# **BMJ Open** Cohort profile: the Norwegian Neck and Back Registry (NNRR): a medical quality registry for patients with neck and back complaints

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### ABSTRACT

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Nils Abel Aars; nils.abel.aars@ nordlandssykehuset.no **Purpose** The Norwegian Neck and Back Registry (Norsk Nakke og Rygg Register, NNRR) was established to improve the quality of diagnosis and treatment in patients with neck and back complaints at Departments of Physical Medicine and Rehabilitation (PMR) in Norwegian hospitals. The purpose of this cohort profile is to describe the data from registered patients from 2016 to 2022 and linkage opportunities.

Participants The registry includes adult patients with neck and back complaints referred to PMR multidisciplinary neck and back outpatient clinics in Norwegian hospitals. As of 2022, more than 8000 men and more than 10 000 women are included in the registry. Patients are predominantly diagnosed with non-specific neck or back conditions. The registry includes baseline and follow-up questionnaires from patients and their clinicians, collecting a broad range of self-reported data including demographic characteristics, employment, benefits, symptoms, diagnosis, treatment and treatment history, as well as quality of life. Participation is voluntary, and all patients in the registry have consented for the collected data to be linked with other national registries, presenting opportunities for large-scale registry-based scientific studies. Recruitment of patients to the registry is ongoing, and since 2016, an increasing number of patients have been included per year, with over 5000 in 2021 and 2022.

**Findings to date** Data from the NNRR have been used to improve our understanding of what characterises neck and back patients in specialist healthcare compared with patients in primary healthcare, how neck and back symptoms differ according to ethnicity and language, how nationality influences outcome trajectories for neck and back patients, and for studying properties of measurement instruments.

**Future plans** Future plans involve expanding the registry to include patients from the remaining three neck and back outpatient clinics in order to obtain a complete national register in Norway, and to facilitate increased use of the data for quality improvement and research purposes. The registry welcomes collaboration with other researchers.

### STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The Norwegian Neck and Back Registry (Norsk Nakke og Rygg Register, NNRR) is a medical quality register including patients with neck or back pain: a group known for considerable healthcare utilisation and societal costs due to serious debilitating conditions.
- ⇒ The registry allows for linkage of patient data with a variety of national registries (including tax and disability registries), enhancing the breadth and applicability of research opportunities.
- ⇒ The NNRR incorporates detailed patient and clinician-reported data through a comprehensive questionnaire, capturing multiple dimensions of patient health and socioeconomic status.
- ⇒ Changes in data collection methods over the registry's existence may impair the ability to compare some variables consistently over time.
- ⇒ In the initial years, the response rate for data collection in the registry was low, but this has been substantially improved, ensuring increasing representativeness.

## INTRODUCTION

The high prevalence of musculoskeletal disorders poses a great burden to society. Worldwide, approximately two-thirds of working people's anticipated rehabilitation needs are attributed to musculoskeletal disorders, which also account for the majority of years lived with disability.<sup>1 2</sup> These conditions often result in a substantial economic burden due to increased healthcare costs, absenteeism from work and reduced productivity.<sup>3 4</sup> Moreover, these disorders play a dominant role in diminishing both the health and quality of life of the individuals affected.<sup>4</sup> This is also found in global studies of ill health due to musculoskeletal disorders.<sup>5</sup>

Patients suffering from neck or back pain have high levels of healthcare utilisation, both in primary and specialist healthcare.<sup>6</sup> Much research has been conducted on these patient groups, but often for very specific purposes or outcomes. However, given the high prevalence of these conditions, the high demand for treatment and finite healthcare resources, there is a need for more general studies of neck and back patients, using registerbased approaches with high coverage and longitudinal patient data with opportunities for linkage with other data sources. Several spine surgery registers exist,<sup>7</sup> but most patients suffering from back pain are treated conservatively, not surgically. A national registry collecting data from conservatively treated patients with unspecific neck or back pain was lacking in Norway until 2014 when the Norwegian Neck and Back Registry (Norsk Nakke og Rygg Register, NNRR) was established in response to the increased prevalence of neck and back complaints and the increasing need for large-scale longitudinal patientreported data.8 The establishment of NNRR was inspired by NORspine<sup>9</sup> and SpineData<sup>10</sup> and is now a national medical quality registry which includes patients with neck or back complaints treated at the specialised interdisciplinary neck and back outpatient clinics at Norwegian hospitals.<sup>11</sup> The NNRR holds national status as a medical quality registry, mandated by the Norwegian Directorate of Health, imposing an obligation on relevant units and health personnel to provide relevant and necessary information to the registry. The registry's main purpose is to capture and improve the quality of patient care at specialised multidisciplinary neck and back outpatient clinics in Norway. With this, the NNRR provides an opportunity to aid our understanding of the characteristics of patients with neck and back complaints at scale, explore factors associated with patients' treatment, recovery and longer-term outcomes across a range of life domains. Furthermore, the registry's data can be used to provide insights into possible differences in patient treatment pathways and their outcomes across individual outpatient clinics across the country, as well as differences between specialist and primary health services.<sup>12</sup> In addition, the registry contributes to the evaluation of the structure of the service, treatment processes and results after completion of treatment.

The purpose of this cohort profile is to describe the data available from the NNRR cohort for the period 1 January 2016 to 12 December 2022. The registry has reached a substantial number of patients and is increasingly being used for scientific purposes. This warrants a description of the registry structure and data collection procedures, the coverage and quality of data and its linkage opportunities.

#### COHORT DESCRIPTION Setting/patient population

Since its inception in 2014, the NNRR has been based at the Department of Physical Medicine and Rehabilitation (PMR) at the University Hospital of North Norway (UNN). From its start, the registry has consistently expanded its network of outpatient clinics contributing data. As of 2023, 14 clinics actively provide data to the registry. Data collection began in 2015, initially involving four university hospital neck and back outpatient clinics localised in the four Norwegian Health regions: Haukeland University Hospital in Bergen, Oslo University Hospital, St. Olavs Hospital and UNN in Tromsø.

In 2023, an additional nine units have joined the registry, including UNN Harstad, Helgeland Hospital Trust (Sandnessjøen), Sørlandet Hospital, Levanger Hospital, Ålesund Hospital, Vestre Viken Hospital Trust (Drammen), Stavanger Hospital, Vestfold Hospital Trust (Stavern) and Nordland Hospital (Bodø). In 2024, Innlandet Hospital (Brumunddal) also started providing data to the registry (online supplemental figure 1). To be eligible for participation in NNRR data collection, outpatient clinics must be multidisciplinary in nature, provide specialist healthcare and be connected to hospital PMRs.

