Data and Measurement for Chronic Pain Services:

A Pilot Study to Inform National Service Improvement

NHS Fife
NHS Lothian
NHS Tayside

Contents

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Executive Summary

In Scotland, and across the world, chronic pain is the greatest cause of disability (Vos et al., 2015). The prevalence of chronic pain depends on the precision of definition and identification. Chronic Pain is known to considerably impair quality of life for approximately 15% of the Scottish population (NHS Healthcare Improvement Scotland, 2014). The adverse effects of chronic pain can be wide ranging, impairing physical and emotional functioning, relationships, employment status and general health. Improving outcomes for chronic pain patients is a priority area for the Scottish Government, and NHS Scotland, and there has been substantial investment in service improvement (NHS Healthcare Improvement Scotland, 2007).

This pilot project was set up in answer to the lack of standardised routine data reporting across Chronic Pain Services in Scotland. The current report explores the most appropriate methods for collecting data in order to measure service provision, outcomes, and improvement. There is currently a wide range of breadth and depth of data being collected to evaluate this and no unified approach. The project's aim was to assess the process, utility and challenges associated with data collection currently occurring routinely in Pain Services in NHS Fife, NHS Lothian, and NHS Tayside. With the results, this project has made initial recommendations for a sustainable and standardised approach to data collection in specialist Pain Services across Scotland and extrapolating to Primary Care and other related services. These will need to be tested in the next phase of this project.

Authors

[redacted]

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Recommendations

Below are the recommendations for core data collection.

1. We recommend the establishment of a common minimum core dataset for Level 3 and 4 Pain Services across Scotland (see page 6). Individual centres may wish to add bespoke data items for local purposes (see page 7). This dataset and its collection procedures must be transferable to primary care and other services.

2. Data should be available to individual clinicians, health boards, and NHS Scotland, as appropriate, for service improvement purposes.

3. The electronic input of questionnaire data is strongly recommended, rather than accumulating completed hard copy questionnaires. Electronic Databases make for faster and more effective evaluations of individual Pain Services and for comparative national reporting. Therefore all questionnaires must be amenable to digital data entry. Time and resources must be available for data entry.

4. Questionnaires must be unambiguous, reliable, valid and easy to complete, producing data that are easy to enter and analyse.

5. For patient completed questionnaires it is recommended that to maximise questionnaire completion rates, access to assistance, if required, must be made available. This includes addressing common barriers, such as visual impairment, literacy and assisting non-native English speakers.

6. The development of a close collaboration with I.T. Services will be essential in developing a mechanism for inputting and extracting questionnaire data from existing NHS online operating systems (e.g. TRAK). Ultimately national consistency is required.

7. The Quality Performance Indicators (QPIs) drafted in this Pilot Study must be subject to a comprehensive and iterative consultation process. The key objective is to ensure suitable clinical benchmarks are reached. QPIs must be realistic and applicable to all Pain Services in Scotland.

i. Common Minimum Core Dataset

Below are the recommendations for a common minimum core dataset for Level 3 and 4 Pain Services across Scotland. This objective of a 'minimum' dataset is to provide the sufficient data that will allow adequate comparisons between services.

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.

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

    a. Age
    b. Gender
    c. Pain Site(s): List of Body Parts.
    d. Pain Duration: Categorised list
    e. Pain Severity: Question 1 of the Chronic Pain Grade Questionnaire (CPG) (Smith et al., 1997).
    f. Underlying Diagnosis: Map to ICD-11 (develop Read code/SNOMED)
    g. Emotional Impact: Patient Health Questionnaire-2 (PHQ-2) (Kroenke et al., 2014).
    h. Functional Impact: Question 5 of the Chronic Pain Grade Questionnaire (CPG) (Smith et al., 1997). No conclusive evidence exists regarding a single self-report physical activity questionnaire (Silsbury et al., 2015).
    i. Health-Related Quality of Life: Question 1 of the Short Form Health Survey (SF-36).

