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## LITERATURE REVIEW

# The Norwegian Patient Registry and the Norwegian Registry for Primary Health Care: Research potential of two nationwide health-care registries

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### Abstract

In Norway, the Directorate of Health is responsible for two nationwide registries – the Norwegian Patient Registry (NPR) and the Norwegian Registry for Primary Health Care (NRPHC) – which together cover all governmental-funded health care. The NPR (specialist health care) was established in 2008, while the NRPHC (primary health care) was established in 2017. Data from the NPR are extensively used in a large variety of studies. We expect that data from the NRPHC will increase in importance when the registry covers a longer time period. The NRPHC will be especially important for studying conditions mainly treated in primary care and for investigation of patient trajectories. The main aim of this paper is to give an overview of the history and content of the NPR and its research possibilities. In addition, we introduce the NRPHC as a possible future research tool and the potential for studying patient trajectories when combining data from the two registries.

**Keywords:** *Registries, primary health care, specialist health care, epidemiology, public-health research*

### Introduction

The mandatory, population-based registries in the Nordic countries contain detailed medical information. Personal identifiers facilitate follow-up of individuals within registries, linkages between registries, and between registries and other data sources [1–8]. Many of the registries include total populations over long time periods. Thus, study populations in registry-based epidemiology most often consist of total populations, and study designs with a long follow-up time can be applied. Studies based on registries can provide useful insights into topics that for ethical or practical reasons cannot be investigated in randomised trials, such as studies of drug safety during pregnancy [5,7,9,10].

The Norwegian Patient Registry (NPR) holds data at the individual level from 2008 onwards [11]. The registry covers all public specialist health-care services in Norway, including private institutions and medical specialists contracted to the regional health authorities.

A new mandatory registry for municipal/primary health and care services, the Norwegian Registry for Primary Health Care (NRPHC), was established on 1 December 2017 [12]. At the time of writing, the registry holds information on patients' contacts with general practitioners, out-of-hours services and physiotherapists and use of home-based services and nursing homes. The registry will gradually expand with data from other municipal health and care services.

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The main aim of this paper is to give an overview of the history and content of the NPR and its research possibilities. In addition, we introduce the NRPHC as a possible future research tool.

### Setting

In Norway as in the other Nordic countries, primary care, specialised health care and long-term care is mainly provided by tax-based public services [13]. Information from specialised health-care services is routinely reported to the national patient registries [5]. About one fifth of the Nordic population lives in Norway [13], with a population of 5.3 million inhabitants as of 1 January 2018 [14]. The personal identification number (PIN) is unique to every Norwegian citizen and is a key element in the national registry [15] and in many other registries and databases.

### History and objective of the NPR

The NPR was established at the private research institute SINTEF (Trondheim, Norway) in 1997 and transferred to the Norwegian Directorate of Health in 2007 [16]. Before 2008, the Norwegian Data Inspectorate approval did not include registration of the PIN. Reporting of the PIN has, however, been mandatory from 2008 after a law amendment. The PIN enables specialist health-care patient trajectories and linkage to other health registries to be studied, and is crucial for most objectives of the NPR.

The key elements of the registry are (a) administrative data such as place and time of treatment and information on referrals to treatment and waiting time; (b) demographic information such as each patient's sex, year of birth and residency at the municipality level; (c) coded medical information such as diagnoses and surgical, medical and radiological procedures; and (d) reimbursement information. Administrative, demographic and medical information is reported from the health-care institutions, while reimbursement information is derived from certain reported variables (e.g. medical codes). The International Statistical Classification of Diseases and Related Health Problems (ICD-10) is used for diagnostic data.

The main objectives of the NPR are to facilitate administration, management, financing and quality assurance of the specialist health services. Other important objectives include health-related research and providing data for medical quality registries.

When established in 1997, the NPR covered inpatients in somatic hospitals only, but the registry expanded considerably over the following years

(Figure 1). Data from mental health-care facilities for adults were included in 2001, while data from mental health-care facilities for children and youths were included in 2003. From 2006 to 2010, the registry was further expanded to include information on injuries treated at hospital emergency departments and in municipal emergency rooms, specialised interdisciplinary addiction treatment, emergency medical dispatch and Finnmark County infirmaries (wards).

A large proportion of specialised outpatient treatment in Norway is carried out outside hospitals by private specialist practices contracted by the public regional health authorities. Specialists with such practices are obliged to report to the NPR [13]. The regional health authorities furthermore purchase services from private rehabilitation institutions [17]. Contracting specialists in somatic health care and private rehabilitation institutions started reporting to the NPR in 2006, while reporting from contracting specialist practices in mental health care started in 2008 (Figure 1).