#### Design

According to Norwegian national clinical guidelines, patients with neck and back complaints should, in principle, primarily be recommended to receive treatment in the primary healthcare service. However, if a patient has not resumed normal activities or continues to be on sick leave after 4-6 weeks, referral to a specialist healthcare service is advised. In the specialist healthcare setting in Norway<sup>13</sup> and internationally,<sup>14</sup> an interdisciplinary approach to treatment is advocated, particularly if the patient's condition indicates factors that may lead to prolonged pain or frequent recurrences of musculoskeletal complaints. Patients with neck or back pain complaints are referred to a PMR, most often by their general practitioner (GP), but also occasionally from manual therapists, doctors in specialist healthcare and psychologists. After referral, a senior physician at the PMR evaluates patient eligibility based on guidelines for admission. Accepted referrals are eligible for inclusion in the NNRR if the patient is above 18 years of age and if the cause of referral is predominantly neck or back related. The patient receives an appointment according to availability in the clinic, with the deadline for assessment ranging between 12 and 26 weeks depending on the severity of symptoms. 16 days before the scheduled appointment, the patients automatically receive a digital invitation to fill in an online intake questionnaire through a national digital health platform (HelseNorge). After the patient's first appointment, the clinician completes a survey with questions about the consultation. Patients receive online follow-up questionnaires 6 and 12 months after their initial consultation. From 2021, the registry became fully digital with an upgraded uniform registration from all participating units. Prior to 2021, follow-up surveys were issued to patients via ordinary mail, with responses recorded on paper and sent back to the registry. From 2021, the questionnaire has been available in both Norwegian and English. The sequence of surveys is shown in online supplemental figure 2.

#### Sample size and data quality

Since the first year of registration in 2015, the registry has on average collected data from 2429 patients per year. As shown in online supplemental table 1, the number of recruited patients per year has increased in line with the expansion of the number of included clinics, from 1263 patients and four clinics in 2015 to 5296 patients per year among 12 clinics in 2022. Simultaneously, the 6-month follow-up completion rate has increased from 31% since its introduction in 2016 to 65% in 2022, with a marked increase in the response rate when the whole registry became digital in 2021. Since 2015 was the first year of registration, which also involved implementation challenges, data from this year is not included in the cohort profile.

NNRR receives information about how many patients were referred to and examined at the neck and back outpatient clinics from each unit and can thereby estimate the number of patients who declined to share data with NNRR, as a means of data quality improvement. The participation rate increased in 2021 and 2022, meaning that a higher proportion of the total patient group attending consultations provided data to the registry. The increase in participation rate and response rate at follow-up is probably due to the digitised data collection in 2021 and translation to English. The low participation rate in 2020 is most likely caused by COVID-19, where a high proportion of the appointments were conducted over telephone.

#### **Recruitment and consent process**

Patient recruitment to the registry is based on informed consent in accordance with national guidelines for conducting health research. The patient cannot submit the questionnaire without actively opening and responding to the consent form, indicating an active decision to provide consent. Furthermore, the patient is provided with written information regarding the processing of their personal data in accordance with guidelines for general health research. The electronic consent system enables easy documentation of the consent and provides an easy process to search for and delete patients who potentially want to withdraw from participation. The consent form is available in Norwegian and English. A copy of the current consent form in English is attached (online supplemental appendix 1).

Patients who do not wish to complete the questionnaire and share data with the registry can decline to do so. According to guidelines for health research, this has no negative consequences for those who choose not to participate, and all patients will still be offered an appointment and follow-up in the specialist healthcare system. Patients declining to participate in data collection can also provide the same information from validated screening tools to the clinician on paper for clinical purposes if they want. The patient consent includes for the collected data to be used in quality improvement and research, as long as it is within the purpose of the NNRR. The purpose of the NNRR is specified in the consent form (online supplemental appendix 1), while the general purpose and mandate of medical quality registers are specified in the regulations on medical quality registries, § 19a.<sup>15</sup>

## Legal basis, data protection and processing of personal information

The data processing for the registry adheres to the Personal Protection Regulation article 6, 1e (public interest) and follows the regulations for medical quality registers. A comprehensive Data Protection Impact Assessment has been conducted by the data protection officer at UNN to ensure data security and privacy. As specified in the consent (online supplemental appendix 1), only the institution that examines the patient and the registry administration has access to the patients directly identifiable information. All directly identifiable personal characteristics such as birthdate and address are not shared with other clinical units or with researchers.

The Norwegian Directorate of Health has granted the NNRR national status as a medical quality registry. As outlined in the regulations on medical quality registries § 2–3, second paragraph, the relevant units and health staff are required to enter relevant and essential data. The registration process relies on the data subject's explicit consent, as specified in § 2–3, third paragraph. To ensure the secure transfer and storage of health information, the responsibility is entrusted to 'Norsk helsenett', a Norwegian state enterprise established and owned by the Ministry of Health and Care Services. They are responsible for the implementation and secure operation of the registry database and work in collaboration with Hemit HF (Central Norway Regional Health Authority's IT department). Registration is carried out using standard browsers, employing an encrypted connection between the browser and the server (data store) based on digital certificates. Data are stored on hardware protected by multiple firewalls, ensuring a robust security framework. Patient forms are stored in a manner that only allows access to the relevant institution. This system enables the involved clinics to access data from patients attending their clinic and, if desired, also to receive reports prepared by the statistician at NNRR.

#### Data sources and measures in patient survey

The questionnaires given to patients prior to their first consultation collect information on demographics, musculoskeletal health and mental health, listed in table 1. Demographic items collected are, among others, patient age, sex, educational level and occupation. Self-reported patient information concerning workplace characteristics (eg, current work status, current work capability and job satisfaction) and musculoskeletal complaints (eg, duration of current pain, location of painful body regions and causes of pain) are obtained. 
 Table 1
 List of administered question domains for patients at baseline questionnaire, and at 6 and 12 months follow-up questionnaire

Domain	Item assessment	Instrument (where applicable)	Included in follow- up questionnaires
Demographics			
Patient data	National ID, address, age, gender, completion date		
Family	Marital status, number of own children and in household		
Nationality	Nationality, interpreter present (yes/no)		
Education and profession	Education level, profession		
Difficulty reading and writing	Indication of reading and writing difficulties		
Employment characteristics			
Current employment	Currently employed (yes/no), if so full-time equivalent %		Х
Current work status	Current work status, for example, working, sick leave, disability benefit		Х
Sickness absence	Instances of sickness absence for condition during the past 2 years and start date of last sick leave with exact date or month and year if day unknown		
Disability benefit or disability pension	Application made (yes/no)		
Perception of employer's RTW stance	Do you feel that your employer would like to have you back at work?		
Current work capability	Perceived current work ability compared with work ability when at its best		Х
Physical and mental work capability	Work capability self-rating for physical and mental demands of the job		
Job satisfaction	Job satisfaction self-rating		
Musculoskeletal pain			
Duration of complaints	Self-reported indication of duration of current pain complaints		
Causes of pain	Indication from list of 8 causes		
Location of painful body regions	Indication of areas of pain past 14 days		
Pain experience	Rating of pain at rest and pain during activity in past week	Numeric rating scale, pain	Х
Back pain	Back pain intensity and disability across 10 domains	Oswestry Disability Index Version 2	Х
Neck pain	Neck pain intensity and disability across 10 domains	The Neck Disability Index	Х
Fear-avoidance beliefs	Fear of backpain caused by physical activity or work	The Fear-Avoidance Beliefs Questionnaire	
Mental health			
Mental health symptoms	Symptoms of depression and anxiety (10 items)	Hopkins Symptom Checklist-10	
Other			
Smoking	Daily smoking (yes/no)		
Painkillers	Prescription and over the counter painkiller intake in past month		Х
Previous treatment	Treatment received (yes/no), if so which kind and its effectiveness		Х
			Continued

