

## Observational study

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# The Oslo University Hospital Pain Registry: development of a digital chronic pain registry and baseline data from 1,712 patients

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### Abstract

**Background and aims:** Chronic pain is a leading cause to years lived with disability worldwide. However, few of the interventions used in pain medicine have proven efficacy, and evidence from the existing studies may not be valid for the general pain population. Therefore, it is of utmost need that we describe chronic pain conditions in their most relevant aspects, their various guises, as well as

the real world outcomes of our clinical interventions. The most obvious and crude way to make these assessments are through large registries where patient characteristics, treatment characteristics (including but not limited to what, when, how often and by whom), treatment outcomes and patient outcomes are scrutinized and recorded. **Methods and results:** This article describes in detail the design and baseline data of the comprehensive Oslo University Hospital Pain Registry (OPR). OPR is the local registry of the largest university and interdisciplinary outpatient pain clinic in Norway. Data registration started in October 2015, and approximately 1,000 patients are assessed and treated at the clinic each year. During the first 2 years of running the OPR (through September 2017), a total of 1,712 patient baseline reports were recorded from 2,001 patients. Clinicians enter data about relevant treatments and interventions, while patients provide self-reported data on aspects related to pain and pain management. The patients complete an electronic registration immediately before their first consultation at the outpatient pain clinic. The baseline questions of the OPR cover: Basic demographics; The Modified Oswestry Disability Index to assess general function; A pain drawing to assess pain location; Questions regarding the temporal aspects of pain; Six 0–10 Numeric Rating Scales to assess pain intensity and bothersomeness; The EQ-5D-5L to measure health-related quality of life; The Hopkins Symptom Check List-25 to assess psychological distress; A single question about self-rated health; The general self-efficacy scale to assess the patient's perceived self-efficacy; The Bodily Distress Syndrome checklist to assess functional disorders; The Injustice Experience Questionnaire to assess whether the patients experience injustice; Chalder Fatigue Questionnaire to assess fatigue; The Insomnia Severity Index to assess the levels of insomnia symptoms; The Pain Catastrophizing Scale to measure pain catastrophizing and exaggerated negative orientation toward pain stimuli and pain experience; And the SF36v2 to assess patients' self-report of generic health and wellbeing. The baseline

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data show that chronic pain patients have a high degree of negative impact in all aspects of their lives.

**Conclusions and implications:** The OPR is the most comprehensive pain registry for multidisciplinary and interdisciplinary outpatient pain clinics in Norway. Detailed design of the registry and key baseline data are presented. Registries are of great value in that they enable real world effectiveness outcomes for patients with chronic pain conditions. The OPR can thus serve as a model for similar initiatives elsewhere. The OPR cohort may also serve as a historical control in future studies, both with experimental and observational design.

**Keywords:** registry; epidemiology; patient reported outcome measures; chronic pain; effectiveness.

## 1 Introduction

Pain is the most common symptom that patients present in physician consultations. In addition, chronic pain is the most frequent condition leading to the most years lived with disability [1]. Despite these facts, there are few treatments in the field of chronic pain medicine that have scientifically been shown – including reproduced – to be statistically and clinically superior to placebo treatments. For conditions such as chronic primary pain (i.e. the ICD-11 classification of non-specific chronic pain conditions like most low back and neck pains, fibromyalgia, and irritable bowel syndrome), there are no evidence from sufficient scientific and rigorous trials of treatments with long term benefits on pain intensity, physical function, or quality of life [2–6]. This implies that we do not know what truly gives a positive outcome for patients with chronic pain conditions. Furthermore, we are unaware of what hinders these positive outcomes, and we do not know much about treatment characteristics. We need to clarify what we are doing to these patients in terms of treatments modalities, when and how often we treat them, and by whom (i.e. clinicians and system-level of care) these patients are treated.

