Specifications:	**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. **Denominator:** All patients that attend an NHS Service for pain treatment. **Exclusions:** Patients that do not attend an NHS Service for pain treatment. Patients that decline receiving additional information regarding exercise uptake.
Target	90% of patients with chronic pain who were provided with information and support regarding physical activity, exercise and/or exercise therapy

Appendix 5 - Improving Data Collection – Examples of Good Practice from across the World

1) Australia and New Zealand- ePPOC (electronic Persistent Pain Outcomes Collaboration)

ePPOC
electronic persistent pain outcomes collaboration

ePPOC (electronic Persistent Pain Outcomes Collaboration) is a new program which aims to help improve services and outcomes for chronic pain patients through standardisation of care and treatment. ePPOC is an initiative of the Faculty of Pain Medicine, and has been further developed in recent years by the Faculty, the Australian Pain Society and the wider pain sector.

ePPOC involves the collection of a standardised dataset and assessment tools by specialist pain services throughout Australia and New Zealand to measure treatment outcomes for their patients. This information will be used to develop a national standardised system for the pain sector, which will lead to better outcomes and best practice interventions for patients in chronic pain. The information will also enable development of a coordinated approach to research into the management of pain in Australasia.

The first phase of ePPOC began in 2013, with eight adult pain services in NSW trialling the measures, process and software for collection of the information. ePPOC is now being progressively rolled out to adult and paediatric specialist pain services throughout Australia and New Zealand.

The ePPOC dataset includes the following outcome measures:

- Brief Pain Inventory (BPI)
- Depression, Anxiety and Stress Scale (DASS)
- Pain Self-Efficacy Questionnaire (PSEQ)
- Pain Catastrophising Scale (PCS)

The Annual Report from 2016 demonstrated that 46 services provided information on 16,790 patients and, in total, these patients had 12,624 episodes of care and 8,673 pain management pathways in this reporting period (1st of January 2016 to 31st December 2016) (Electronic Persistent Pain Outcomes Collaboration, 2016). Number of recorded questionnaires in this period are also noted with 11,763 questionnaires received from all services at referral with 212 at the beginning of the programme and 221 at programme end.

2) Germany- VAPAIN (Validation and Application of a patient relevant core outcome set to assess effectiveness of multimodal PAIN therapy)

Universitätsklinikum Carl Gustav Carus
DIE DRESDNER.

The aim of this project is to determine interdisciplinary consensus recommendations to define relevant areas of the disease experience as well as a core set of outcome measures in order to reliably measure the treatments for chronic pain. This project is led by Principal Investigator Dr Ulrike Kaiser at the University Hospital Carl Gustav Carus, Dresden.

Part A: The recommendations will be developed by an interdisciplinary team in the context of a Delphi process consisting of representatives of medicine, psychotherapy, physiotherapy, care research and patients. In addition to the defined areas, reliable and sensitive measuring instruments should be discussed. The aim of this process is to provide an overview of current research on instruments and a data set of patients with chronic pain retrospectively analysed.

Part B: A questionnaire set is produced from the resulting recommendations which will be administered in four multimodal facilities regarding their quality criteria and significance for the effectiveness of the therapy.

To date, the VAPAIN team have conducted a systematic review to prepare a list of the most reported outcome domains in the context of IMPT (Deckert et al., 2016). In addition panel members (who were experts in the field) were addressed by online survey to decide for COS for effectiveness studies and daily record keeping and to add relevant outcome-domains not found among the 19 pre-selected domains. The pre-selected domains were provided with definitions according to literature. After round 2 a consensus was not reached, so third round was skipped and panel members were invited to face-to-face meeting for final

voting. The last two stages of the project are currently in progress: a systematic review of the measurement instruments for the selected core outcomes, validation of existing or developing new instruments (if necessary) and decision on appropriate instruments.

