

Data and Measurement for Chronic Pain Services.

A Project to Inform National Pain Service improvement.

Draft Progress Report

Cara Richardson, Magda Laskawska, Katherine Berlouis, Paul Cameron, Lesley Colvin
and Blair H Smith

Executive Summary

This project was established to address the lack of standardised measurement of chronic pain in Scotland, and of services provided to manage chronic pain. This is an important issue as there is no clear way of measuring the prevalence of chronic pain nationally, understanding the demographics and needs of the patient group, the impact chronic pain has on them, or the effectiveness of any service provision or service improvement initiatives which often presents a problem when funding services and treatments for patients.

One of the key aims of this project is to develop, test and implement a Core Minimum Dataset for Chronic Pain, collected by all Pain Services, which will assess key areas such as Age, Gender, Pain Duration, Pain Severity, Emotional Impact, Functional Impact, Health-Related Quality of Life, Pain Site and Underlying Diagnosis. An optimum dataset has also been established detailing a range of measures in key domains such as Emotional Impact, Functional Impact and Health-Related Quality of Life. This purpose of this dataset is to allow clinicians to incorporate additional measures, to the core dataset, for clinical or research purposes.

A second key aim is the development of Quality Performance Indicators (QPIs) for Chronic Pain Services. These QPIs are a set of standards used to measure and monitor chronic pain service provision in Scotland. QPIs are designed to capture quality of care and outcomes for patients, rather than solely measuring access to services. This allows measures used to be integrated with indicators to demonstrate improvement, and quality of care.

A third key aim of this project is to develop a Policy Matrix for Chronic Pain. This Matrix provides an overview of the principal policies relevant to health and social care provision in Scotland, identifying the key themes that will be addressed by good management of chronic pain. The over-arching policy is Realistic Medicine.

Key Findings

1. There is currently a wide range of breadth and depth of data being collected to evaluate this and no unified approach.
2. The timing of data collection varied across health board - for example, Fife and the Lothian PMP provide pre and post outcome data whereas Tayside focus on data collection at initial assessment.
3. Data across all three health boards are used in planning individual care.
4. Fife and Lothian also utilise pain data in service audits, yet 50% of sampled clinicians indicated there a lack of clarity in regards to the usefulness of the collected data.
5. All three health boards are either currently using or moving over to TRAK.
6. The speed of I.T. Systems was rated by clinicians as the most poorly rated feature of their clinical databases, with 'lack of time' rated the most significant barrier to data entry.
7. Development of a draft CMD, with changes and responses to a national consultation exercise.
8. Development of an Optimum Dataset, to allow clinicians to incorporate additional measures to the core dataset.
9. Iterative development of a draft set of QPIs, through an ongoing national consultation process.
10. The creation of the Policy Matrix for Chronic Pain demonstrated that the management of chronic pain is central to a wide range of policies and presenting it in this way can aid policy makers in identifying the gaps in current health and social care strategies.

Next Steps

1. **March 2018:** Submission of Caldicott application (for the validation phase of the project).
2. **February-March 2018:** Devise a data collection form for the Quality Performance Indicators (QPIs).
3. **Timing dependent on Caldicott approval:** Validation of the Core Minimum Dataset in Level 3 Pain Services in NHS Tayside, Lothian and Fife (see Appendix 1 for more information).
4. **April 2018:** Trial run of the Quality Performance Indicators (QPIs) in one Pain Service.
5. **August 2018:** In light of consultation and pre-pilot feedback, develop the Quality Performance Indicators for wider pilot testing.
6. **2018:** Pilot testing of the Quality Performance Indicators (timing to be discussed with the DCMO).

7. **2018:** Identification and development of digital approach to data collection for the CMD.
8. **2018:** Further development of the Optimum Dataset, incorporating potential suggestions from the consultation and pilot testing.
9. **2018:** Further dissemination of the Policy Matrix for Chronic Pain to the National Advisory Committee for Chronic Pain (NACCP).

To be completed by the end of the funding period (August 2019)

1. A validated Core Minimum Dataset ready for implementation in Pain Services across Scotland.
2. An agreed set of Quality Performance Indicators (QPIs) ready for implementation in Pain Services across Scotland.
3. Dissemination and initial evaluation of The Management of Chronic Pain in Children and Young People: A National Clinical Guideline.

Core Minimum Dataset and Optimum Dataset

The purpose of these datasets is to allow for a more accurate picture of Chronic Pain in Scotland, to enhance service improvement needs assessment and evaluation of the delivery of services. The aim is to identify a Core Minimum Dataset (CMD), to be collected by all Pain Services in NHS Scotland, and an Optimum Dataset from which Pain Services may select additional data collection instruments, compatibly with other services

The CMD will be implemented in level 3 services in the first instance. Version 1.0 has undergone a pre-pilot testing in NHS Tayside, and a national consultation exercise. The consequent revised version (2.0) will be subjected to validity testing against the current measures used in NHS Tayside, Lothian and Fife.

Core Minimum Dataset

Below are the recommendations for a core minimum dataset for Level 3 and 4 Pain Services across Scotland. The primary objectives of a 'minimum' dataset are to provide sufficient data that will allow measurement of baseline and outcomes among patients attending each service, and direct comparisons between services and time periods.

The priority is for this dataset to serve clinical rather than research purposes. Thereby, practicalities for clinical use were the principal consideration in the selection of questionnaire items and data collection.