Randomized controlled trials (RCTs) are considered the gold standard for testing the efficacy of treatments. However, RCTs are expensive, labor intensive and will only reveal treatment efficacy on narrowly selected patients that do not necessarily represent the patient population as a whole. Important heterogeneity effects may therefore be lost. Besides, many RCTs have short follow-up time, and insufficient power to analyze the effect of more than one outcome variable. The RCT research design is often associated with problems such as research waste and inability to

convert the findings into clinical practice [7–10]. However, effectiveness studies, such as cohort and registry studies, reflect how well treatments work in real world settings (i.e. daily clinical setting, the patients' home/work setting). These effectiveness studies are therefore an important correction for a blind confidence in experimental studies investigating patients in laboratory settings or constructed and unnatural clinical settings. Effectiveness studies are alas uncommon in the field of chronic pain medicine. One of the major caveats in such observational studies is the variables that we do not know influence what we observe, and therefore do not measure. Hence, it is of utmost need that we portray chronic pain conditions in their most relevant aspects, and their various guises. The most obvious and crude way to make these assessments are through large registries where patient characteristics, treatment characteristics (including what, when, how often, and by whom), treatment outcomes and patient outcomes are collected and analyzed. Registries also serve an important purpose as a system for clinical quality assessments. Registries are scarce within the field of chronic pain medicine. As of today, we are only aware of two other currently active registries in the world, covering both clinical and research purposes of different – and not pre-defined – chronic pain conditions in both a multidisciplinary and interdisciplinary pain clinic setting [11–13].

Complete or near complete local, regional and national registries might be considered the benchmark of clinical practice in the real world, with a true heterogeneity of patients. This is possible in Norway due to the unique social security number, assigned to all Norwegian residents. An essential premise is, nevertheless, the collection of a sufficient number of relevant and reliable variables, and large enough follow-up material from most of the patients included at baseline.

This background served as an impetus to create the Oslo University Hospital Pain Registry (OPR). This article outlines the details regarding development, content, running and baseline results from the OPR's first 2 years of running.

## 2 Methods

OPR is a local registry for the largest university and interdisciplinary outpatient pain clinic in Norway. The registration of data started October 1, 2015. In clinical care we have physicians (covering anesthesiology; neurology; gynecology; and physical medicine and rehabilitation); psychologists (both clinical psychology covering

children; adolescents; and adults, and neuropsychology); specialized physiotherapists; registered nurses (with specialties in pain management, palliative and cancer care, cognitive behavior therapy, anesthesiology and intensive care); and an occupational therapist. The clinicians cover a wide spectrum of treatment modalities, from multidisciplinary and interdisciplinary pain treatment to more experimental treatments like spinal cord stimulation and vagal nerve stimulation. The clinicians at OPR assess and treat approximately 1,000 new patients each year.

## 2.1 The OPR questions and questionnaires

The questions of the OPR cover basic demographics (age; sex; cohabiting; marital status; number/age of children; education; employment; social benefits; self-rated evaluation of personal economy; application for disability pension; and litigation due to pain condition). In addition, the following questionnaires are included in the registry:

- Modified Oswestry Disability Index (ODI) to assess function. The original ODI has 10 items concerning back pain and different activities of daily life (personal care, lifting, walking, sitting, standing, sleeping, sexual life, social life and travelling). Each item is scored from 0 to 5, with higher values representing more disability. ODI has high reliability and validity [14], and is validated in Norwegian [15]. The modified ODI used in the OPR is identical to the original ODI with one exception; the word “back” is deleted. It only occurs once, in the introduction of the form. This is done to later validate if the modified ODI might be used as a generic outcome for function in our population with a variety of chronic pain conditions.
- Pain drawing to assess pain location. The electronic body manikin (front and back) has an overlaying grid. The squares ticked by the patient, indicate how many painful bodily regions (range 0–10) the patient has experienced over the last 7 days. The bodily regions are: Head, neck, shoulder and upper arm, elbow and lower arm, wrist and hand, upper back, lower back, hip and thigh, knee and lower leg, and ankle and feet.
- 0–10 Numeric Rating Scales (NRS) to assess pain intensity (i.e. highest, mean, and lowest pain intensity last week, pain right now). NRS reports on an 11-point numerical rating scale with anchors of 0 (“no pain at all”) and 10 (“worst pain possible”). The reliability and validity of the pain NRS is well documented [16]. The four pain intensity measures are based on the work of Cleeland and Ryan [17] and the Brief Pain Inventory. This questionnaire is widely used, and research shows that it is a valid and reliable measure of non-cancer and chronic pain intensity both in English [17–19] and Norwegian [20].
- EQ-5D-5L to measure health-related quality of life. EQ-5D is a standardized instrument developed by the EuroQol Group as a measure of health-related quality of life [21]. The EQ-5D consists of a descriptive system and the EQ VAS, and is translated and validated in Norwegian. The descriptive system comprises five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. The EQ VAS records the patient’s self-rated health on a vertical visual analogue scale.
- Hopkins Symptom Check List-25 (HSCL-25) to assess psychological distress [22]. HSCL-25 consists of 25 questions concerning anxiety, depression and somatization, and has been validated in Norwegian [23]. A mean total score of <1.75 is within the normal range, while a score of 1.75 and above indicates psychological distress in need of treatment [24].
- Two 0–10 NRSs to assess usual pain intensity and bothersomeness of pain. The reliability and validity of the numerical rating scale is well documented [16]. Pain intensity, as well as the degree of bothersomeness of the chronic pain experience, is commonly assessed and important features to evaluate in patients with chronic pain. These features allow for comparing our sample with other pain registry samples. The NRS is superior in terms of being easy to understand for patients, practical in use, and detecting differences in pain intensity over time compared to other scales and single measures of pain [25]. These two NRS questions are identical to those in a large Norwegian population study, and allows for comparison of pain between patients with chronic pain and the general population.
- Duration of pain condition (in years and months) and temporal aspect of pain to assess whether the pain is persistent, with or without fluctuations during the day or week, or if the pain is recurring. These questionnaire used by the four university outpatient pain clinics in Norway and have not been validated yet.
- Self-rated physical activity is a valid predictor for mortality in Norwegian population studies [26]. This measure was therefore included to assess if it has a similar predictive value for outcomes in a population of different chronic pain conditions. It consists of one question with four text answers.
- Self-rated health (SRH) to assess whether this simple outcome measure has similar correlation for treatment response in our patients as it has for morbidity