2) The proposed common minimum core dataset should be subject to extensive field testing across services before its implementation

Please see Appendix 7 for this dataset in its entirety.

ii. 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)
    - Patient Health Questionnaire (PHQ-9)
    - General Anxiety Disorder Questionnaire (GAD-7)
    - The Profile of Mood States (POMS)
    - Cognitive Fusion Questionnaire (CFQ)
    - Clinical Outcomes in Routine Evaluation (CORE-10)
    - Self-Compassion Scale (SCS)

- **Functional Impact**:
    - The Brief Pain Inventory (BPI)
    - The Multidimensional Pain Inventory (MPI)
    - Owestry Low Back Pain Disability Questionnaire
    - Roland and Morris Back Pain Disability Questionnaire (RDQ)

- **Health-Related Quality of Life:**
    - The EuroQol Dimension Questionnaire (EQ-5D)
    - The Medical Outcome Study Short Form Survey Instrument (SF-36)
    - PSYCHLOPS
    - Work and Social Adjustment Scale (WSAS)
    - Short Form Health Survey (SF-36)

We cannot recommend a definitive common optimum dataset based on current evidence but we should work towards this based on national consensus. This will be included in ongoing work.

Purpose

The project was initiated to collect detailed data on a one-year long pilot study across three NHS Pain Services (Lothian, Tayside, and Fife) in Scotland. Its aim was to assess the process, utility, and challenges associated with data collection within these services and to improve these NHS services for people affected by chronic pain.

There is currently no standardised routine reporting in specialist Pain Services in Scotland, with disparate outcome measures and I.T. systems used in different health boards. The wide range of breadth and depth of data collected was utilised to make recommendations for a unified approach and extrapolating to Primary Care and other related services.

The project was led by the Scottish National Chronic Pain Improvement Group (NCPIG), Research Subgroup, and was formally based within the Chronic Pain Research Group in the Division of Population Health Sciences at the School of Medicine, University of Dundee.

The pilot study was funded by the Scottish Government and carried out by a partnership of NHS Tayside (led by [redacted] Lothian (led by [redacted] and Fife (led by [redacted]

The overall aims of this project, for which this is the pilot, were:

1. To establish the most appropriate data and methods for collecting data in NHS Pain Services across Scotland, in order to measure service provision, outcomes, and improvement.
2. To assess the process, utility and challenges associated with data collection currently occurring routinely in Pain Services in NHS.
3. To examine data currently available on Pain Service provision and clinical outcomes, assessing their value, exploring strength and weaknesses of their collection.
4. To research alternative and/or additional data and collection methods, and compile results to report on the existing and potential ways to collect data that inform Pain Service improvement.
5. To propose recommendations for a national approach to Pain Service data collection, and the subsequent development of Quality Performance Indicators.

Methods

To deliver this over a year long period, the project was divided into three phases.

Phase One

[redacted] project assistants (PAs) applied for and gained access (through honorary contracts) into the Pain Service databases in NHS Tayside, Lothian, and Fife. They also underwent training for the respective I.T. systems, enabling them to assess interfaces, responsiveness, and efficiency of these systems.

Phase Two

Clinician questionnaires sent out and results compiled; testimonials and data collection procedures recorded, the efficiency of each health board procedures were assessed and compared.

Phase Three

Data were utilised to draft national Quality Performance Indicators (QPIs), highlighting benchmarks in patient assessment, information and referral pathways for each Pain Service.