Table 1   Continued			
Domain	Item assessment	Instrument (where applicable)	Included in follow- up questionnaires
Physical activity during leisure time	Indication of level of activity during leisure time in past year	Saltin-Grimby Physical Activity Scale	
Health problems last 30 days	Health problems in past month (list of 29 for men, 33 for women)	Subjective Health Complaints	
Treatment satisfaction	Treatment satisfaction rating for current condition		Х
Health symptoms on day of intake	Health-related quality of life (overall rating and across 5 domains)	EQ visual analogue scale and EQ5D-5L	Х
EQ-5D-5L, European Quality of Life 5-Di	mension 5-Level; RTW, return to work.		

To attain the registry's main goal of improving the quality of patient care at specialised multidisciplinary neck and back clinics in Norway, variables to measure Patient Reported Experience Measures are obtained. The registry also includes Patient-Reported Outcome Measures (PROMs), which are validated and standardised forms adapted to the patient population. To facilitate ongoing evaluation, the NNRR conducts 6 and 12 months patient follow-up surveys. During these surveys, patients provide feedback on the treatment they have received after their initial consultation at the outpatient clinic. This feedback helps the NNRR gauge the effectiveness of interventions and identify potential areas for improvement in patient care. The questionnaires and variables collected in NNRR are inspired by and somewhat overlap those of NORspine<sup>9</sup> and SpineData.<sup>10</sup>

Participants complete the 10-item Oswestry Disability Index (ODI) Version 2<sup>1617</sup> to assess low back pain severity. ODI measures back pain severity as well as disability in areas of everyday life (eg, personal care, walking, sleeping) as a consequence of the pain experience. Respondents indicate their answers on a 6-point Likert-type scale ranging from 0 to 5, whereby higher values indicate more severe pain and disability. To create scores, response values are summed and expressed as a percentage. Consequently, ODI scores could range from 0% to 100%, with functional limitation categories of 0%–20%=minimal, 21%–40%=moderate, 41%–60%=severe, 61%–80%=very severe and 81%–100%=bedridden or over-reported.<sup>16 18</sup>

The severity and impairment resulting from neck complaints are assessed using the 10-item Neck Disability Index (NDI).<sup>19</sup> NDI items describe neck pain severity and daily task impairments, such as reading and driving, as well as problems with concentration and headaches. Respondents indicate their pain and disability levels on a 6-point Likert-type scale ranging from 0 to 5, with higher values indicating more patient-related disability. Vernon<sup>20</sup> recommends scoring the NDI out of 100%, with disability categories of 0%–8%=no disability, 9%–29%=mild, 30%–49%=moderate, 50%–69%=severe and 70%–100%=complete disability.

Patients indicate their location of painful areas from a list of areas/regions of both the front and back of the body.

Fear of physical and work activity is assessed using the Fear-Avoidance Beliefs Questionnaire<sup>21</sup> developed for patients with back pain.

Mental health symptoms of anxiety and depression are measured using the 10-item short form of the Hopkins Symptoms Checklist (HSCL-10).<sup>22</sup> Strand *et al*<sup>23</sup> have estimated that the cut-off for HSCL-10 in a Norwegian population setting is 1.85 for the scale ranging from 1 to 4, indicating that those above the cut-off value have symptoms of anxiety or depression.

Health-related quality of life is presently measured using the European Quality of Life 5-Dimension 5-Level questionnaire<sup>24</sup> (EQ-5D-5L), changed from the 3L version in late 2020. The EQ-5D-5L measures the five mental and physical health dimensions of mobility, self-care, usual activities, pain/discomfort and anxiety/depression on the day of assessment. Response levels range from 1 to 5, with higher values indicating lower quality of life experiences. A sixth item enquires about the health level experienced on the day on a percentage scale, ranging from 0% (worst health) to 100% (best health). In this article, responses to the EQ-5D-5L are scored according to the Western preference pattern (WePP), which constitutes the recommended weighting for Western countries.<sup>25</sup> The highest score of the WePP index is 1, which indicates a state of complete physical and psychological health.<sup>26</sup> Responses to the EQ-5D-3L were scored according to the Swedish value sets.<sup>27</sup>

Leisure physical activity level is obtained using the Saltin-Grimby Physical Activity Scale.<sup>28</sup> To assess health problems during the last 30 days, the Subjective Health Complaints (formerly Ursin Health Inventory)<sup>29 30</sup> is used.

Lastly, in the follow-up surveys, patients report on the treatment they have received at the PMR outpatient clinics, including whether they have received any treatment in primary care since inclusion.

Table 2         List of administered question dom	ains for clinicians in the clinician questionnaire shortly after patient consultation
Domain	Item assessment
Patient data	
Patient demographic	Patient name, personal identification number, age, gender, interpreter present
Medical history	Patient's former neck or back surgery
Consultation data	
Profession	Profession of involved clinician(s)
Type of consultation	Content in the consultation (coping-oriented, individual counselling regarding lifestyle and/or medication, mapping of functional ability related to work and education).
Medication	Frequency of patient painkiller intake, type of painkillers categorised by highly addictive (eg, Morphine), addictive but not as strong (eg, tramadol), all other pain medication that require a prescription.
Diagnosis	
Patient diagnosis	Results from diagnostic imaging, clinical diagnoses related to neck and back complaints
Treatment trajectory	
Follow-up in the municipal health service	Patient referred for follow-up by doctor, physiotherapist, manual therapist, chiropractor or work-oriented follow-up in the municipal health service
Follow-up in the specialist health service	Patient referred for assessment of surgery, referred to assessment with another specialist, control after assessment or treatment individual or group follow-up, or other training/rehabilitation centre

#### Data sources and measures in clinician questionnaire

In addition to basic patient information, data on healthcare utilisation are systematically collected from clinician questionnaires. As shown in table 2, the NNRR gathers data on the type of consultation and/or treatment the patient has received, providing valuable insights into the patient's healthcare utilisation. To enhance the understanding of patient care, the NNRR records the professional group or groups of (allied) health professionals involved in the patient's assessment and treatment. A medical doctor is consulted when setting a diagnosis, which we classified as non-specific conditions (such as ICD-10 M54.5 or M54.2), neurological dysfunction (such as ICD-10 M51.1 or M50.1) and specific neck or back-pain disorders (such as ICD-10 M41.9 or M46.0), reflecting the categorisation used in national clinical guidelines for low back pain.<sup>13</sup> To monitor the patient's treatment trajectory, the NNRR registers treatment paths, indicating whether further follow-up will occur at the municipal level for further investigation or rehabilitation, or within the specialist health service. In cases where follow-up is initiated at the specialist outpatient clinic, the NNRR records the individual or group-based services planned for the patient's comprehensive care. It is also recorded if the service is interdisciplinary or monodisciplinary.