- and mortality in other studies [27–30]. The measure consists of one question with four text answers.
- The general self-efficacy scale (GSE) to assess the patient's perceived self-efficacy [31], independent of morbidity and disability. Potentially, self-efficacy is both protective and serves as a mediator between pain and disability in those suffering from chronic musculoskeletal pain [32]. GSE is validated in Norwegian [33].
  - The Bodily Distress Syndrome (BDS) to assess functional disorders. This checklist consists of 25 questions, grouped into four symptom categories: cardiopulmonary, gastrointestinal, musculoskeletal and general symptoms [34]. BDS is divided into no BDS, moderate BDS, and severe BDS.
  - Injustice Experience Questionnaire (IEQ) to assess whether the patients experience injustice. A phenomenon that encompasses the degree of blame as well as the magnitude and irreparability of loss related to having a chronic pain condition [35]. The English version of the questionnaire is a valid and reliable tool of assessing perceived injustice in patients with chronic pain conditions [35, 36]. The Norwegian version is translated from English to Norwegian using the linguistic validation method [37, 38]. Its' validity and reliability is assessed with quantitative analyses of the OUS registry data and qualitative analyses of a patient focus group interview. These analyses indicate that the Norwegian version is both valid and reliable, and results from these studies will soon be published.
  - Chalder Fatigue Questionnaire to assess fatigue. This 11-item scale measures physical and mental fatigue. The sum score can range from 0 to 33; a bimodal score ranging from 0 to 11 can also be obtained. The fatigue scale is extensively used in research, has good psychometric properties [39], and is also validated in Norwegian [40].
  - The Insomnia Severity Index (ISI) assesses the levels of insomnia symptoms, measuring the nature, severity and impact of insomnia symptoms over the past 2 weeks. In chronic pain populations, sleep disorders are common and debilitating, and in Norway the most frequent sleep disorder is insomnia. The ISI has good reliability and validity [41, 42], and is recommended as an outcome measure for insomnia in clinical trials due to its sensitivity to changes in insomnia symptoms and sleep patterns [41].
  - Pain Catastrophizing Scale (PCS) to measure pain catastrophizing and “exaggerated negative orientation toward pain stimuli and pain experience” [43, 44]. The scale consists of 13 items, and the full scale-score has high internal consistency and reliability. It has also been validated in Norwegian [45].
  - SF36v2 to assess patients' self-report of generic health and wellbeing. The questionnaire includes 36 questions regarding eight health domains (i.e. physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional and mental health). The results are given in two scores: The physical component summary score and the mental component summary score. This questionnaire is widely used for a range of health conditions, and both the English and Norwegian [46] versions show good validity and reliability.

The rationale behind the choices of questionnaires in the OPR is based on consensus meetings with researchers at the four university outpatient pain clinics in Norway, as well as experiences and expertise within the Norwegian pain research community. While there is no consensus on compulsory variables for pain assessment, the research group behind the OPR chose questionnaires that are mainly freely available, validated, responsive, as well as logically sound and clinically purposeful to researchers and clinicians.