The following seven domains are recommended for inclusion in the CMD: Pain Site(s), Pain Duration, Pain Severity, Underlying Diagnosis, Emotional Impact, Functional Impact and Health-Related Quality of Life. Suggested items pertaining to each domain are as follows:

- a. CHI Number
- b. Age
- c. Gender
- d. Postcode
- e. Pain Site(s): List of Body Parts.
- f. Pain Duration: Categorised list
- g. Pain Severity: Question 1 of the Chronic Pain Grade Questionnaire (CPG) [1].
- h. Underlying Diagnosis: Map to ICD-11 (develop Read code/SNOMED)
- i. Emotional Impact: Patient Health Questionnaire-2 (PHQ-2) [2].
- j. Functional Impact: Question 5 of the Chronic Pain Grade Questionnaire (CPG) [1].
No conclusive evidence exists regarding a single self-report physical activity questionnaire [3].
- k. Health-Related Quality of Life: Question 1 of the Short Form Health Survey (SF-36) [4].

See Appendix 2 for dataset in full.

Optimum Dataset

An optimum dataset (in addition to the core minimum) may include some or all of, but is not restricted to, the following domains/measures:

- **Emotional Impact:**
 - The Hospital Anxiety and Depression Scale (HADS) [5]
 - Patient Health Questionnaire (PHQ-9) [6]
 - General Anxiety Disorder Questionnaire (GAD-7) [7]
 - The Profile of Mood States (POMS) [8]
 - Cognitive Fusion Questionnaire (CFQ) [9]
 - Clinical Outcomes in Routine Evaluation (CORE-10) [10]

- Self-Compassion Scale (SCS) [11]

- **Functional Impact:**
 - The Brief Pain Inventory (BPI) [12]
 - The Multidimensional Pain Inventory (MPI) [13]
 - Oswestry Low Back Pain Disability Questionnaire [14]
 - Roland and Morris Back Pain Disability Questionnaire (RDQ) [15]

- **Health-Related Quality of Life:**
 - The EuroQol Dimension Questionnaire (EQ-5D) [16]
 - Short Form Health Survey (SF-36) [4]
 - PSYCHLOPS [17]
 - Work and Social Adjustment Scale (WSAS) [18]
 - Short Form Health Survey (SF-36) [4]

- **The NHS Friends and Family Test (FFT) [19]**
 - Would you recommend this service to your friends and family? (Extremely likely – Extremely Unlikely or I Don't Know)

We cannot recommend a definitive common optimum dataset based on current evidence but we should work towards this based on national consensus.

Quality Performance Indicators (QPIs)

Background

Targets can be described as ‘a way of expressing the priority of the organisation’. Furthermore, indicators illustrate ‘how an organisation is progressing in pursuit of its aim’ [20]. Both targets and indicators are central in improving many aspects of health and social care. The recent review conducted by Burns [1] states that ‘the present system of targets and indicators is fragmented and many of the indicators do not lend themselves to effective improvement interventions’. Most importantly, this report provides us with guidelines on how the indicators and targets should be developed in order to improve health, reduce inequalities and provide high quality services in Scotland. The main objective of this summary is to describe how these key recommendations relate to the current project, which involves the development of QPI for treatment of chronic pain across primary, secondary, and tertiary services.

As suggested by Burns [20], there is need for a more collaborative approach (which involves staff that deliver the indicators as well as the recipients of the service) in order to develop better indicators of progress. This approach is likely to lead to better outcomes. The current project (on the development of the QPIs) addresses this issue by engaging patients as well as NHS staff (NHS boards) in the process of developing QPIs and targets, for people that suffer from chronic pain. In summary, our targets and QPIs are consistent with the person-centred approach to care. They are also important to patients. Both of these elements are emphasised in the review conducted by Burns [20].

In addition, the new approach to targets and indicators should ideally focus on patients’ outcomes. However, it needs to be kept in mind that this is not always possible to achieve (e.g. ‘outcome measures are not always available in a meaningful form’ [21]). Therefore, a pragmatic approach should be adopted ‘where the processes are essential to the delivery of desired outcomes’ [20]. The current project incorporated both result as well as

process based targets and indicators. Process indicators such as ‘advice to increase or maintain physical activity’ are important since there is a large body of evidence to suggest that exercise therapy is beneficial in improving outcomes for people that suffer from chronic pain. In summary, the current project is consistent with the pragmatic approach proposed by Burns [20].

There are disadvantages associated with the introduction of targets. For instance, there is a possibility that targets may widen social inequalities [22]. The current project is central to reducing social inequalities. The findings obtained from this project could help us to understand how the QPIs work across different subgroups. This in turn could help to reduce social and geographical inequalities. Moreover, the current project recommends that pain education (e.g. educational booklets at GP practices) should be available in languages other than English. In addition, indicators such as Exercise and Activity Therapy are inexpensive to implement as most people have access to some form of physical activity. Consequently this will help to reduce inequalities. In summary, the current project takes into account the differences between more and less advantaged groups.

