

1. **Scottish Government Progress Report on Project:**

2. **Data and Measurement for Chronic Pain Services. A Pilot Study to Inform National Service Improvement.**

3. **Leads**

4. **Project aims**

Aims

1. To determine, in three specialist pain services in NHS Scotland, the processes of collecting routine data on services, processes and outcomes, and their utility for addressing questions relevant to service improvement;
2. Based on these, to propose an approach to measuring pain services that will inform service evaluation and improvement, including a core dataset and the development of quality practice indicators (QPIs).

5. **Project objectives**

1. To determine the nature and extent of data currently collected routinely by specialist pain services in NHS Lothian, NHS Tayside, and NHS Fife
2. Through analysis of these datasets and discussions with some of the people collecting and storing them, to address the following questions:
 - a. What are the **descriptive** data currently available on outcomes of specialist pain service provision in NHS Lothian, Tayside and Fife?
 - b. What are the **challenges** in collecting and storing these data, using existing NHS IT systems?
 - c. What questions about service provision can currently be answered using these data?
 - d. What important questions cannot be answered using these data?
 - e. What QPIs can potentially be developed using these data?
 - f. How do the different data collection systems compare?
 - g. How can this information be harnessed to perpetuate an improvement cycle?
3. Based on the answers to these questions, to propose recommendations for the **minimum** and **optimum** data collection approaches (measures and collection systems), for consideration by NHS Boards and the Scottish Government Pain Service Improvement Programme.

6. **Progress to date**

Staff

research assistants [REDACTED] appointed and commenced in post on 1/09/2016, based in Population Health Sciences Division, University of Dundee. All

February 2017

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INTERIM REPORT APRIL 2017

**Improving Pain Management across
Scotland**

A Pilot Study





Table of Contents

INTERIM REPORT APRIL 2017..... 1

 Background..... 4

 Project Management Team..... 4

 Project Assistants..... 4

 Current status..... 5

 A. Chronic Pain Data and Measurement: A Pilot Study..... 5

 B. Management of Chronic Pain in Children and Young People..... 5

 C. Interventions to Support Patients in Reducing or Stopping Strong Opioids..... 5

 D. SPaRC Annual Scientific Meeting, Project Management..... 6

A. Data and Measurement for Chronic Pain Services: A Pilot Study to Inform National Service Improvement..... 7

 Executive Summary..... 7

 Purpose of this Pilot Study..... 7

 Key Findings..... 9

 Data Collection Processes..... 9

 The Utility of Acquired Data..... 9

 I.T. Systems used within these Services..... 9

 The Clinician Perspective..... 9

 Methods..... 10

 Phase One..... 10

 Phase Two..... 10

 Phase Three..... 10

 Area Profiles..... 11

NHS Tayside Pain Service..... 12

 Overview of the Data*..... 12

 i. Key Findings..... 12

 Good Practice Points..... 12

 Potential Areas of Improvement..... 13

 ii. Clinician Questionnaire..... 13

 iii. Additional Comments from Clinicians..... 14

 iv. Conclusions..... 14

NHS Fife Pain Service..... 16

 i. Key Findings..... 16

 Good Practice Points..... 16

 Potential Areas of Improvement..... 16

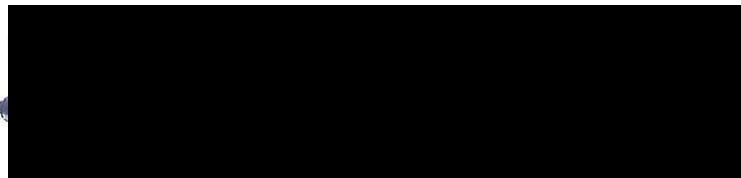
ii. Clinician Questionnaire.....	16
iii. Additional Comments from Clinicians.....	17
NHS Lothian Pain Service.....	18
i. Clinician Questionnaire.....	18
ii. Additional Comments from Clinicians	19
Quality Performance Indicators (QPIs).....	20
Improving Data Collection – Examples of Good Practice across the World	21
Australia and New Zealand- ePPOC (electronic Persistent Pain Outcomes Collaboration)	21
Germany- VAPAIN (Validation and Application of a patient relevant core outcome set to assess effectiveness of multimodal PAIN therapy)	22
B. Management of Chronic Pain in Children and Young People: A National Clinical Guide line ...	23
C. Interventions to support patients in reducing or stopping strong opioids	24
D. SPaRC Annual Scientific Meeting, Project Management.....	24
References	25
Appendices.....	26
Appendix 1: Progress (to date)	26
Appendix 2: NHS Tayside Pain Service Data	27
Appendix 3: NHS Fife Pain Service Data.....	33
Appendix 4: Scottish Service Model for Chronic Pain.....	38
Appendix 5: Snapshot of PROSPERO Protocol.....	39
Appendix 6: SPaRC ASM 2017 Programme	40
Appendix 7: Short Life Working Group Poster (SPaRC 2017).....	42

Background

This proposal relates to our current project, Chronic Pain Data and Measurement: pilot study, which was funded under section 16B of the National Health Service (Scotland) Act funding. It is scheduled to run for one year, from 1st September 2016.