3) Canada – QPR (The Quebec Pain Registry)

The Quebec Pain Registry is an administrative and research database which provides standardized data on a large cohort of chronic pain patients who are described using a set of common demographic and clinical measures based on uniform and validated measurement tools.

It was developed in 2007 as a strategic initiative of the Quebec Pain Research Network. Currently 9,363 patients are enrolled in the registry with 5 participating clinics.

quebec pain registry
An integrated clinical research strategy on chronic pain

The aims of the database are to:

1. Facilitate and stimulate clinical pain research for both academia and industry;
2. Provide standardized data on a large cohort of patients with chronic non-cancer pain;
3. Provide accelerated access to well-characterized datasets for multisite clinical trials;
4. Provide a greater understanding of the impact of chronic pain on society.

The outcomes assessed in this database include:

- Pain characteristics (duration, frequency, intensity, etc.) and impact on various aspects of daily living including sleep;
- Specific pain diagnosis established by pain clinicians;
- Psychological well-being (depression, suicide ideation) and pain catastrophizing tendency;
- Health-related quality of life;
- Medical history + consumption habits (cigarettes, alcohol, drug);
- Past and current pain treatment (pharmacological and non-pharmacological);
- Patient expectations re: pain treatment;
- Patient global impression of change re: pain, functioning and quality of life, and treatment satisfaction;
- Socio-demographics.

4) America – CHOIR (Collaborative Health Outcomes Information Registry)

In response to the Institute of Medicine's Report Relieving Pain in America, Stanford has developed and implemented the Collaborative Health Outcomes Information Registry (CHOIR) system. This open source, open standard, free data-collection software was created in partnership with the National Institutes of Health. CHOIR allows clinicians to collect qualitative information on pain patients in a safe, secure, and easy-to-use system.

CHOIR was first introduced at Stanford Pain Management Center on August 14, 2012. It has been integrated into the clinic using Internet-enabled mobile devices (such as iPads). At present, there are approximately 15,000 unique patients, 64,000 visits, and 40,000 follow-up visits. In addition to Stanford, medical centres across the country use CHOIR in clinical practice and in biomedical research.

Steps in the CHOIR process:

1. The patient gives consent;
2. A staff member enters the patient's email address into CHOIR;
3. CHOIR then sends the patient an email with a web link to the New Patient survey. The email asks the patient to either fill out the survey at home on a computer, tablet, or smartphone, or to arrive 30 minutes early for their appointment to fill out the survey at the Clinic.

The initial survey:

- Contains an interactive Body Map
- Collects between 50 and 100 discrete pieces of information on:
    o Demographics;
    o Pain beliefs and treatments;
    o PROMIS measures: Pain Intensity, Pain Behaviour, Pain Interference, Fatigue, Physical Function, Depression, Anxiety, Sleep Disturbance, Sleep Related Impairment and Pain Catastrophizing.

A follow up survey is emailed to the patient:

- An Interactive Body Map

- Questions on PROMIS measures
- Questions on pain catastrophizing

Future Directions include:

- Dashboards for: Pain Psychologists, Physical Therapists and Nursing;
- Survey modules for the practice needs of: Pain Psychology and Pain Physical Therapy;
- Survey modules for specific conditions, such as: Headache, Orofacial Pain and Pelvic Pain;
- Patient Reported Outcomes On Demand: Dynamic, provider-initiated ordering of data on specific patient-reported outcome measures.

Appendix 6 – Chronic Pain Clinician Questionnaire

Chronic Pain Clinician Questionnaire

NHS Fife **NHS** Lothian **NHS** Tayside

Participation in this very short questionnaire is an opportunity to evaluate the I.T. systems handling patient records in your NHS Pain Service. The aim of our project is to assess which outcome measures are best to collect routinely and how the NHS IT systems can be used to facilitate this in an efficient way.

Results from this questionnaire will contribute to an ongoing National Outcomes project funded by the Scottish Government. Led by Prof Lesley Colvin, Dr Paul Cameron and Prof Blair Smith, this project aims to assess the process, utility and challenges associated with data collection within NHS Pain Services in Scotland.