Systems thinking is central when it comes to the design of indicators and targets. “Systems thinking” describes the processes of developing an understanding of a system by examining the linkages and interactions between the elements that compose the entire system [20]. The indicators developed in this study have been designed to reflect the performance across the whole system they are trying to measure. First, the current project takes into account the Scottish Service Model for chronic pain [8]. Specifically, the QPIs were modelled against the four levels of the Scottish Service Model [8]. Further, this project facilitates ‘system thinking’ by involving different public organisations (primary, secondary and tertiary services) in the delivery of the same set of QPIs and outcome measurements. This integration is important because as suggested by Burns [20], there is a need to examine the performance of the system as a whole. Most importantly, this project will help to reduce the number of patients that use higher level services (e.g. level

four services) by implementing more consistent standards at all other levels. It can be concluded that this study adheres to the principles for the good design of indicators.

In summary, the current project is consistent with the key principles outlined in the review conducted by Burns [20]. It adopts a collaborative approach and focuses on pragmatism and also considers outcome based QPIs. In addition, it promotes 'systems thinking' by aiming to develop a standardised set of QPIs and a core outcome dataset across many different services in Scotland. All of these will help us to improve our understanding of how different services are working as a whole and what changes need to be made in order to improve their effectiveness.

Quality Performance Indicators (QPIs)

In accordance with the objectives of the National Outcomes project, collated information from research across the country and a literature review was used to develop evidence-based recommendations for minimum standards of pain service provision. The QPIs have been modelled against the four levels of the Scottish Service Model [23].

Quality Performance Indicators (QPIs) are a set of standards used to measure and monitor chronic pain service provision in Scotland. The aim of QPIs is to drive continuous quality improvement in the care of patients with chronic pain. QPIs are designed to be clear and measurable, based on sound clinical evidence whilst also taking into account other recognised standards and guidelines. The main source of evidence for these QPIs is SIGN 136 and the National Prescribing Strategy (which is in its final stages before publication).

The QPIs are have undergone a formal and rigorous consultation process with feedback welcome on all areas, specifically attainable and realistic targets for each indicator.

Five QPIs have been developed initially in the following areas (see Appendix 3 for QPIs in full):

1. Pain Education
2. Outcome Measures
3. Pharmacy Review
4. Service Evaluation and Audit
5. Exercise and Activity Therapies

Policy Matrix – Chronic Pain

This Matrix provides an overview of the principal policies relevant to health and social care provision in Scotland, identifying the key themes that will be addressed by good management of chronic pain. The over-arching policy is Realistic Medicine.

Shared decision making is important in the treatment of patients with chronic pain as chronic pain is a complex condition, often requiring input from a range of services, and shared decision making could lead to the best possible outcomes for patients. Services should aim to reduce unwanted harm, waste and variation in care and the Quality Performance Indicators (developed through the National Outcomes project) aims to facilitate this standardisation of care. Patients should receive a personalised approach when it comes to the treatment of chronic pain, being involved in the decision making in relation to their care and treatment. Early assessment can allow patients to be triaged to the most appropriate service for their needs. Enhancing the availability of appropriate information for relevant parties can allow services to share common issues and examples of good practice which can inform decisions on service delivery, performance and improvement. Services need to be reflective of the population they serve and changes to this population should be taken account of. Financial considerations are important as services need to ensure they are delivering services within their capacity. Finally cluster working and collaboration between services allows for improved communication between services which can benefit patients which chronic pain.

All health policies were taken from 2012 to 2018. Each of these policies cover a wide range of themes, often overlapping with each other. Chronic pain management is central to a wide range of policies and presenting it in this way can aid policy makers in identifying the gaps in current health and social care strategies.

	Realising Realistic Medicine [24]	Quality Prescribing for Chronic Pain. A Guide for Improvement. 2017-2020 [25]	eHealth Strategy 2014-2017 [26]	Effective Prescribing [27]	National Clinical Strategy [28]	AHP Delivery Plan [29]	Achieving Excellence in Pharmaceutical Care: A Strategy for Scotland [30]	Improving together: A National Framework for Quality and GP Clusters in Scotland [31]	Allied Health Professions Co-creating Wellbeing with the People of Scotland The Active and Independent Living Programme in Scotland [32]	Health and Social Care Delivery Plan [33]	Targets and Indicators in Health and Social Care in Scotland A Review [20]
Shared Decision Making.	✓		✓					✓	✓	✓	✓
Reducing Harm, Waste and Variation in Care.	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓
Personalised Approach to Care.	✓		✓		✓	✓	✓		✓	✓	
Early Assessment	✓	✓									
Ongoing Review	✓	✓		✓							
To enhance the availability of appropriate information for relevant parties to inform decisions on service delivery, performance	✓		✓	✓	✓	✓	✓	✓	✓		

	Realising Realistic Medicine [24]	Quality Prescribing for Chronic Pain. A Guide for Improvement. 2017-2020 [25]	eHealth Strategy 2014-2017 [26]	Effective Prescribing [27]	National Clinical Strategy [28]	AHP Delivery Plan [29]	Achieving Excellence in Pharmaceutical Care: A Strategy for Scotland [30]	Improving together: A National Framework for Quality and GP Clusters in Scotland [31]	Allied Health Professions Co-creating Wellbeing with the People of Scotland The Active and Independent Living Programme in Scotland [32]	Health and Social Care Delivery Plan [33]	Targets and Indicators in Health and Social Care in Scotland A Review [20]
and improvement.											
Demographic changes in our population.	✓				✓		✓	✓	✓		✓
Financial considerations.	✓		✓	✓	✓			✓		✓	✓
Cluster working and collaboration between services.	✓		✓			✓	✓	✓	✓	✓	✓