The current main project is a pilot study to collate and evaluate information on the systems and processes for collecting routine data relating to Level 3 Pain Services in NHS Fife, Lothian and Tayside, and the nature and utility of the data collected by these systems and processes. This will inform the next phase of this project. [REDACTED] Project Assistants (PAs) were appointed to carry out this work ([REDACTED]), under the supervision of the Project Officers. In addition to this work, it was subsequently agreed by the funders and Project Officers that there was both need and capacity for other projects to be carried out, at no additional cost.

Project Management Team



Project Assistants



Current status

See Appendix 1 for more information on the progress of this project

A. Chronic Pain Data and Measurement: A Pilot Study

This information collection and evaluation exercise is intended to inform further, more substantial work aiming to develop a core dataset and Quality Performance Indicators (QPIs) for implementation across Pain Services in Scotland. These are required to measure current status and treatment outcomes in a standardised way, and to drive and evaluate service improvement. This project is well advanced, and on schedule for completion by the end of the project period – see Appendix 1 for the progress to date.

B. Management of Chronic Pain in Children and Young People: A National Clinical Guideline

This project aims to produce the first national clinical guideline in this important area. It is conducted under the auspices of the Scottish Medical and Scientific Committee (SMASAC) and is supported by the Scottish Inter-collegiate Guideline Network (SIGN). Chronic pain in children is common and distressing, for management of which no evidence-based guidelines exist. Because of the relative lack of published high quality studies to guide management, there was insufficient substance for SIGN to support a formal guideline. However, they provided support to develop this guideline, under the auspices of SMASAC, which necessarily contains a lower grade of evidence, and a lower level of recommendations, yet represents the state of the art. Led by a short-life working group of experts (chaired by [REDACTED]), it will provide recommendations on the management of pain in children and young people based on the best available current evidence and, where that is deficient, expert consensus. The PAs have produced a draft version of the guideline, and have sent this out widely for consultation, with a return deadline of 5th May 2017 – available on request.

C. Interventions to Support Patients in Reducing or Stopping Strong Opioids

Many patients who have been taking long-term opioids are keen to reduce or stop their prescriptions, but find this difficult for reasons of physical and psychological dependence. Healthcare professionals, including pharmacists and physicians currently lack an effective method of supporting their reduction and cessation. This clinical issue has been identified by the Scottish Pain Research Community (SPaRC) as a clinical and research priority. This project aims to identify the evidence for any tools currently available to support patients in reducing or stopping strong opioids, and will update a previous Cochrane review. This will inform the next stage, which will be to develop a practical tool that can be introduced in Scotland, and that will be suitable for evaluation in clinical research. The PAs have completed the systematic review, and are now writing this up as a report and potential scientific paper – available on request.

D. SPaRC Annual Scientific Meeting, Project Management

The Scottish Pain Research Community (SPaRC) aims to promote the aspirations that: (1) clinical practice in managing chronic pain is informed by current research; and (2) current research in chronic pain is relevant to clinical practice. The 7th SPaRC Annual Scientific Meeting (ASM) was held in Dundee on 24th March 2017. A substantial contribution to project management was provided by the PAs, supporting the conference organization, and contributing to a very successful meeting. Formal evaluation of the meeting is now being conducted, with a view to informing the planning of the 8th ASM next year. See attached Appendix 6 for the 2017 SPaRC ASM Programme.

A. Data and Measurement for Chronic Pain Services: A Pilot Study to Inform National Service Improvement

Executive Summary

Chronic Pain is known to considerably impair quality of life for the 800,000 people affected in Scotland. 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 recognised clinical priority area of both the Scottish Government and NHS Scotland and there has been substantial investment in service improvement.

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 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.