## 2.2 Procedure for data registration in the OPR

All patients who attend the pain clinic meet 1 h prior to their first scheduled consultation to provide information to the registry. They receive a pre-programmed tablet, and are guided through a series of questions and questionnaires. Most patients complete these questionnaires in 20–45 min.

When the patients complete the last questionnaire, interpreted scores are generated in a report which is available for the clinicians on a secure web-page. This report is constructed to facilitate the clinical implementation of the knowledge acquired from the broad registry assessment of each patient. The report can be copied and pasted into the electronic medical record.

A paper-based form is provided to patients who are not able to answer the questionnaires electronically. Secretaries at the pain clinic reregister all paper forms to the electronic system. A short form of the registry questionnaire package is provided to patients who have cognitive impairments, are in need of an interpreter, or otherwise communicate problems with completing the questionnaires. The short form questionnaire package includes basic demographics, ODI, pain drawing, four NRS' assessing pain intensity, and EQ-5D. If patients run out of time before all questionnaires are completed, the secretaries submit the unfinished reporting to the registry system.

Data from patients who voluntarily sign a written informed consent is included in the OPR's research database. A total of 74% of the patients provided consent as of September 30, 2017. The proportion of consent increased to 82% as of September 30, 2018. All consenting patients receive an encrypted link on e-mail requesting follow-up data at 12 and 36 months after their first consultation at the pain clinic. Data from patients who do not sign the consent, are only used for clinical purposes. The follow-up questionnaires cover: Patient global impression of change (PGIC; seven items); EQ-5D-5L; ODI; two NRS' (i.e. usual pain intensity and bothersomeness of pain); and two basic demographic questions (i.e. employment and social benefits).

### 2.3 Additional registrations in the OPR from January 1st 2017

After each clinical consultation clinicians complete a form covering information on time spent on the consultation; the presence of an interpreter; which healthcare professions that were present during the consultation; diagnosis (ICD-10 and ICD-11); the national procedural codes (NCMP; Norwegian classification of medical procedures); and some administrative information (e.g. next appointment). In addition, detailed pharmacological (posology, clinical effect and adverse effects) follow-ups by phone are completed by nurses. The patients have designated nurses that are responsible for the follow-up, and the nurses discuss deviations from the predefined treatment plan with the responsible physician. Clinical effects and adverse events are assessed by patient report. General clinical effect is investigated by a question regarding the change of the overall symptom burden since last nurse consultation (i.e. much better, a little better, no change, a little worse, a lot worse). In addition, assessments with 0–10 NRSs of pain intensity, pain bothersomeness, and satisfaction with the patients' sleep since last telephone consultation also indicate clinical effect. Adverse effects are identified from a list of common analgesic adverse effects, and their severity and bothersomeness are indicated on 0–10 NRSs. The nurses also record whether the side effects are constant or fluctuating in nature.

### 2.4 Ethics

The data from the OPR are stored on a server only accessible to the leader of the registry (first and corresponding author). The data are stored with an encrypted patient

identifier and thus publications of aggregated data, like the present paper, are done in accordance with an approval from the local Data Protection Officer. All other studies need an approval from the Regional committees for medical and health research ethics (REK) in advance.

### 2.5 Statistics

Only descriptive data are reported, and analyses are performed with the freely available software PSPP (<https://www.gnu.org/software/pspp/>; last accessed 02.24.17).

Due to legal restrictions in Norway, we are not allowed to publish data files from the OPR.

## 3 Results

During the first 2 years of running the OPR – from October 1 2015 through September 30 2017 – a total of 1,712 patient reports were recorded. Of these, 170 reports were short versions. The total number of patients seen for their first assessment in the same period is 2001. Only a few patients refused to provide information to the registry, and technical issues are the main reason for missing recordings. The proportion of missing data is expected to substantially decrease as experience with the OPR is accumulating. Patient demographics and baseline patient characteristics are displayed in Tables 1 and 2, respectively.