References

1. Smith, B.H., et al., *The Chronic Pain Grade questionnaire: validation and reliability in postal research*. Pain, 1997. **71**(2): p. 141-147.
2. Kroenke, K., et al., *Operating characteristics of PROMIS four-item depression and anxiety scales in primary care patients with chronic pain*. Pain Medicine, 2014. **15**(11): p. 1892-1901.
3. Silsbury, Z., R. Goldsmith, and A. Rushton, *Systematic review of the measurement properties of self-report physical activity questionnaires in healthy adult populations*. BMJ Open, 2015. **5**(9).
4. RAND. *36-Item Short Form Survey (SF-36)*. Available from: https://www.rand.org/health/surveys_tools/mos/36-item-short-form.html.
5. Zigmond, A.S. and R.P. Snaith, *The hospital anxiety and depression scale*. Acta psychiatrica scandinavica, 1983. **67**(6): p. 361-370.
6. Spitzer, R.L., et al., *Validation and utility of a self-report version of PRIME-MD: the PHQ primary care study*. Jama, 1999. **282**(18): p. 1737-1744.
7. Spitzer, R.L., et al., *A brief measure for assessing generalized anxiety disorder: the GAD-7*. Archives of internal medicine, 2006. **166**(10): p. 1092-1097.
8. McNair, D.M., M. Lorr, and L.F. Droppleman, *Profiles of mood states*. San Diego: Educational and Industrial Testing Services, 1971.
9. Gillanders, D.T., et al., *The development and initial validation of the cognitive fusion questionnaire*. Behav Ther, 2014. **45**(1): p. 83-101.
10. Evans, J.M.-C.F.M.M.B.K.A.J.C.G.M.C., *CORE: Clinical Outcomes in Routine Evaluation*. Journal of Mental Health, 2000. **9**(3): p. 247-255.
11. Neff, K.D., *The development and validation of a scale to measure self-compassion*. Self and identity, 2003. **2**(3): p. 223-250.
12. Cleeland, C.S. and K.M. Ryan, *Pain assessment: global use of the Brief Pain Inventory*. Ann Acad Med Singapore, 1994. **23**(2): p. 129-38.
13. Kerns, R.D., D.C. Turk, and T.E. Rudy, *The West Haven-Yale Multidimensional Pain Inventory (WHYMPI)*. Pain, 1985. **23**.
14. Fairbank, J.C., et al., *The Oswestry low back pain disability questionnaire*. Physiotherapy, 1980. **66**(8): p. 271-3.
15. Roland, M. and R. Morris, *A study of the natural history of back pain. Part I: development of a reliable and sensitive measure of disability in low-back pain*. Spine (Phila Pa 1976), 1983. **8**.
16. EuroQol, G., *EuroQol--a new facility for the measurement of health-related quality of life*. Health policy (Amsterdam, Netherlands), 1990. **16**(3): p. 199.
17. Ashworth, M., et al., *Measuring mental health outcomes in primary care: the psychometric properties of a new patient-generated outcome measure, 'PSYCHLOPS' ('psychological outcome profiles')*. Primary care mental health, 2005. **3**(4).
18. Mundt, J.C., et al., *The Work and Social Adjustment Scale: a simple measure of impairment in functioning*. The British Journal of Psychiatry, 2002. **180**(5): p. 461-464.
19. NHS England. *The NHS Friends and Family Test (FFT)*. Available from: <https://www.nhs.uk/NHSEngland/AboutNHSservices/Pages/nhs-friends-and-family-test.aspx>.
20. Burns, H., *Targets and Indicators in Health and Social Care in Scotland. A Review*. The Scottish Government 2017.