Please indicate;

1) Your Profession   Click here to enter text.

2) Your NHS Health board   Click here to enter text.

3) I.T. System(s) used (Please select):   **MIDIS** ☐ **Oasis** ☐ **Tiara** ☐ **Topaz** ☐ **Trak** ☐

4) Any imminent replacement I.T. System(s)   Click here to enter text.

5) How attractive, clear and concise is the user interface design of your NHS I.T. system? Please rate:

1☐	2☐	3☐	4☐	5☐	6☐	7☐	8☐	9☐	10☐
Poor									**Excellent**

6) Please rate the responsiveness of your NHS I.T. system (i.e. are there long delays, are command/input gestures ignored?).

1☐	2☐	3☐	4☐	5☐	6☐	7☐	8☐	9☐	10☐
Poor									**Excellent**

7) Please rate ease of data entry in regards to dropdown menus within your NHS system (i.e. do dropdown menus contain all necessary answers?).

1☐	2☐	3☐	4☐	5☐	6☐	7☐	8☐	9☐	10☐

Poor   **Excellent**

8) Please rate the usability and convenience of free-text within your NHS system (i.e. is the frequency appropriate?).

1☐	2☐	3☐	4☐	5☐	6☐	7☐	8☐	9☐	10☐

Poor   **Excellent**

9) How would you rate the overall processing speed of your NHS computers?

1☐	2☐	3☐	4☐	5☐	6☐	7☐	8☐	9☐	10☐

Poor   **Excellent**

10) Have you experienced any of the following issues regarding data entry in your health board? (Please tick):

Poor access to IT (e.g. no computers available in consultation rooms) ☐

Lack of consensus regarding who is the appropriate person to input ☐

Lack of time ☐

Lack of clarity concerning the utility or usefulness of data ☐

11) Any other comments?

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Thank you for taking the time to complete this questionnaire.

Appendix 7 – Common Minimum Core Dataset

Demographics

1) 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

2) Gender

☐ Female

☐ Male

☐ Non-binary/ third gender

☐ Prefer to self-describe

_____

☐ Prefer not to say

3) Pain Duration

☐ < 3 months

☐ 3 - 6 months

☐ 6– 12 months

☐ 1 - 3 years

☐ 3 - 6 years

☐ 6 - 10 years

☐ 10 years +

4) Pain Severity

In the past six months, on average, how intense was your pain rated on a 1-10 grade scale where 0 is "no pain" and 10 is "pain as bad as it could be". That is, your usual pain at times where you are experiencing pain.

☐ 0   ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10
No   Pain as
Pain   bad as it
                                                                could be.

5) Emotional Impact

Please circle the option that applies to you.

Over the past 2 weeks, how often have you been bothered by any of the following problems?	Not At All	Several Days	More Than Half the Days	Nearly Every Day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed or hopeless	0	1	2	3

6) Functional Impact

In the past six months, how much has this pain interfered with your daily activities rated on a 1-10 scale where 0 is "no interference" and 10 is "unable to carry on activities"

☐ 0
No interference

☐ 1　☐ 2　☐ 3　☐ 4　☐ 5　☐ 6　☐ 7　☐ 8　☐ 9　☐ 10
Unable to carry on activities

7) Health-Related Quality of Life[1]

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

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[1] SF-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.

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

☐ Abdomen

☐ Pelvis

☐ Arm (L)

☐ Arm (R)

☐ Buttocks

☐ Cervical

☐ Foot (L)

☐ Foot (R)

☐ Hand (L)

☐ Hand (R)

☐ Head

☐ Face

☐ Leg (L)

☐ Leg (R)

☐ Lower Back

☐ Shoulder (L)

☐ Shoulder (R)

☐ Thoracic

☐ Upper Back

☐ Widespread

9) Underlying Diagnosis[2]

Please tick the option that applies.

☐ 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).

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