Purpose of this Pilot Study

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:

- 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.
- Improve access to specialist pain services for patients and services users.
- To assess the process, utility and challenges associated with data collection currently occurring routinely in Pain Services in NHS.
- Reduce unwarranted variation in care.
- To examine data currently available on Pain Service provision and clinical outcomes, assessing their value, exploring strength and weaknesses of their collection.
- 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
- To propose recommendations for a national approach to Pain Service data collection, and the subsequent development of Quality Performance Indicators.

This pilot project was comprised of three distinct components:

- A. A direct analysis of the available data in each Pain Service (including patient outcomes, missing data and instruments used).
- B. Direct consultations with clinicians from each health board to identify the key barriers to data entry in the current work environment.
- C. A questionnaire for clinicians to assess the effectiveness of the various I.T systems used to input and store Pain Service Data.

Key Findings

Data Collection Processes

1. The timing of data collection varies across health board. For example, Fife provide pre and post outcome data whereas Tayside focus on data collection at initial assessment
2. Lothian have large quantities of hard-copy chronic pain questionnaires that are not inputted into electronic databases. The newest form of online database, an SPSS spreadsheet, has encountered licensing issues across NHS Lothian Sites.

The Utility of Acquired Data

1. EQ-5D-5L scores were once tabulated in NHS Tayside and sent to the Scottish Government yet as of two years ago this no longer occurs.
2. 50% of the clinicians sampled felt there was a lack of clarity in regards to the usefulness of the data their health board collected.
3. Patient data in NHS Tayside are predominantly used in planning individual care and is not analysed at group level.
4. In NHS Fife patient data have been used occasionally to audit service provision but is mainly used in individual patient care.

I.T. Systems used within these Services

1. All sampled health boards (Lothian, Tayside and Fife) are either currently using or moving over to TRAK.
2. The speed of IT Systems was rated by clinicians as the most poorly rated feature of their clinical databases. This trend was apparent across all three health boards and the various IT systems.

The Clinician Perspective

1. Lack of time is a significant barrier to data entry for clinicians
2. Some health boards find it easier to designate all data entry responsibilities to specific members of staff (namely Assistant Psychologists, Trainee Physiotherapists and Medical Secretaries).



Methods

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

Phase One

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 programs.