21. Berry, N., T. Gardner, and I. Anderson, *On targets: how targets can be most effective in the English NHS*. 2015: Health Foundation.
22. Elkan, R. and J. Robinson, *The use of targets to improve the performance of health care providers: a discussion of government policy*. Br J Gen Pract, 1998. **48**(433): p. 1515-1518.
23. Healthcare Improvement Scotland, *Chronic Pain Services in Scotland: Where are we now?* 2014.
24. The Scottish Government, *Chief Medical Officer's Annual Report 2015-16: Realising Realistic Medicine*. 2017.
25. The Scottish Government, *Quality Prescribing for Chronic Pain. A Guide for Improvement 2017-2020*. 2018.
26. The Scottish Government, *eHealth Strategy 2014-2017*. 2015.
27. The Scottish Government, *Effective Prescribing 2015*.
28. The Scottish Government, *A National Clinical Strategy for Scotland*. 2016.
29. The Scottish Government, *AHPs as agents of change in health and social care. The National Delivery Plan for the Allied Health Professions in Scotland, 2012–2015*. 2012.
30. The Scottish Government, *Achieving Excellence in Pharmaceutical Care: A Strategy for Scotland*. 2017.
31. The Scottish Government, *IMPROVING TOGETHER: A National Framework for Quality and GP Clusters in Scotland 2017*.
32. The Scottish Government, *Allied Health Professions Co-creating Wellbeing with the People of Scotland. The Active and Independent Living Programme in Scotland*. 2017.
33. The Scottish Government, *Health and Social Care Delivery Plan*. 2016.
34. Crichton, N., *Visual analogue scale (VAS)*. J Clin Nurs, 2001. **10**(5): p. 706-6.
35. Nicholas, M.K., *Pain self efficacy questionnaire (PSEQ)*. Summary of psychometric properties from original Westmead hospital sample (1986e87). Sydney: University of Sydney Pain Management and Research Centre, 1994.
36. Little, P., et al., *Should We Give Detailed Advice and Information Booklets to Patients With Back Pain?: A Randomized Controlled Factorial Trial of a Self-Management Booklet and Doctor Advice to Take Exercise for Back Pain*. Spine, 2001. **26**(19): p. 2065-2072.
37. Scottish Intercollegiate Guidelines Network, *Management of chronic pain*. SIGN 136, 2013.
38. LeFort, S.M., et al., *Randomized controlled trial of a community-based psychoeducation program for the self-management of chronic pain*. Pain, 1998. **74**(2-3): p. 297-306.
39. Trouvin, A., et al., *Assessing the Benefit of an Educational Program in a Rehabilitation Program over a Week in 99 Patients with Chronic Low Back Pain*. J Nov Physiother, 2016. **6**(286): p. 2.
40. Geneen, L.J., et al., *Effects of education to facilitate knowledge about chronic pain for adults: a systematic review with meta-analysis*. Systematic reviews, 2015. **4**(1): p. 1.
41. The Scottish Government, *Quality Prescribing for Chronic Pain: A Guideline for Improvement 2017-2020*. 2018.
42. The British Pain Society, *Guidelines for Pain Management Programmes for adults. An evidence-based review prepared on behalf of the British Pain Society 2013*.
43. National Pain Audit Final Report 2010–2012. Available at: www.nationalpinaudit.org/media/files/NationalPainAudit-2012.pdf; Dr Foster Intelligence, British Pain Society, Healthcare Quality Improvement Partnership;
44. The Faculty of Pain Medicine, *Key Pain Management Standards for CQC inspection frameworks*.
45. Treede, R.-D., et al., *A classification of chronic pain for ICD-11*. Pain, 2015. **156**(6): p. 1003.

46. NHS Scotland, *NHS Scotland Waiting Time Guidance*. 2012.
47. Kylasov, A. and S. Gavriv, *Diversity Of Sport: non-destructive evaluation.*, in *Encyclopedia of Life Support Systems*. 2011, UNESCO: Paris. p. 462-491.
48. World Health Organisation. *Physical Activity*. 2017; Available from: http://www.who.int/topics/physical_activity/en/.
49. Geneen, L.J., et al., *Physical activity and exercise for chronic pain in adults: an overview of Cochrane Reviews*. The Cochrane Library, 2017.
50. Daenen, L., et al., *Exercise, Not to Exercise, or How to Exercise in Patients With Chronic Pain? Applying Science to Practice*. The Clinical Journal of Pain, 2015. **31**(2): p. 108-114.

Appendices

Appendix 1: How the data collected in NHS Lothian, Tayside and Fife matches onto the Core Minimum Dataset

Questionnaires	NHS Tayside	Core Minimum Dataset
Pain Severity	Brief Pain Inventory (BPI) [12]	Question 1 of the Chronic Pain Grade Questionnaire (CPG) [1]
Functional Impact	Brief Pain Inventory (BPI)-question 9(A) [12]	Question 5 of the Chronic Pain Grade Questionnaire (CPG) [1]
Emotional Impact	Hospital Anxiety and Depression Scale (HADS) [5]	Patient Health Questionnaire-2 (PHQ-2) [2]
Health - Related Quality of Life	Clinic questionnaire : Question number 9(G) from BPI [12] asks about enjoyment of life. Research questionnaire: EuroQol Five Dimensions Questionnaire (EQ-5D) [16]	Question 1 of the Short Form Health Survey (SF-36) [4]



Questionnaires	NHS Lothian	Core Minimum Dataset
Pain Severity	Brief Pain Inventory (BPI) [12]	Pain Severity: Question 1 of the Chronic Pain Grade Questionnaire (CPG) [1]
Functional Impact	Brief Pain Inventory (BPI) [12]	Question 5 of the Chronic Pain Grade Questionnaire (CPG) [1]
Emotional Impact	Hospital Anxiety and Depression Scale (HADS) [5]	Patient Health Questionnaire-2 (PHQ-2) [2]
Health - Related Quality of Life	EuroQol Five Dimensions Questionnaire (EQ-5D) [16]	Health-Related Quality of Life: Question 1 of the Short Form Health Survey (SF-36) [4]

Questionnaires	NHS Fife	Core Minimum Dataset
Pain Severity	Visual analogue scale (VAS) [34]	Pain Severity: Question 1 of the Chronic Pain Grade Questionnaire (CPG) [1]
Functional Impact	Pain Self-Efficacy Questionnaire (PSEQ) [35]	Question 5 of the Chronic Pain Grade Questionnaire (CPG) [1]
Emotional Impact	Patient health questionnaire - 9 (PHQ-9) [6]	Patient Health Questionnaire-2 (PHQ-2) [2]
Health - Related Quality of Life	Not recorded.	Health-Related Quality of Life: Question 1 of the Short Form Health Survey (SF-36) [4]



Appendix 2: Core Minimum Dataset¹

Demographics

1) Today's date

2) CHI Number

3) Age

- 18 - 24 years old
- 25 - 34 years old
- 35 - 44 years old
- 45 - 54 years old
- 55 - 64 years old
- 65 - 74 years old
- 75 years or older

4) Gender

- Female
 - Male
 - Non-binary/ third gender
 - Prefer to self-describe
-

- Prefer not to say

5) Postcode

¹ Version 2 – 16/02/2018

10) Health-Related Quality of Life²

Please circle the number that applies to you.