## 4 Discussion

This article describes the development of the first local pain registry in Norway for a multidisciplinary and interdisciplinary outpatient pain clinic; its design, procedures, and characteristics of included patients. Baseline data include patients assessed at the clinic, while follow-up data is limited to those signing informed consent. The OPR will include approximately 1,000 new patients each year, the total number of new patients assessed at the outpatient clinic. Based on the high number of patients already in the registry, as well as our previous experience with other national registries, it is likely that the baseline data displayed in this article are close to true baseline data for this patient group. Including further patients will hardly alter the results in a clinically significant way. In fact, adding the next 934 consecutive patients to the original dataset only insignificantly changed the outcome figures (i.e. mean values changed only on decimal places, and all

**Table 1:** Patient demographics.

Characteristics	N (%) (N <sub>total</sub> = 1,712)	Average (range)/ Relative frequency
Age (years)	1,712 (100%)	49.9 (16–97)
Duration of pain (years)	1,528 (89.3%)	8.49 (0–66)
Sex (female)	1,671 (97.6%)	61.9%
Living alone (yes)	1,628 (95.1%)	31.3%
Patients with children 0–18 years old (yes)	1,666 (97.3%)	31.1%
Education	1,657 (96.7%)	
Comprehensive school (1–10 years)		16.2%
Secondary school/vocational school (11–13 years)		44.2%
College degree (14–17 years)		31.0%
Higher university degree (>17 years)		8.6%
Employment/student, part time or full time (yes)	1,648 (96.3%)	35.7%
Social benefits	1,418 (82.8%)	
State and occupational pension		15.0%
Sick pay		10.7%
Work assessment allowance (AAP)		35.3%
Disability pension		31.9%
Others		7.1%
Self-rated evaluation of personal economy	1,670 (97.5%)	
Good		23.9%
Average		51.2%
Poor		24.9%
Application for disability pension (yes)	1,549 (90.5%)	30.3%
Litigation (yes)	1,631 (95.3%)	14.2%

**Table 2:** Patient characteristics.

Patient reported outcome measure (range)/ Patient characteristic	N (%) (N <sub>total</sub> = 1,712) <sup>a</sup>	Mean	Median	Standard deviation	Comment
Oswestry disability index/function (0–100)	1,711 (99.9%)	42.82	42	17.67	Higher is worse
Affected body regions (0–10)	1,690 (98.7%)	4.23	4	2.86	Higher is worse
Highest pain last week (0–10)	1,678 (98.0%)	7.66	8	1.76	Higher is worse
Mean pain last week (0–10)	1,670 (97.5%)	6.02	6	1.92	Higher is worse
Lowest pain last week (0–10)	1,659 (96.9%)	4.21	4	2.36	Higher is worse
Pain right now (0–10)	1,680 (98.1%)	5.58	6	2.28	Higher is worse
EQ-5D/Quality of Life VAS (0–100)	1,649 (96.3%)	43.94	41	20.72	Higher is better
EQ-5D-Index/Quality of Life (–0.594 to 1.0)	1,711 (99.9%)	0.41	0.45	0.28	Higher is better
HSCL-25/Common psychiatric symptoms (1.0–4.0)	1,518 (88.4%)	2.16	2.1	0.57	Higher is worse
Usual pain intensity (0–10)	1,495 (97.0%)	7.14	7	1.79	Higher is worse
Usual pain bothersomeness (0–10)	1,493 (96.8%)	7.67	8	1.73	Higher is worse
Gothenburg activity scale (1–4; ordinal)	1,456 (94.4%)	1.77	2	0.69	Higher is more active
Self-rated health (1–4; ordinal)	1,506 (97.7%)	3.24	3	0.69	Higher is worse
Self-efficacy (1–4)	1,494 (96.9%)	2.85	2.9	0.57	Higher is better
Bodily distress syndrome checklist (0–4; ordinal)	1,530 (99.2%)	1.49	1	1.17	Higher is worse
Injustice experience questionnaire (0–48)	1,529 (99.2%)	22.36	22	11.58	Higher is worse
Fatigue (0–11)	1,528 (99.1%)	6.48	7	3.39	Higher is worse
Insomnia severity index (0–28)	1,528 (99.1%)	14.79	15	6.97	Higher is worse
Pain catastrophizing scale (0–52)	1,528 (99.1%)	22.52	22	12.79	Higher is worse

The questionnaires are listed in the same chronological order as they are presented to the patients. <sup>a</sup>For the questionnaires HSCL-25 through Pain catastrophizing scale N<sub>total</sub> = 1,542.

median values were unchanged except for the EQ-5D-Index which decreased by a value of 0.013. Data not shown).

In 2017, both extensive recording of all procedures at the clinic and follow-ups of patient reported outcomes commenced in full scale. Thus, OPR is the world's first full scale pain registry that records in detail the demographics, PROMs and treatment details from every consultation the patients attend, with any healthcare worker in the pain clinic.