Phase Two

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



Phase Three

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

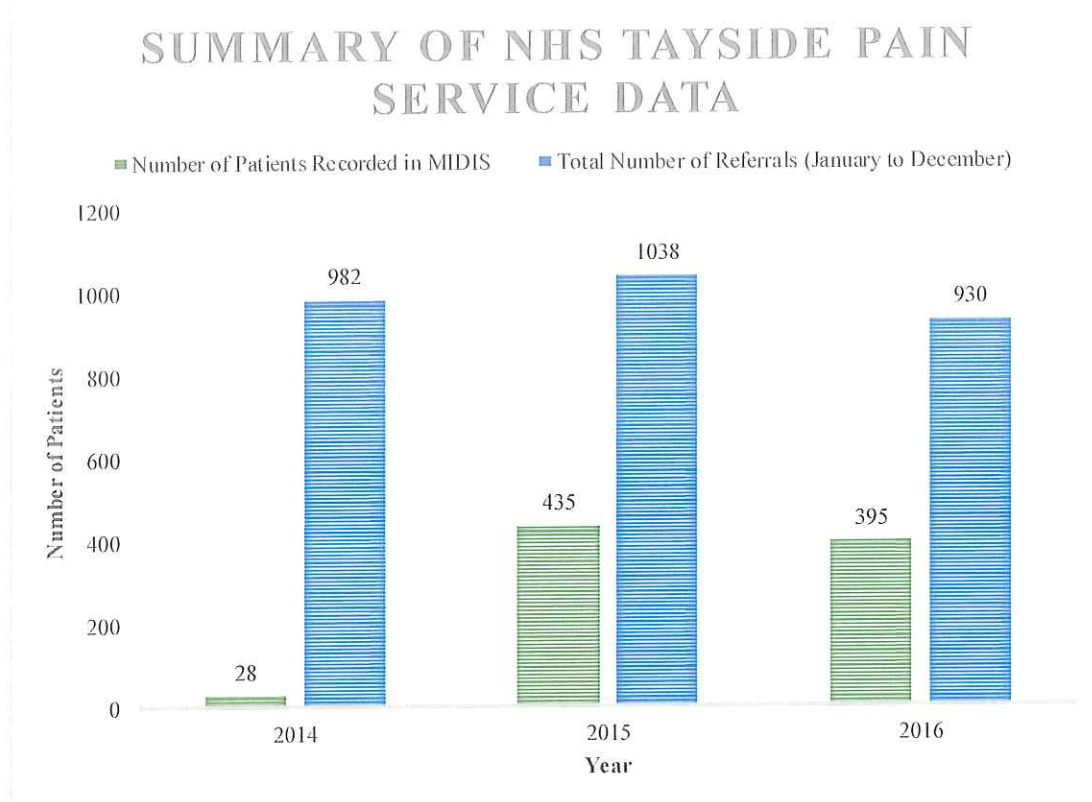
Area Profiles



<i>Recorded Patients (2014-2016)</i>	2084	858 (2014 - June to August, pilot phase, only 28 records)	-
<i>IT Systems Used</i>	OASIS and TIARA Soon moving to Trakcare	MIDIS Soon moving to Trakcare	Trakcare
<i>Clinician Questionnaire Responses</i>	13	12	15
<i>Outcome Measures Used</i>	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)	-
<i>Patient Information</i>	Age	Date of Birth, Period of Absence, Employment Status, Work Status	-
<i>Pain Overview</i>	Pain Site and Duration of Pain	Pain Type, Duration of Symptoms, Location of Pain (Body Parts, Fields 1-4)	-
<i>Admin</i>	Referral Source	Referral Source (e.g. GP, Hospital, Doctor, Self) Date of Record Appointment Date/Type (New or Review)	-
<i>Outcomes Assessed</i>	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 P Other Detail) Procedure (Trigger Point Injection, Lumbar Sympathectomy etc.) TCPS Prescribing	-

NHS Tayside Pain Service

Overview of the Data*



*2014 (June- August, pilot phase), 2015 (February – December), 2016 (January – November)

i. Key Findings

Good Practice Points

1. EQ-5D are easily calculated through a configured Excel sheet, all individual items recorded.
2. Contains the responses for each individual item recorded on the BPI and the EQ-5D, not just totals.
3. Comprehensive overview of Pain (Type of Pain, Duration of Symptoms and Location).

4. In general, responses are nicely grouped, making it easier to analyse and quantify data e.g. Referral Source (Hospital, Doctor, Self).

Potential Areas of Improvement

1. No post-treatment outcome measure data for BPI or in the EQ-5D Excel database.
2. 2014 records contain only data from June-August, hence the low percentage (29.11%) of total patients recorded in MIDIS. Average for 2015-16 around 43% of patients recorded.
3. EQ-5D questionnaire with missing data not inputted and not recorded, albeit hard copies are filed. Data entry for EQ-5D ceased as of 14/02/2017.
4. Numerous data fields are rarely utilised: Outcome 3rd Sector Community; Discharge and NHS Speciality; TCPS (Tayside Chronic Pain Service) Procedure.

ii. Clinician Questionnaire

12 members of staff in the NHS Tayside Pain Service have returned questionnaires (15 distributed).

Time was a main barrier to inputting data.

9 members of staff knew that MIDIS and Topas were going to be replaced by Trak in the near future.

IT System Features (Rated 0-10)	Mean Rating	Standard Deviation
Speed	4.78	2.12
Interface	5.48	1.97
Dropdown	5.56	1.97
Free-text	5.65	2.12
Responsiveness	6.19	1.75



IT Issues	Number of Participants	Percentage of Participants
Lack of time	11	92%
Lack of clarity on usefulness/utility of the data	5	42%
Lack of consensus on data input responsibilities	4	33%
Poor Access to IT	2	17%

iii. Additional Comments from Clinicians

“In Midis too many clicks to get to the correct form, the form itself is OK, I am sure tweaks are planned”.

“Inclusion of pain service data is a recent addition to our system. We had planned to re-evaluate and develop further, based on the first year of its use. This hasn't happened for various reasons, including the imminent arrival of a new computer system, and the absence for health reasons of one of the leaders of the project”.

“One of the biggest barriers is speed of the NHS computer and lack of dedicated time to provide data entry. Are clinicians the most appropriate people to carry out the data entry? This is difficult to answer as there is a clinician interpretation required, however, no time is built into the consultation for this. Regular feedback to clinicians is important to reinforce the rationale for ongoing data collection. The data fields should be relevant to the local service but also meet the national data requirements”.

“Cumbersome, competing with demand to run clinic on time. Lowest priority of all tasks required for out-patient clinic, new additional task, no reward or incentive, not monitored, more feedback needed”

iv. Conclusions

Regarding the number of patient recordings (29.08% of total patients, 42% for 2015 and 2016) it was mentioned that the focus was on inputting new patients into MIDIS. It is difficult to define when a patient has a review (may have multiple reviews leading to messy data). There is also no definitive