Area Profiles

Table 1 – NHS Fife, Tayside and Lothian Area Profile

	NHS Fife	NHS Tayside	NHS Lothian
Recorded Patients (2014-2016)	2,084	858 (2014 - June to August, pilot phase, only 28 records)	1,025 (Pain Management Programme) 160 (Pain Service)
IT Systems Used	OASIS and TIARA Soon moving to TrakCare	MIDIS Soon moving to TrakCare	TrakCare
Clinician Questionnaire Responses	13	12	15
Outcome Measures Used	Visual Analogue Scale **(VAS)** Patient Health Questionnaire **(PHQ-9)** Generalised Anxiety Disorder **(GAD-7)** Pain Self-Efficacy Questionnaire **(PSEQ)**	Brief Pain Inventory **(BPI)** (only items 5 and 9a- g) EuroQol Five Dimensions Questionnaire **(EQ-5D)**	Brief Pain Inventory **(BPI)** Hospital Anxiety and Depression Scale **(HADS)** Self-Report Leeds Assessment of Neuropathic Symptoms and Signs **(S-LANSS)** Tampa Scale for Kinesiophobia **(TSK)** Pain Self Efficacy Questionnaire **(PSEQ)** EuroQol Five Dimensions Questionnaire **(EQ-5D)** Work and Social Adjustment Scale **(WSAS)** Pain Catastrophizing Scale **(PCS)**

	NHS Fife	NHS Tayside	NHS Lothian
Patient Information	Age	Date of Birth, Period of Absence, Employment Status, Work Status	Date of Birth, Gender, Living Status, Receive Benefits, Legal Proceedings/Compensation Related to Pain, GP Visits (past 3 months), Emergency GP Visits, Hospital Visits, Work Status, Educational Attainment, Quality of Life (past 2 weeks)
Pain Overview	Pain Site and Duration of Pain	Pain Type, Duration of Symptoms, Location of Pain (Body Parts, Fields 1-4)	Pain Type, Aetiology, Body Part (s), Medications
Admin	Referral Source	Referral Source (e.g. GP, Hospital, Doctor, Self) Date of Record Appointment Date/Type (New or Review)	Referral Source, Status (e.g. first appointment)
Outcomes Assessed	Secondary Care Department (Referred to) Physiotherapy Outcome Onward Referrals and Outcome (i.e. attended appointment with consultant).	Management, Fields 1-4 List for Procedure (Physio etc.) Exercise Advice (YES or NO) Pain Service Investigations (Blood Test, MRI, Other X-Ray) TCPS Outcome (3rd Sector Community Discharge NHS Speciality Board Procedure (Trigger Point Injection, Lumbar Sympathectomy etc.) TCPS Prescribing	Appointment Outcome

Questionnaire Licensing

Cost-effective datasets are contingent on evolving licensing agreements. Compiled with assistance from NHS Librarians in NHS Greater Glasgow & Clyde, Table 2 displays the features and licensing categories (key overleaf) of outcome measures used in NHS Tayside, Lothian, and Fife.

Table 2 – Features of Outcome Measures used in NHS Tayside, Lothian and Fife

Outcome Measure	**Type**	**Validated**	**Time to Take (mins)**	**Health board Used**	**Copyright/ License Category**
Brief Pain Inventory (BPI)	Pain Score	Yes	5-10	Tayside and Lothian	3
EuroQol Five Dimensions Questionnaire (EQ-5D)	Health-Related Quality of Life	Yes	5	Tayside and Lothian	3
Generalised Anxiety Disorder (GAD-7)	Emotional Functioning	Yes	2	Fife	1
Hospital Anxiety and Depression Scale (HADS)	Psychological Impact	Yes	2-5	Lothian	4
Pain Catastrophizing Scale (PCS)	Psychological Impact	Yes	5	Lothian	1
Patient Health Questionnaire (PHQ-9)	Emotional Functioning	Yes	2	Fife	1
Patient Self-Efficacy Questionnaire (PSEQ)	Patient Beliefs	Yes	2	Fife and Lothian	2
Self-Compassion Scale (SCS)	Psychological Impact	Yes	5	Lothian	1
Self-Report Leeds Assessment of Neuropathic Symptoms and Signs (S-LANSS)	Pain Type	Yes	5	Lothian	1
Tampa Scale for Kinesiophobia (TSK)	Psychological Impact	Yes	5-10	Lothian	1
Visual Analogue Scale (VAS)	Pain Score	Yes	2	Fife	2
Work and Social Adjustment Scale (WSAS)	Functional Impairment	Yes	5	Lothian	1

Table 3 – License Categories for Instruments

License Category	Explanation
1	**Unlimited National Permission: These are public domain or national permission has been granted through either license or explicit permission from the copyright owner.**
2	Limited Permission: National permission has been granted through either license or explicit permission, however, some limits will apply.
3	Application Required: Permission may be considered by the copyright owner, however, individuals need to apply.
4	Commercially Licensed: These are commercially licensed tools, a charge may be applied – we would also recommend that you consult with your local procurement department prior to purchase as a local license may already be in situ.
5	Orphan works: Do not use - The owner cannot be traced, note you may be able to apply for a license from the government to use, speak to your Copyright Champion.
6	Permission Denied: Do not use – No permission has been granted, or the permission has been denied by the copyright owner.