### Changes to the questionnaires and data collection

Changes to the questionnaires are decided by the scientific board of the NNRR. The vast majority of variables have been stable from 2015 onwards, but some changes have been carried out since the registry's inception. For instance, information on the patient's employment status was previously obtained via the clinician questionnaire, but from the patient questionnaire since October 1, 2020. On the same date, EQ5D was changed from the 3L to the 5L version. A substantial change was made in late 2020, when the solution for data collection was digitised, and the patients were able to fill in questionnaires at home, instead of on pen and paper or on a computer in the waiting area at the hospital. Prior to 2019, technical problems with data collection from the hospital units resulted in a high proportion of missing diagnoses in the register. Regarding the clinician survey, filing a diagnosis became mandatory for the clinicians when the register was upgraded in late 2020.

A metadata model for the registry's codebook has recently been published on the NNRR website<sup>31</sup> and includes detailed information concerning variable names before and after changes, descriptions of the variables, valid time period for collection and variable history in the registry.

Because of the changes in questionnaires, the substantial improvements to data collection and the subsequent improvement in response rate in late 2020, data in the present article are presented according to periods 1 January 2016–12 December 2020 and 1 January 2021–13 December 2022.

#### **Opportunities for research and linkage between registries**

The NNRR registry has unique opportunities for data linkage as patients consent to the linkage of data from NNRR with several national health registries, medical records and population studies (online supplemental figure 3), making it possible to investigate how these patient groups fare with regard to, for instance, sickness absence, disability pension, comorbidity and healthcare utilisation.

Access to NNRR data requires (1) a research project which falls within the purpose and mandate of the registry, (2) application to and approval from the scientific board of NNRR, specifying all research questions and requested variables based on a template available from NNRR and (3) approval from a Norwegian Regional Committee for Medical and Health Research Ethics (REC). In the REC application, the applicant must specify where the data are to be stored and handled, once received from NNRR. Only Norwegian research institutions may apply to REC, meaning that international researchers need to have a collaboration with a Norwegian university, hospital or research institution in order to obtain data from NNRR. The scientific board of NNRR evaluates applications for data on a running basis. Once all necessary requirements are granted and obtained, NNRR will deliver data as password-protected files in spreadsheet format within 30 days of approval. At present, there are no costs to the applicant. Analysis of NNRR data requires basic proficiency in statistical software packages, and NNRR supplies the applicant with a codebook along with the requested data. Further linkage of NNRR data with other data sources, registries or claims records usually requires applications to the individual registries. Linkage of NNRR data to other registries is a stepwise process. First, NNRR sends a list of patients, in the form of 11-digit personal identifiers unique to every Norwegian citizen, to 'registry X' along with a unique pseudonym for every personal identifier. The 11-digit identifier is necessary to identify the individual in 'registry X'. Second, NNRR and 'registry X' individually deliver the requested patient data to the researcher, where the unique 11-digit personal identifier has been removed from the files. Every patient in the two different data sources will thus have the same unique pseudonym. The recipient of data (the researcher) performs linkage by his/her self. This procedure ensures data are not shared between different registries and ensures correct linkage of different data sources.

#### **Characteristics of patients in the NNRR cohort**

All patients (N=18982) who consented to be included in the NNRR were included for analysis. The time frame captured is from 2016 to 2022.

Baseline demographics of the NNRR cohort are shown in table 3. For all included variables, the percentage of missing data is lower in the later period. In general, the distribution across categories does not vary substantially between the two periods. The presence of an interpreter is higher in the later period, which is a likely reflection of a higher number of non-European patients in this period than in the former. In accordance with the inclusion of more PMRs in the later period, the prevalence of patients from the different regional health authorities differs between periods.

#### **Employment characteristics**

The employment characteristics of the NNRR cohort are shown in table 4. The questions concerning current fulltime work and whether the patient has been sick-listed for the same condition in the past 2 years were introduced in late 2020, explaining the high proportion of missing data for these variables in the first period. In general, there was a substantial reduction in missing responses in the second period of the cohort.

#### **Health characteristics**

Table 5 provides the health characteristics of the NNRR cohort. The number of missing responses declined in the second period relative to the first. There was a slight decline in levels of physical activity between periods, and a slight increase in symptoms of anxiety or depression. The different modes of measuring health related quality of life, and the different value sets used in the calculation of utility index, mean that comparisons cannot be made between the two periods.

The treatment characteristics from the clinicians' reports from the clinician questionnaires are shown in table 6. In both periods, the patients were classified according to diagnostic triage into non-specific conditions, neurological dysfunction and specific neck or backpain disorders. The majority of patients in the cohort were classified with non-specific neck conditions or non-specific back conditions. The first consultation was mainly conducted by a doctor or a physiotherapist. A substantial proportion of patients used painkillers, either prescribed addictive medication such as Tramadol or non-addictive medication where prescription is required. The high number of patients without a health condition classification in the first period of the registry reflects technical problems with the registration of diagnosis.

#### Neck and/or back pain

Table 7 reports musculoskeletal complaints and disability among the patients in the cohort. Almost 50% reported that their current musculoskeletal pain had lasted for more than 2 years. Around 5% reported suffering from their current complaints for less than 3 months. In the questionnaire, the patients were asked about their perceived cause of pain. Suggested answers are workload, load at home, emotional distress, injury, leisure activity or malpractice. The four most reported perceived causes of pain among the cohort included pain due to workload, skeletal, muscular and nerve injury. This means that the majority of the cohort believes that their current complaints are due to injury or workload. The average functional disability from back pain was around 30% according to ODI, thus in the range of moderate disability. Average functional disability from neck pain was slightly higher, but in the same category of disability.

#### **Cohort versus norm data**

Table 8 compares selected variables in the NNRR cohort to registry or survey data from other published sources.