In general, would you say that your health is:

Excellent	1
Very good	2
Good	3
Fair	4
Poor	5

²SF-36 is reproduced here (in part) with permission from the RAND Corporation. Copyright © the RAND Corporation. RAND's permission to reproduce the survey is not an endorsement of the products, services, or other uses in which the survey appears or is applied.

11) Pain Site (tick any/all that apply)

Head

Facial/Dental

Cervical Spine

Upper Limb: Shoulder/Arm/Wrist/Hand

Chest

Thoracic Spine

Abdomen

Lumbar/Sacral

Pelvis

Lower Limb: Hip/Buttock/Ankle/Foot

Widespread

12) Underlying Diagnosis²

Please refer to the ICD 11 classification section
(below) for further details

Please tick all of the options that apply.

- Chronic primary pain
- Chronic cancer pain
- Chronic postsurgical and posttraumatic pain
- Chronic neuropathic pain
- Chronic headache and orofacial pain
- Chronic visceral pain
- Chronic musculoskeletal pain

² Proposed ICD-11 classification (Treede et al, 2015)

1. Chronic primary pain is pain in 1 or more anatomic regions that persists or recurs for longer than 3 months and is associated with significant emotional distress or significant functional disability (interference with activities of daily life and participation in social roles) and that cannot be better explained by another chronic pain condition.
2. Chronic cancer pain includes pain caused by the cancer itself (the primary tumour or metastases) and pain that is caused by the cancer treatment (surgical, chemotherapy, radiotherapy, and others).
3. Chronic postsurgical and posttraumatic pain is pain that develops after a surgical procedure or a tissue injury (involving any trauma, including burns) and persists at least 3 months after surgery or tissue trauma.
4. Chronic neuropathic pain is caused by a lesion or disease of the somatosensory nervous system.
5. Chronic headache and chronic orofacial pain is defined as headaches or orofacial pains that occur on at least 50% of the days during at least 3 months.

6. Chronic visceral pain is persistent or recurrent pain that originates from the internal organs of the head and neck region and the thoracic, abdominal, and pelvic cavities.
7. Chronic musculoskeletal pain is defined as persistent or recurrent pain that arises as part of a disease process directly affecting bone(s), joint(s), muscle(s), or related soft tissue(s).

Appendix 3: Quality Performance Indicators (QPIs)³

QPI 1 – Pain Education (Levels 1-4)

QPI Title:	Pain Education (Levels 1-4)
Description:	Patients attending an NHS service that provides chronic pain treatment should have access to advice and information about pain. These services include, but are not restricted to, Specialist Pain Services, General Practices, Community Pharmacies and relevant AHP clinics. Pain information should be accessible and might take the format of signposting to relevant services, literature and/or pain education sessions. Clear (legible, audible, understandable) information should include information pertaining to types of pain, coping mechanisms, dealing with sleep and anxiety and the origins of pain. Information should also be provided on exercise and self-management. Where appropriate, this should be provided or signposted in languages other than English.
Rationale and Evidence:	An RCT conducted by Little, Roberts [36] found that providing educational booklets and exercise advice to patients with lower back pain can increase satisfaction and moderately improve functional outcomes. SIGN 136 recommends pain information sessions as safe, low technology, community based and affordable interventions to help patients better manage their condition [37]. Pain education programmes have been found to increase chronic low back pain patients' likelihood of achieving their goals and can result in significant behaviour changes [38, 39]. A decrease in pain can also be found following these programmes as well as physiological improvements [39], though these tend to be short-term improvements [38]. Pain neurophysiology education has been shown to be effective in conjunction with other pain management approaches [40].
Specifications:	<p>Numerator: Number of NHS services making information about chronic pain available (including visible signposting relevant to pain education).</p> <p>Denominator: Number of NHS services providing chronic pain treatment</p> <p>Exclusions: No exclusions.</p>
Target	Each service provides information about chronic pain.

³ Version 2 – 16/02/2018

QPI 2 – Outcome Measures (Levels 2-4)

QPI Title:	Outcome Measures (Levels 2-4)
Description:	<p>Patients being treated for chronic pain should be administered relevant outcome measures at the beginning of treatment and at least once after treatment to gauge process (minimum 6 weeks, maximum one year).</p> <p>Health professionals are advised to record the following core minimum data:</p> <ol style="list-style-type: none"> 1) Age 2) Gender 3) Pain Site(s): List of Body Parts. 4) Pain Duration: Categorised list 5) Pain Severity: Question 1 of the Chronic Pain Grade Questionnaire (CPG) [1]. 6) Underlying Diagnosis: Map to ICD-11 (develop Read code/SNOMED) 7) Emotional Impact: Patient Health Questionnaire-2 (PHQ-2) [2]. 8) Functional Impact: Question 5 of the Chronic Pain Grade Questionnaire (CPG) [1]. No conclusive evidence exists regarding a single self-report physical activity questionnaire [3]. 9) Health-Related Quality of Life: Question 1 of the Short Form Health Survey (SF-36). <p>The same set of measures completed during and after treatment (if possible) allows assessment of progress since treatment began.</p>
Rationale and Evidence:	<p>Repeating relevant measures before and after treatment is a central tenet of patient care, facilitates audit and allows service evaluation and improvement. SIGN 136 states that health professionals should assess a chronic pain patient’s history, pain type, severity and functional impact. An examination and biopsychosocial assessment should also be completed in order to inform treatment selection [37].</p>
Specifications:	<p>Numerator: Number of patients being treated for chronic pain who have the recommended data recorded at least once. (In Level 3 and 4 services, this means</p>