An important limitation of the registry is that only local data are recorded. This limits our knowledge in respect of pain treatments in general, but specifically it limits our knowledge regarding smaller clinics and clinical settings not able to provide interdisciplinary pain treatment. The legal, technical and financial issues that temporarily hinders this expansion of a pain registry to either regional or national scope is a work in progress with a positive prospect. An additional limitation is that clinicians have recorded a varying amount of information in the form covering the content of the consultation. However, a new set up and procedure is developed to eliminate this problem. The new setup ensures that all clinician's relevant information is registered in the OPR. The implementation of the OPR upgrade will start in the beginning of 2019. Importantly, this new procedure will not require the clinicians to do more work or spend more time on their electronic systems than before.

An important issue to consider is the follow-up registrations. After thorough discussions, we decided to have fixed follow-up times at 12 months and 36 months after the patients' first consultation at the pain clinic. These fixed follow-ups may cause some irregularities in the patients' registration of self-reported outcomes, and in terms of the changes that occur with pain treatment. For instance, treatment may be ongoing for some months or for more than a year. Thus, the 12 months registration will for some patients with a long treatment period be an assessment during a treatment course rather than a follow-up after treatment. To overcome this challenge, we could settle for more flexible follow-up times, such as 6 months after the final rather than first consultation. However, in clinical practice, flexible follow-ups are also challenging for a number of reasons. In the pain clinic, we do not apply predetermined treatment plans, and each consultation can in theory be the last. In addition, treatment series are sometimes interrupted or stopped for various reasons, such as significant progress, lack of progress or significant life events. Therefore, we believe that a follow up registrations based on the time passed from the first consultation, is a more stable measure that is not affected by a number of factors that cause irregular variations in

follow-up registration. Another issue is the follow-ups after 36 months. This time period might be considered too long, since it is impossible to know what have happened in the meantime, and we have no knowledge of factors that have influenced the patients. Nevertheless, disability caused by chronic pain conditions tend to interfere with most aspects of patients' life. It is therefore reasonable that truly clinically and lasting effective treatments will have similar broad impact on patients' lives. Thus, it is reasonable to have long time follow-ups to see if we succeed in achieving this goal. Not doing this, will on the other hand, potentially inflate our effect estimates.

Previously the field of chronic pain medicine has been plagued with unsatisfactory diagnostic coding systems. With the introduction of the ICD-11 this has fundamentally changed. In ICD-11, officially released in June 2018, chronic pain got its own classification for persistent and recurring pain continuing for at least 3 months. Thus, it is easier for the clinician to classify both the overarching pain condition, but also comorbidity from the perspective of chronic pain medicine. This new chronic pain classification will most likely improve physicians' inter-rater reliability in diagnosing chronic pain conditions, and that might benefit the patient communication.

Many clinicians, researchers, patients and next of kin may object that the OPR is too comprehensive, and include too many questions, thus making it burdensome to complete. They may be right in the latter, but these extensive recordings are necessary for the time being. We know too little about which factors are important and how to influence them. The OPR might therefore be the first real attempt to sufficiently solve parts of this challenge. The extensive data recorded in the OPR will enable thorough analyses with analytical tools and methods as causal inference, machine learning, and other techniques suited for pressing research questions in the field of chronic pain medicine. Furthermore, the OPR cohort may also serve as a historical control in future studies, both with experimental and observational design.

Another aspect is that chronic pain is a complex condition covering a wide range of underlying pathologies. In such a heterogeneous patient population, we are obliged to record a broad range of variables to try to disentangle which variables are common and unique to which conditions, and individuals. We will strive towards better – and hopefully more succinct – PROMs for chronic pain conditions. In the coming era of precision medicine the possibility of combining all these registry data with a biobank might prove valuable to improve both tailoring of pain rehabilitation, simpler pain treatment modalities and treatment outcomes. Thus, we will eventually incorporate a biobank in the OPR.

All these variables might also be beneficial in randomized registry trials or other designs that might prove more feasible than rigorous randomized controlled trials.

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**Ethical approval:** This article contains only aggregated data, and is not in need of an approval from the Regional committees for medical and health research ethics (REK).

**Authors' contributions:** LPG conceived the study and wrote the first draft. SER, HBJ, AS and TML have made substantial contributions to the revisions, additions and reflections resulting in the final manuscript.

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