Table 3         Patient characteristics among the NNRR cohort at the first consultation (overall n=18982)						
	Total		2016–2020		2021-2022	
	Response	Question	Response	Question	Response	Question
Demographics	n (%)	n*	n (%)	n*	n (%)	n*
Age (in years)		18982		9803		9179
Under 20	197 (1.0)		104 (1.1)		93 (1.0)	
20–29	2491 (13.1)		1381 (14.1)		1110 (12.1)	
30–39	4087 (21.5)		2125 (21.7)		1962 (21.4)	
40–49	4703 (24.8)		2450 (25.0)		2253 (24.5)	
50–59	4368 (23.0)		2292 (23.4)		2076 (22.6)	
60–69	2091 (11.0)		1024 (10.4)		1067 (11.6)	
70 and above	1045 (5.5)		427 (4.4)		618 (6.7)	
Gender		18982		9803		9179
Male	8397 (44.2)		4196 (42.8)		4201 (45.8)	
Female	10585 (55.8)		5607 (57.2)		4978 (54.2)	
Educational level among 25-66 years old		15661		8149		7512
Primary school, 7–10 years	1924 (12.3)		997 (12.2)		927 (12.3)	
Vocational school	5340 (34.1)		2829 (34.7)		2511 (33.4)	
Senior high school	1858 (11.9)		994 (12.2)		864 (11.5)	
College or university (<4 years)	3305 (21.1)		1729 (21.2)		1576 (21.0)	
College or university (≥4 years)	3231 (20.6)		1600 (19.6)		1631 (21.7)	
Below/over 25–66 years old	2660		1287		1373	
Missing	661 (4.0)		367 (4.3)		294 (3.8)	
Marital status		18238		9365		8873
Married	8264 (45.3)		4130 (44.1)		4134 (46.6)	
In a relationship	4811 (26.4)		2555 (27.3)		2256 (25.4)	
Single	5163 (28.3)		2680 (28.6)		2483 (28.3)	
Missing	744 (3.9)		438 (4.5)		306 (3.3)	
Number of own children		17414		8799		8615
0	3735 (21.4)		1844 (21.0)		1891 (22.0)	
1	2848 (16.4)		1419 (16.1)		1429 (16.6)	
2	6081 (34.9)		3129 (35.6)		2952 (34.3)	
3 or more	4750 (27.3)		2407 (27.3)		2343 (27.1)	
Missing	1568 (8.3)	15050	1004 (10.2)		564 (6.1)	
Number of children in household		15353		7095		8258
0	7517 (49.0)		3371 (47.5)		4146 (50.2)	
1	2816 (18.3)		1243 (17.5)		1573 (19.1)	
2	3228 (21.0)		1576 (22.2)		1652 (20.0)	
3 or more	1792 (11.7)		905 (12.8)		887 (10.7)	
Missing	3629 (19.1)	47.500	2708 (27.6)	0000	921 (10.0)	0000
Nationality	15500 (00 7)	17582	7001 (01 0)	8683	7000 (00 0)	8899
Norwegian	15599 (88.7)		7931 (91.3)		7008 (80.2)	
	704 (4.5)		497 (5.7)		692 (7.8)	
Viner	1 400 (7.4)		255 (3.0)		539 (6.U)	
	1400 (7.4)	10,000	1120 (11.4)	0000	280 (3.1)	0170
	491 (0 5)	18982	70 (0 0)	9803	102 (1 1)	9179
ies No	401 (2.5)		7 ο (U.δ)		403 (4.4)	
Missing	0		9729 (99.2)		0,10 (95.0)	
wissing	0		0		0	

Continued

#### Table 3 Continued

	Total		2016–2020		2021–2022	
	Response	Question	Response	Question	Response	Question
Demographics	n (%)	n*	n (%)	n*	n (%)	n*
Reading and writing difficulties		18227		9364		8863
Yes	3126 (17.2)		1403 (15.0)		1723 (19.4)	
No	15101 (82.8)		7961 (85.0)		7140 (80.6)	
Missing	755 (4.0)		439 (4.5)		316 (3.4)	
Regional health authority		18982		9803		9179
South-East Norway	5879 (31.0)		1721 (17.6)		4158 (45.4)	
Western Norway	5233 (27.6)		3356 (34.2)		1877 (20.4)	
Central Norway	4243 (22.4)		2407 (24.6)		1836 (20.0)	
Northern Norway	3487 (18.4)		2313 (23.6)		1168 (12.7)	
Unknown	140 (0.7)				140 (1.5)	

\*The number of patients completing each question varied because responses were not mandatory. Missing reported in n. NNRR, Norwegian Neck and Back Registry.

Demographics in the NNRR cohort compared with the total population in Norway show that the NNRR cohort is older and includes more women. Compared with the general Norwegian population within working age,<sup>32</sup> the patients in the NNRR cohort have a slightly higher level of education.

In Norway, 8.8% of the Norwegian population live in Northern Norway, and therefore, within the catchment area of the Northern Norway Regional Health Authority. However, in the total NNRR cohort, 17.8% of the patients lived within this catchment area. This means that the cohort, overall, is over-represented by patients from Northern Norway. In the second period of data collection this proportion is substantially lower, indicating that the representation has changed in line with the inclusion of more PMRs providing data to NNRR. Another possible explanation is the higher availability of private healthcare services in the south-east of Norway, which in turn do not provide data to the NNRR.

The percentage of people on sickness absence in the Norwegian population in the period 2016–2022 was 6%, based on data from Statistics Norway.<sup>33</sup> In contrast, 32% of employees in the NNRR cohort reported being on sick leave during the same timeframe. The population data on sickness absence encompassed the total working-age population and are thus considerably healthier than patients. Also, the population data include both self- and GP-reported sickness absence, whereas the NNRR cohort relies on self-report, which is generally less accurate than official registry data.

Among the working-age population in Norway from 2020 to 2021,<sup>34</sup> 4.9% received work assessment allowance (WAA). In comparison, 8.4% of the patients included in the NNRR cohort report receiving WAA at the time of the intake questionnaire.

#### **Future plans**

Data collection is expected to be ongoing in the foreseeable future. A goal for the registry is that collected data are used increasingly in national quality improvement projects and for scientific purposes. This could, for instance, include exploration of geographical variation, types of treatment and outcomes of treatment, quality of life or patient satisfaction. Another goal for the registry is that all PMRs in Norway are included in the registry (presently 15 out of 16 PMRs are included), and to achieve over 80% participation rate of patients referred to PMRs for neck or back pain. This would expand the registry's catchment area and subsequent cohort size. All Norwegian national medical quality registers are graded by the Norwegian Directorate of Health using a multilevel scale from 1c (initial phase, lowest grade) to 4a (highest grade).<sup>35</sup> At present, the NNRR is graded at 3a, with ambitions to achieve 4a status in the near future. The registry will then have a complete overview of the investigation and treatment of neck and back disorders at PMR outpatient clinics in the specialist health service in Norway, which will make the data increasingly valuable to research.