	<p>all patients; in Level 2 services it is more complex to identify these patients, and this may require specified Read codes, or setting prescribing parameters).</p> <p>Denominator: All patients being treated for chronic pain.</p> <p>Exclusions: Patients with chronic pain already assessed and who are stable (i.e. accessing the same prescriptions for at least a year), or who decline to complete relevant measures.</p>
Target	<p>90% of patients have at least 50% of the recommended data recorded at least once.</p> <p>75% have 100% of the recommended data recorded at least once.</p> <p>50% have at least 50% of the recommended data recorded at least twice in the previous 18 months.</p>

QPI 3 – Pharmacy Review (Level 2-4)

QPI Title:	Pharmacy Review (Levels 2-4)
Description:	Patients prescribed medication for chronic pain should have their medication reviewed at least annually by their GP, Nurse, Pharmacist or Allied Health Professional, or within their specialist pain clinic. This can be face-to-face review, a review of health records or a combination but must include steps 1-7 below..
Rationale and Evidence:	<p>SIGN 136 states that an individual’s success in pharmacological treatments is dependent on regular, scheduled re-assessment of pain relief and side effects [37]. It has also been found that if an individual has not responded to treatment after two to four weeks after titration to an adequate dose, then they are unlikely to develop a response thereafter [37]. SIGN 136 recommends several key areas to include in an audit including:</p> <ul style="list-style-type: none"> - The number of patients using analgesics to manage chronic pain who receive annual review. - The number of patients using strong opioids and gabapentinoids who receive an annual review of their medications. <p>More recently across Scotland, the number of patients on daily morphine equivalent doses of 50mg or above was found to be roughly 6 per 1000 list size [41]. Clinicians should ensure these patients are reviewed at least annually.</p> <p>Key recommendations from the “Quality Prescribing for Chronic Pain: A Guide for Improvement” [41] are:</p> <ul style="list-style-type: none"> - Clinicians should review effectiveness, tolerability and compliance on an ongoing basis. The burden of medicines should be reduced where possible, in line with Polypharmacy guidance. - Follow a clinically appropriate approach to initiation of analgesia, discussing expectations, risks and benefits and incorporating agreed criteria for stopping/continuing medication. <p>Review of medication must include an assessment of [41]: Step 1: What matters to the patient.</p>



	<p>Step 2: Identify essential drug therapy.</p> <p>Step 3: Does the patient take unnecessary drug therapy?</p> <p>Step 4: Are therapeutic objectives being achieved?</p> <p>Step 5: Is drug therapy cost-effective?</p> <p>Step 6: Is drug therapy cost-effective?</p> <p>Step 7: Is the patient willing and able to take drug therapy as intended?</p>
Specifications:	<p>Key areas to be included in an audit:</p> <ul style="list-style-type: none"> - 90% of patients using analgesics to manage chronic pain receive an annual review. - 90% of patients using strong opioids and gabapentinoids receive an annual review. - 90% of patients on >180mg/day morphine or equivalent referred for specialist assessment/ advice [37]. More recently [41] suggests that opioids should not be prescribed at higher than 90mg morphine equivalent/day without specialist referral/ advice. Therefore this specification may change.
Target	<p>90% patients who are being prescribed medication to manage their pain should receive an annual medication review. As specified above.</p>

QPI 4 – Service Evaluation and Audit (Levels 3 and 4)

QPI Title:	Service Evaluation and Audit (Levels 3 and 4)
Description:	Pain Services should be evaluated, at a minimum, on an annual basis. Pain Services should be evaluated to determine their effectiveness, use of resources and the extent to which they are fit for purpose.
Rationale and Evidence:	<p>Evaluation of the relevant outcomes in patients attending a Pain Service should be standard practice. This should include the “Core Minimum Dataset”. Patients attending Pain Management Programmes should demonstrate significant change in the specified domains of function, psychological well-being, healthcare use, quality of life and work status where relevant [42].</p> <p>The National Pain Audit Final Report 2010–2012 [43]in England and Wales identified 7 key factors to be included in an audit [43]:</p> <ul style="list-style-type: none"> - Type of clinic. - Staffing Standards. - Diagnosis and Treatment Coding Standards. - Waiting Times. - Multidisciplinary Care. - Change in Pain and Quality of Life Affected by Pain. - Numbers Receiving Advice and Guidance on Managing Pain. <p>The Faculty of Pain Medicine [44] - Key Pain Management Standards for CQC inspection frameworks:</p> <ol style="list-style-type: none"> 1. A specialist pain management service will have at least two consultants who have achieved competencies and experience in advanced pain medicine, as defined by the Faculty of Pain Medicine of the Royal College of Anaesthetists, and undergo successful annual appraisal. Where two or more consultants are not available, then cluster working with other regions Pain Services should be identified to ensure cover, peer networking, and support.

