Yes, all the time
   - Yes, most of the time
   - Sometimes
   - Not really
   - Never

3. I was always given the opportunity to be involved as much as I wanted to be in any discussions about me or about my care
   - Yes, all the time
   - Yes, most of the time
   - Sometimes
   - Not really
   - Never

4. Do you feel that when you spoke to staff they were listening properly to what you had to say?
   - Yes, all the time
   - Yes, most of the time
   - Sometimes
   - Not really
   - Never
5. Do you feel that you got the care you needed?
   - Yes, all the time
   - Yes, most of the time
   - Sometimes
   - Not really
   - Never

6. Overall, how would you rate the care you received?
   - Excellent
   - Good
   - Average
   - Poor
   - Very poor

7. Do you have any other comments or suggestions for improvement?
The EQ-5D-5L: a quality of life measure

What is the EQ-5D-5L?

The EQ-5D-5L is 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, http://www.euroqol.org/)

It is used widely throughout the UK and globally within healthcare services to provide information at the individual patient, service and/or population level to provide information of use to patients, services and policy makers.

The EQ-5D-5L is used and/or recommended for use as a standard outcome measure by a number of national organisations and services throughout the UK including the Scottish Government and NICE. The Chartered Society of Physiotherapy for example, is one organisation that recommends its use within MSK services and is actively supporting its UK wide use including negotiating a licence for its use in these settings.

Why use the EQ-5D-5L?

There is a need to be able to demonstrate the quality and effectiveness of chronic pain services throughout Scotland to support and monitor progress. The use of PROMs are recognised as a key way to measure the impact of health care interventions from the patients perspective. The EQ-5D-5L is promoted for this use by many organisations including the Kings Fund in their publication ‘Getting the most out of PROMS (2010)’. We are recommending chronic pain services throughout Scotland use the EQ-5D-5L to provide key local and national information.

There are a number of attractive features of the EQ-5D-5L:

- It is simple and quick to use, it takes less than two minutes to complete
- It is ideally suited for use in postal surveys, over the telephone or in face to face interviews
- It has been robustly developed and has a strong academic basis
- It can give simple and relevant data
- Allows comparisons within and across conditions /services
- It has the potential for use in economic analysis / cost-effectiveness

What does it consist of?

It has two parts: a descriptive part and a Visual Analogue Scale (VAS). The descriptive system has five dimensions and for each dimension there are five responses, ranging from 'I have no problems....' to 'I am unable to'. The five dimensions relate to: -

- Mobility,
- Self-care,
- Usual activities,
- Pain/discomfort
- Anxiety/depression.
The VAS asks the patient to assess their health ‘today’ on a scale of 0-100. **The VAS is important when undertaking research but is not essential in routine clinical outcome measurement and therefore, this is not an essential part of the chronic pain national measurement set.**

**How is it scored?**

- The response to each of the five dimensions is assigned a number 1 to 5 with ‘1’ representing no problem through to ‘5’ representing the most severe category.
- These figures have no arithmetic value and result in a 5 digit number which describes the patient’s ‘health state’. For example, a patient with no problems in any dimension would have a health state of 11111.
- This 5 digit number can be converted into a weighted score using the provided spreadsheet.
- Collecting the same information at discharge generates a second single index score. It is the difference in these scores that generates the change in the quality of life of the patient.
- EQ-5D-5L data is also used to calculate quality of life adjusted years (QALY), the unit of measurement used by the national organisations (Healthcare Improvement Scotland (HIS) and Institute of Clinical Excellence (NICE)) to assess the value of health outcomes.

See the EuroQol website for full details of administration and scoring [www.euroqol.org](http://www.euroqol.org)

**When should the EQ-5D-5L be completed?**

- The EQ-5D-5L should be completed at/around the first and last contact to provide both a baseline and comparative score.
- Patients should be encouraged to complete the measure unassisted wherever possible.
- Assistance may be required where there are problems with reading, a lack of understanding or visual disturbance.

**Where can I find further information about the EQ-5D-5L?**

- Chronic pain website: [www.chronicpainscotland.org](http://www.chronicpainscotland.org)
- [http://www.euroqol.org/](http://www.euroqol.org/)
- Devlin NJ, Appleby J. *Getting the most out of PROMS.* 2010.
Under each heading, please tick the ONE box that best describes your health TODAY

MOBILITY
I have no problems in walking about
I have slight problems in walking about
I have moderate problems in walking about
I have severe problems in walking about
I am unable to walk about

SELF-CARE
I have no problems washing or dressing myself
I have slight problems washing or dressing myself
I have moderate problems washing or dressing myself
I have severe problems washing or dressing myself
I am unable to wash or dress myself

USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)
I have no problems doing my usual activities
I have slight problems doing my usual activities
I have moderate problems doing my usual activities
I have severe problems doing my usual activities
I am unable to do my usual activities

PAIN / DISCOMFORT
I have no pain or discomfort
I have slight pain or discomfort
I have moderate pain or discomfort
I have severe pain or discomfort
I have extreme pain or discomfort

ANXIETY / DEPRESSION
I am not anxious or depressed
I am slightly anxious or depressed
I am moderately anxious or depressed
I am severely anxious or depressed
I am extremely anxious or depressed
Patient consent form

Consent to providing information for the Pain Management Service.

Please read, complete, and sign the consent form. Should you require clarification of any statement, please contact the Service.

1. I agree that for purposes relating to my pain management that the healthcare team may access my GP/Hospital medical records. (Please tick the relevant box).

   YES, I agree to the above ☐        NO, I do not agree ☐

2. I agree that any information collected by the Pain Management Service may be entered in a computer database and used to help plan and improve health services locally, and nationally. The data may also be used in research projects approved by the appropriate Research Ethics Committee. **Details identifying me will be removed** from any information used for this purpose (Please tick the relevant box).

   YES, I agree to the above ☐        NO, I do not agree ☐

3. I agree that members of the Pain Management Service may contact me in the future in relation to my experience in the service, for research purposes (Please tick the relevant box).

   YES, I agree to the above ☐        NO, I do not agree ☐

Please note that you can withdraw your consent at any time, and are not obligated to take part in any future research. This will not affect the treatment you receive.
4. I agree, if it is required, for purposes relating to my pain management that a named Community Pharmacist may access my GP/Hospital medical records. (Please tick the relevant box).

YES, I agree to the above ☐ NO, I do not agree ☐

5. I agree that members of the Pain Management Service may refer me to Pain Association Scotland and/or Active Options for ongoing management of my pain if deemed appropriate. (Please tick the relevant box).

YES, I agree to the above ☐ NO, I do not agree ☐

Patient: ______________________________
Print Name: ______________________________
Signature: ______________________________
Date: ______________________________

Clinical Service Lead: ______________________________
Print Name: ______________________________
Signature: ______________________________

Thank You