NNRR will continue ongoing validation projects to strengthen the reliability of NNRR's data; both to explore representativeness of collected follow-up data and to look at the responsiveness of used PROMs, including calculation of minimal important difference. The registry also aims to carry out an inter-rater reliability survey. From 2024, the questionnaires were also made available in Polish and Norwegian Nynorsk. In addition, the registry is planning to translate the patient questionnaires into more languages.

The patient group recorded in the registry are individuals experiencing long-term neck and/or back complaints. The group predominantly comprises individuals of working age. However, the impact on society

Table 4         Employment characteristics among the NNRR cohort at the first consultation (overall n=18982)							
	Total		2016–2020		2021–2022		
	Response	Question	Response	Question	Response	Question	
Employment characteristics	M (SD)/n (%)	n*	M (SD)/n (%)	n*	M (SD)/n (%)	n*	
Currently working full time	4799 (74.8)	6420	124 (81.0)	153	4675 (74.6)	6267	
Missing	12562 (66.2)		9650 (98.4)		2912 (31.7)		
		18982		9803		9179	
Frequency of selected statuses							
Working	9438 (49.7)		5156 (52.6)		4282 (46.6)		
On sick leave	6301 (33.2)		3457 (35.3)		2844 (31.0)		
Sick leave 100%	3738 (60.4)	6190	2077 (59.0)	3522	1661 (62.3)	2668	
Average sick leave	82%		81.1%		83.3%		
Work assessment allowance	1637 (8.6)		758 (7.7)		879 (9.6)		
Retired	1443 (7.6)		625 (6.4)		818 (8.9)		
Disability benefit	1298 (6.8)		719 (7.3)		579 (6.3)		
Disability benefit 100%	903 (61.0)	1480	527 (67.2)	784	376 (54.0)	696	
Average disability benefit	72.7%		81.5%		62.8%		
Student	854 (4.5)		410 (4.2)		444 (4.5)		
Unemployed	585 (3.1)		304 (3.1)		281 (3.1)		
Homemaker (unpaid)	225 (1.2)		72 (0.7)		153 (1.7)		
Applied for disability benefits		17270		8646		8624	
Yes	1516 (8.8)		734 (8.5)		782 (9.1)		
No	15754 (91.2)		7912 (91.5)		7842 (90.9)		
Missing	1712 (9.0)		1157 (11.8)		555 (6.0)		
Applied for work assessment allowance		16991		8322		8669	
Yes	604 (3.6)		321 (3.9)		293 (3.3)		
No	16387 (96.4)		8001 (96.1)		8386 (96.7)		
Missing	1991 (10.5)		1481 (15.1)		510 (5.6)		
Sick leave same condition past 2 years		9390		218		9172	
Yes	1449 (15.4)		40 (18.3)		1409 (15.4)		
No	7941 (84.6)		178 (81.7)		7763 (84.6)		
Missing	9592 (50.5)		9585 (97.8)		7 (0.1)		
Perception that employer would like patient back at work		14653		6955		7698	
Yes	11945 (81.5)		5868 (84.4)		6077 (78.9)		
No	2708 (18.5)		1087 (15.6)		1621 (21.1)		
Missing	4329 (22.8)		2848 (29.1)		1481 (16.1)		
Perceptions about work							
Self-reported work capability on scale 0–10	4.39 (3.1)	8533	4.4 (3.0)	157	4.4 (3.1)	8376	
Physical and mental work capability o	n a scale 1–5						
Physical job demands	2.7 (1.2)	8886	2.7 (1.2)	168	2.7 (1.2)	8718	
Mental job demands	3.7 (1.2)	8849	3.8 (1.2)	167	3.7 (1.2)	8682	
Job satisfaction on a scale 0–10	7.5 (2.6)	16032	7.6 (2.4)	8247	7.4 (2.7)	7785	

\*The number of patients completing each question varied because responses were not mandatory, and all work-related questions were not relevant for all patients (students, disability pension, retired).

NNRR, Norwegian Neck and Back Registry.

	Total		2016-2020	2021-2022	1–2022	
	Response	Question	Response	Question	Response	Question
General health	M (SD)/n (%)	n <sup>a</sup>	M (SD)/n (%)	n <sup>a</sup>	M (SD)/n (%)	n <sup>a</sup>
Physical activity		17928		9181		8747
Physically inactive	2506 (14.0)		1212 (13.2)		1294 (14.8)	
Light physical activity	11629 (64.9)		5929 (64.6)		5700 (65.2)	
Regular physical activity and training	2964 (16.5)		1595 (17.4)		1369 (15.7)	
Hard physical training	829 (4.6)		445 (4.8)		384 (4.4)	
Missing	1054 (5.6)		622 (6.3)		432 (4.7)	
Smoking daily		18179		9323		8856
Yes	2697 (14.8)		1548 (16.6)		1149 (13.0)	
No	15482 (85.2)		7775 (83.4)		7707 (87.0)	
Missing	803 (4.2)		480 (4.9)		323 (3.5)	
Painkiller use		18982		9803		9179
OTC painkillers daily (% yes)	14857 (78.3)		7697 (78.5)		7160 (78.0)	
Prescription painkillers daily (% yes)	12713 (67)		6686 (68.2)		6029 (65.7)	
HSCL-10	2.00 (0.64)	16839	1.94 (0.65)	8227	2.02 (0.64)	8612
Missing	2143 (11.3)		1567 (16.0)		567 (6.2)	
HSCL10 score ≥1.85	8827 (52.4)		4058 (49.3)		4769 (55.4)	
Most common health problems last 30	days (mild, mod	erate or seve	ere complaints)			
Headache	12881 (72.0)	17886	6646 (74.0)	8985	6235 (70.0)	8901
Neck pain	12741 (71.4)	17845	6561 (73.2)	8959	6180 (69.5)	8886
Upper back pain	11510 (65.7)	17508	5813 (66.6)	8722	5697 (64.8)	8786
Lower back pain	15397 (86.7)	17764	7448 (83.9)	8880	7949 (89.5)	8884
Shoulder pain	11973 (67.4)	17773	6175 (69.2)	8919	5798 (65.5)	8854
Sleep problems	14604 (81.4)	17948	7238 (80.2)	9022	7366 (82.5)	8926
Tiredness	15040 (84.1)	17879	7492 (83.4)	8980	7548 (84.8)	8899
Health-related quality of life						
Health today (visual analogue scale)	52.9 (20.1)	14325	54.8 (19.9)	6901	51.1 (20.1)	7424
Missing						
Utility index (EQ5D5L)	-	-	-	-	0.65 (0.2)	7604
Missing					1731 (18.5)	
Utility index (EQ5D3L)		-	0.79 (0.1)	8583	-	-
Missing			1220 (12.5)		-	_

Utility index calculated using the Swedish experience-based value sets for EQ-5D-3L (2016–2020), and the Western Preference Pattern for EQ-5D-5L (2021–2022). For EQ-5D-3L, missing was not distinctly separated from '0'.