	<ol style="list-style-type: none"> 2. No sole practitioner acting in isolation, whatever their profession, can claim to run a pain management clinic or service. 3. Specialist pain management services will involve nursing, physiotherapy, occupational therapy and clinical psychology staff. These specialists will have dedicated sessional time in the pain management service and attend multidisciplinary team (MDTs) meetings. 4. Specialist pain management services must have access to dedicated pharmacy input. 5. Input from other local specialists, e.g. psychiatry, palliative medicine, surgical and medical specialities, gynaecology, paediatrics, neurology and rehabilitation medicine must be available, as needed, to manage the patient case mix.
<p>Specifications:</p>	<p>Areas to be included in an audit:</p> <ul style="list-style-type: none"> - Type of clinic - Services as classified by self-assessment according to the IASP definitions: <ol style="list-style-type: none"> 1. Modality orientated clinic: clinic carrying out one treatment only. 2. Pain clinic: clinic carrying out more than one treatment but service has single profession. 3. Multidisciplinary pain clinic: service carrying out more than one treatment, with more than one type of healthcare professional. 4. Multidisciplinary pain centre: as per multidisciplinary pain clinic but also carrying out research. - Staffing Standards <ul style="list-style-type: none"> o Minimum staffing levels of a consultant pain specialist, psychologist and physiotherapist [43]. If these standards are not met, cluster working with other regions Pain Services should be identified to ensure cover, peer networking, and support. o A specialist pain management service will have at least two consultants who have achieved competencies and experience in advanced pain medicine [44]. If these standards are not met, cluster working with other regions Pain Services should be identified to ensure cover, peer networking, and support. o Specialist pain management services will involve nursing, physiotherapy, occupational therapy and clinical psychology

	<p>staff. These specialists will have dedicated sessional time in the pain management service and attend multidisciplinary team (MDTs) meetings [44].</p> <ul style="list-style-type: none"> ○ No sole practitioner acting in isolation, whatever their profession, can claim to run a pain management clinic or service. <ul style="list-style-type: none"> - Diagnosis and Treatment Coding Standards - Use the proposed ICD-11 classifications [45] in accordance with the “Core Minimum Dataset”. - Waiting Times [46]: <ul style="list-style-type: none"> ○ 18 weeks Referral to Treatment Standard. - Multidisciplinary Care. <ul style="list-style-type: none"> ○ The minimum standard for multidisciplinary care as defined by the availability of medical, rehabilitation and psychological expertise [43]. - Change in Pain and Quality of Life Affected by Pain - The proposed minimum core dataset includes questions on: <ul style="list-style-type: none"> ○ Pain Site(s). ○ Underlying Diagnosis. ○ Pain Duration. ○ Pain Severity. ○ Emotional Impact. ○ Functional Impact. ○ Health-Related Quality of Life. - Numbers Receiving Advice and Guidance on Managing Pain.
<p>Target</p>	<p>The following areas should be routinely recorded:</p> <ul style="list-style-type: none"> - Type of clinic. - Staffing Standards. Clinical discipline and WTE* - Diagnosis and Treatment Coding - Waiting Times (average wait to first appointment; percentage waiting >12 weeks). - Multidisciplinary Team meetings. - Change in Pain and Quality of Life Affected by Pain. - Numbers Receiving Advice and Guidance on Managing Pain. <p>*Appropriate standards for these remain to be determined</p>

QPI 5 – Exercise and Activity Therapies (Levels 1-4)

QPI Title:	Exercise and Activity Therapies (Levels 1-4)
Description:	<p>Patients should be provided with advice to increase and/or maintain their physical activity and/or improve their exercise uptake and signposted to a relevant service to improve adherence to exercise, where relevant.</p> <p>Physical exercise is defined as is any bodily activity that enhances or maintains physical fitness and overall health and wellness [47].</p> <p>Physical activity is defined as any bodily movement produced by skeletal muscles that requires energy expenditure [48].</p> <p>We cannot make specific recommendation as specific exercise will depend on individual needs.</p> <p>Information regarding the benefits of activity and exercise should be provided by the Pain Service. The following examples are recommended by Scottish Intercollegiate Guidelines Network [37]:</p> <ol style="list-style-type: none"> 1) Provision of educational material 2) Signposting to online resources (e.g. Couch to 5k) 3) Supervised exercise or activity sessions. 4) Individualised exercises in group settings. 5) Provision of a combined group and home exercise and activity programmes. 6) Referral to external provider (e.g. Live Well) <p>The patient should be provided with support to improve their adherence to the exercise regime.</p>



<p>Rationale and Evidence:</p>	<p>SIGN 136 recommends all forms of exercise and exercise therapy in the treatment of chronic pain patients [37]. It has been found that physical activity and exercise therapy is safe and beneficial in the treatment of chronic pain [49], particularly those with chronic tension-type headaches and migraine [50]. However this needs to be appropriately managed and tailored to the individual with a particular emphasis on managing flare-ups and promoting recovery [50]. Advice to exercise alone, unaccompanied by support, is not sufficient [37].</p>
<p>Specifications:</p>	<p>Numerator: Number of patients with chronic pain recorded as being provided with information regarding the importance of activity and exercise, and support to increase this where relevant.</p> <p>Denominator: All patients that attend an NHS Service for pain treatment.</p> <p>Exclusions: Patients that do not attend an NHS Service for pain treatment. Patients that decline receiving additional information regarding exercise uptake.</p>
<p>Target</p>	<p>90% of patients with chronic pain who were provided with information and support regarding physical activity, exercise and/or exercise therapy</p>