Overview of the Clinician Questionnaire

In order to garner the clinician's perspective on current data collection procedures, a short questionnaire (see Appendix 6) was disseminated to 40 pain clinicians, across the three health boards. The sample included representatives from a range of disciplines, including Physiotherapists, Psychologists, Nurses and Consultants in Pain Medicine.

The 11 item questionnaire had an emphasis on clinical practicalities and focused on ascertaining the speed and quality of the different online data entry and storage systems. Another key objective was to identify day-to-day barriers that were perceived to negatively impact the completeness of the Pain Service dataset.

Table 4 – Health Board Summary

Health board	IT System Used	Planned Replacement IT Systems	Number of Clinicians Responded
NHS Fife	Tiara and Oasis	Trak and Tiara (for more services)	13
NHS Lothian	Trak	Sci Clinical Portal (for some services)	15
NHS Tayside	MIDIS and Topaz	Trak	12

Table 5 – I.T. System Features

IT System Features (Rated 0-10)	NHS Fife		NHS Lothian		NHS Tayside	
	Mean	**SD**	**Mean**	**SD**	**Mean**	**SD**
Speed	4.2	2.2	4.7	2.1	4.8	2.1
Dropdown	4.6	2.0	5.2	2.0	5.6	2.0
Interface	4.7	1.7	5.5	2.0	5.5	2.0
Free-text	4.6	2.3	5.4	2.2	5.7	2.1
Responsiveness	5.2	2.2	5.9	2.2	6.2	1.8

Table 6 – Barriers to Inputting Data

Barriers to Inputting Data								
Issues	**Poor Access to IT**		**Lack of Consensus on Data Input Responsibilities**		**Lack of Time**		**Lack of Clarity on Usefulness of the Data**	
	N	%	N	%	N	%	N	%
NHS Fife	4	33%	1	8%	6	46%	9	69%
NHS Lothian	5	33%	2	13%	11	73%	6	40%
NHS Tayside	2	17%	4	33%	11	92%	5	42%

Observations

Speed was the most poorly rated feature of all sampled NHS I.T. Systems.

Lack of time and lack of clarity concerning the usefulness of the data are a significant barrier to data entry.

The Lothian Pain Management Programme designate data entry responsibilities to specific members of staff.

Areas of Improvement for Individual Services

Below are suggested areas of improvement specific to the three health boards sampled in this Pilot Study.

NHS Tayside

- Collect both pre and post outcome data.
- Input outcome measures in full to allow missing scores to be dealt with in a standard way.
- Keep online records of spoiled questionnaires that are not inputted into the databases.

NHS Fife

- Input outcome measures in full to allow missing scores to be dealt with in a standard way.
- Use standardized answers for some of the columns, e.g. referral source.
- High rate of missing data for some outcome measures e.g. the Visual Analogue Scale (VAS) at pre-assessment (59%) and at follow-up (79%).
- Include questions on Pain type and Work Status.

NHS Lothian

- Input outcome measures in full to allow missing scores to be dealt with in a standard way.
- More guidance is needed when administering questionnaires to patients.
- A large number of questionnaires leads to attrition towards the end, with some patients missing out entire questionnaires or missing out questions.
- Pain type is not well recorded, which is an important area to cover.
- Patient information (CHI number, date of birth etc.) is often not matched with the questionnaire pack which highlights an issue of the usefulness of this data in planning patient care.
- The body map where patients indicated the site of pain was difficult to interpret as this does not appear to have been verified by the clinicians.