<sup>a</sup>The number of patients completing each question varied because responses were not mandatory

EQ-5D-5L, European Quality of Life 5-Dimension 5-Level; HSCL-10, 10-item short form of the Hopkins Symptoms Checklist; NNRR, Norwegian Neck and Back Registry; OTC, over the counter.

is notable, primarily in the form of sickness absence. The treatment provided by the units contributing data to the registry is primarily aimed at achieving symptom relief, with the ultimate goal of facilitating the patients' return to work. By focusing on alleviating symptoms and enhancing functional capacity, the registry aims to support the successful reintegration of these individuals into the workforce, promoting improved quality of life and reduced societal burden. Given that the registry was established to improve the quality of diagnosis and treatment of patients with neck and back complaints, future studies should seek to determine if this objective indeed has been met. The findings presented in this cohort profile indicate that compared with the general population, the patients in the NNRR in general have less work participation, higher consumption of painkillers, are less physically active, have more emotional stress and considerable comorbidity. In

Table 6         Treatment characteristics for the NNRR cohort based on data from clinician questionnaire (N=18982)						
	Total	2016–2020	2021-2022			
	Response	Response	Response			
Treatment characteristics	n (%)	n (%)	n (%)			
Initial diagnostic triage						
Neck						
Non-specific conditions	3657 (24.9)	1581 (28.7)	2076 (22.6)			
Neurological dysfunctions	333 (2.3)	129 (2.3)	204 (2.2)			
Specific diagnosis for neck pain	6 (<1.0)	4 (<1.0)	2 (<1.0)			
Back						
Non-specific conditions	8343 (56.8)	3088 (56.0)	5255 (57.3)			
Neurological dysfunctions	1730 (11.8)	466 (8.5)	1264 (13.8)			
Otherspecific diagnosess for back pain	222 (1.5)	81 (1.5)	141 (1.5)			
Additional diagnosis	401 (2.7)	164 (3.0)	237 (2.6)			
Diagnosis not given	4290	4290	0			
First consultation conducted by						
Doctor	12101 (63.7)	7627 (77.8)	7352 (80.0)			
Nurse	2705 (14.3)	2492 (25.4)	340 (3.7)			
Physical therapist	5949 (31.3)	4486 (45.8)	2862 (31.1)			
Other clinical profession*	193 (1.0)	119 (1.2)	97 (1.1)			
Patient use of prescribed medication						
Does not use	4937 (26.0)	2063 (21.0)	2874 (31.3)			
Highly addictive	572 (3.0)	236 (2.4)	336 (3.7)			
Addictive	3736 (19.7)	2031 (20.7)	1705 (18.6)			
Other non-addictive	10727 (56.5)	5396 (55.0)	5331 (58.1)			

\*Other clinical profession includes psychologist, social worker or occupational therapist.

NNRR, Norwegian Neck and Back Registry.

summary, the patient group in NNRR is at a disadvantage according to most epidemiological measures. The registry has a responsibility to be an active part in shaping future guidelines and treatments for these patients, and for informing policy and decision makers on the context and characteristics of patients suffering from unspecific neck or back pain.

## **Findings to date**

From the registry's inception, it has continuously increased in terms of involved clinics and cohort size, resulting in a large sample with substantial data for research projects. There are several ongoing research projects using data from the NNRR cohort. NNRR has provided data to a research project at the Centre for Work and Mental Health (CWMH) at Nordland Hospital in Bodø, which will link NNRR data to data on social security and welfare from the Norwegian Labour and Welfare Administration for 13 years per individual for 19000 individuals. In addition, data from NNRR is being used to supply self-reported health data retrospectively in two randomised controlled trials led by CWMH.<sup>36</sup> OsloMet is using data from NNRR in a project to examine risks of negative patient outcomes after different treatment strategies, linked with data from Statistics Norway.

To date, four scientific articles using data from the NNRR have been published. The first study examined differences between patients treated in primary and specialist healthcare and found that patients in specialist healthcare had higher levels of pain and lower health-related quality of life and socioeconomic status compared with the patients in primary healthcare.<sup>12</sup> The second study compared the symptom burden and treatment outcomes among neck or back patients between Norwegians, non-Norwegians, and patients requiring translator services.<sup>37</sup> Findings indicated non-Norwegian patients experienced higher symptom burdens, and while the rate of multidisciplinary treatment was similar between Norwegian and non-Norwegian patients, those requiring a translator were significantly less likely to receive such treatment. The third explores responsiveness and minimal important change of specific and generic PROMs<sup>38</sup> and found that the condition-specific ODI instrument was more responsive to change between baseline and

Table 7         Musculoskeletal complaints among the NNRR cohort at the first consultation (overall n=18982)							
	Total		2016–2020		2021-2022		
	Response	Question	Response	Question	Response	Question	
Musculoskeletal complaints	M (SD)/n (%)	n*	M (SD)/n (%)	n*	M (SD)/n (%)	n*	
Duration of current complaints		18191		9340		8851	
No pain	125 (0.7)		72 (0.8)		53 (0.6)		
Less than 3 months	849 (4.7)		396 (4.2)		453 (5.1)		
3–12 months	5530 (30.4)		2843 (30.4)		2687 (30.4)		
1-2 years	3130 (17.2)		1599 (17.1)		1531 (17.3)		
>2 years	8557 (47.0)		4430 (47.4)		4127 (46.6)		
Missing	791 (4.2)		463 (4.7)		328 (3.6)		
Perceived causes of pain		18982		9803		9179	
Workload	7501 (39.5)		3936 (40.2)		3564 (38.8)		
Load at home	1828 (8.6)		805 (8.2)		823 (9.0)		
Emotional distress	1830 (9.6)		898 (9.2)		932 (10.2)		
Leisure activities	1297 (6.8)		716 (7.3)		581 (6.3)		
Skeletal injury	6337 (33.4)		2994 (30.5)		3343 (36.4)		
Muscular injury	5619 (29.6)		2662 (27.2)		2957 (32.2)		
Nerve injury	5484 (28.9)		2370 (24.2)		3114 (33.9)		
Malpractice	736 (3.9)		362 (3.7)		374 (4.1)		
Don't know	5841 (30.8)		3061 (31.2)		2780 (30.3)		
Average number of causes reported (0-9)	1.9 (1.3)		1.8 (1.3)		2.0 (1.4)		
Missing	0		0		0		
Oswestry Disability Index (0%-100)	30.4 (7.4)	15585	28.6 (7.0)	7703	32.0 (7.7)	7882	
Missing	3397 (17.9)		2100 (21.4)		1297 (14.1)		
Neck Disability Index (0%-100)	35.6 (8.1)	7430	35.9 (8.3)	8118	35.2 (8.0)	8751	
Missing	11552 (60.9)		5363 (39.8)		6189 (41.4)		
Fear-Avoidance Beliefs for Back Pain							
Average physical activity sum score (0-24)	12.8 (5.8)	16869	11.6 (13.9)	8118	13.9 (5.4)	8751	
Missing	2113 (11.1)		1685 (17.2)		428 (4.7)		
Average work sum score (0-42)	21.3 (SD 11.6)	15218	19.9 (SD 11.9)	7046	22.6 (SD 11.1)	8172	
Missing	3764 (19.8)		2757 (28.1)		1007 (12.3)		
Location of painful body regions							
Frequency of reported cases		18982		9803		9179	
Head	4385 (23.1)		1760 (18.0)		2625 (28.6)		
Neck	9326 (49.1)		4654 (47.5)		4672 (50.9)		
Lower back	12928 (68.1)		6208 (63.3)		6720 (73.2)		
Pain (0–10)							
At rest	5.4 (2.3)	18148	5.3 (2.4)	9327	5.5 (2.3)	8821	
Missing	834 (4.4)		476 (4.9)		358 (3.9)		
During activity	6.4 (2.2)	18075	6.3 (2.2)	9274	6.6 (2.2)	8801	
Missing	907 (4.8)		529 (5.4)		378 (4.1)		

\*The number of patients completing each question varied because responses were not mandatory. NNRR, Norwegian Neck and Back Registry.

follow-up than the more generic instruments. The fourth article examines the difference in trajectories of pain, disability and health-related quality of life between non-Norwegians and Norwegian patients.<sup>39</sup>

Findings indicate that non-Norwegians have more pain, greater disability and lower health-related quality of life than Norwegians over time. Finally, four master's degrees have used data from NNRR.

Table 8         Patient characteristics comparing patients in the NNRR cohort with Norwegian population data						
	NNRR cohort		Norm data			
	Total	2016–2020	2021–2022			
Demographics	M (SD)/%	M (SD)/%	M (SD)/%	<b>M</b> /%		
Age (years)	45.6 (14.0)	45.0 (13.7)	46.3 (14.4)	41.0		
Gender						
Female	55.8	57.2	54.2	49.0		
Male	44.2	42.8	45.8	51.0		
Highest educational level*						
Primary school	12.3	12.2	12.3	19.8		
Senior high school	11.9	12.2	11.5	34.0		
Vocational school	34.1	34.7	33.4	3.3		
College or university <4 years	21.1	21.2	21.0	29.0		
College or university >4 years	20.6	19.6	21.7	13.9		
Marital status†						
Married	45.3	44.1	46.6	44.8		
Cohabiting	26.4	27.3	25.4	22.4		
Single	28.3	28.6	28.3	32.8		
Average number of own children	1.8 (1.3)	1.8 (1.3)	1.8 (1.3)	1.8		
Nationality						
Norwegian	88.7	91.3	86.2	88.8		
Other	11.3	6.7	15.8	11.2		
Regional health authority‡						
South-East	31.0	17.6	45.4	56.8		
Western	27.6	34.2	20.4	25.7		
Central	22.4	24.6	20.0	8.7		
Northern	18.4	23.6	12.7	8.8		
Unknown	0.7		1.5			
Work status						
Working§	49.7	52.6	46.6	86.5		
On sick leave¶	33.2	35.3	31.0	6.0		
Work assessment allowance**	8.6	7.7	9.6	4.9		
Disability benefit <sup>++</sup>	6.8	7.3	6.3	10.2		

\*Norm data for educational level were measured among population 25-66 years for the period 2015-2022.

†Norm data for marital status were measured among population 20-79 years for the period 2017-2022.

‡Regional health authority usage in the NNRR cohort compared with number of inhabitants in the catchment area.

§Working employed people 2015-2022, age 15-74.

¶On sick leave, self-reported and doctor reported, for the period 2015–2022.

\*\*Work assessment allowance among people 18–67 years, in period 2020–2021.

++Disability pension among people 18–67, in period 2015–2022.

NNRR, Norwegian Neck and Back Registry.

#### Patient and public involvement

Users have been consulted and involved since the inception of the registry and are integral to the management of the registry. A user representative holds a permanent seat on the scientific board of the NNRR and is thus involved in all decisions relating to the operation of the registry and use of the data collected. The user representative participates in all board meetings and is invited to scientific seminars arranged by the registry.

#### Collaboration

The registry has an ongoing collaboration with Oslo University Hospital on a national quality improvement project and with a patient-led spine association in Norway. The registry also collaborates with Nordland Hospital, OsloMet and Oslo University Hospital on different research projects.

The collaboration between NNRR and the national quality improvement project aims to increase the

proportion of patients who receive interdisciplinary treatment and improve the quality of the service for patients with an immigrant background at Norwegian neck and back outpatient clinics. The project is led by MW (University Hospital North-Norway and NNRR) and JB (Oslo University Hospital).

The registry welcomes all applications for data for scientific purposes, provided the hypotheses fall under the purpose and mandate of the registry. Researchers with an interest in scientific collaboration and the data collected by NNRR are advised to contact the scientific board.

#### FURTHER DETAILS Strengths and limitations

The NNRR has several strengths. It entails a large cohort of nationally representative individuals from a patient group which suffers from serious debilitating problems and incurs substantial societal costs in the form of healthcare utilisation and sickness absence or disability. The registry's consent includes the possibility to link patient data to a broad range of national registries, including other patient registries and tax- and disability registries, providing a broad range of research opportunities. The registry includes comprehensive questionnaires, comprising both patient-reported and clinician-reported data and follow-up data, ensuring that multiple facets of the patient's situation are covered. Lastly, since its inception, the registry has continuously improved its procedures for data collection, which are now successfully implemented, robust and easy to complete for patients, contributing to a continued improvement in response rate.

A limitation of the cohort is the changes to data collection during the registry's existence, which may impair comparisons over time for some variables. Changes to what data are collected are, however, inevitable and may arguably constitute an improvement rather than a limitation. Further, the fact that the registry does not yet include all PMR clinics as of date means that the cohort does not include the entire patient group it in theory should entail. The response rate was initially lower, affecting representativeness, but this has been improved in later years, likely attributed to improvements in the manner of data collection.

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Patient consent for publication Not applicable.

Ethics approval This study involves human participants and the study describes data collected by a national medical quality register and the process of collecting these data. In Norway, national medical quality registers collect routine clinical data and are thus exempted from obtaining an ethics application. However, any scientific use of the data thereafter must seek approval from an ethics committee. The use of the registrys data for this particular manuscript was approved by the Regional Medical Ethics Committee (REC North, #138597). Participants gave informed consent to participate in the study before taking part.

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