### History and objectives of the NRPHC

The NRPHC was formally established in December 2017 and holds individual-level data from July 2016 onwards. Like the NPR, this registry is also the responsibility of the Norwegian Directorate of Health.

The administrative system for reimbursement to primary health-care practitioners is one of the pillars of the NRPHC. The primary health-care reimbursement database holds information for all patient visits in primary health care (PIN, diagnoses, tariff codes and date of visit) and is routinely incorporated in the NRPHC. The main elements in the NRPHC can be grouped as administrative data, demographic information, coded medical data and reimbursement data. The International Classification of Primary Care version 2 coding system is used for diagnostic data.

The main objectives of the NRPHC are to facilitate administration, management, financing and quality assurance of the primary health and care services [18]. In addition, data from the registry can be used to aid quality improvement and for research.

### Use of health-care services by sex and age

As part of the preparatory work for the establishment of the NRPHC, a project was carried out linking data from the NPR, the primary health-care reimbursement database and the national registry [19]. The main purpose of this project was to explore treatment trajectories between primary health care and specialist health care.

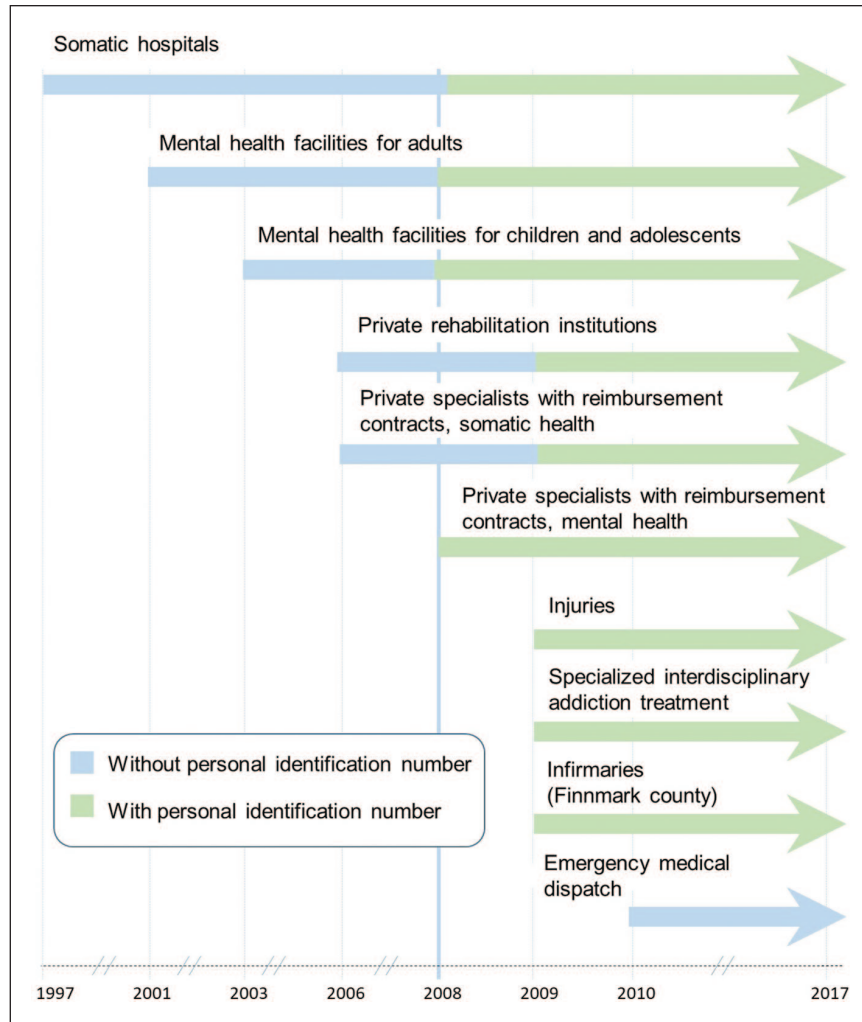


Figure 1. Timing of reporting to the Norwegian Patient Registry (NPR) by health-care sector.

The ubiquitous use of governmental reimbursed health care underlines the importance of registries for primary and specialist health care for research (Figure 2). While primary-care visits were most common in all sex and age categories, specialist health-care outpatient visits were also frequent. In the age group 15–40 years (fertile age), women utilised all levels of care far more than men. As expected, health-care utilisation increased with age. In the oldest age group, many people reside in nursing homes and receive medical care outside the ordinary primary-care and outpatient settings. Medical health care in nursing homes is not reported to either the NPR or the NRPHC. The lack of reporting explains the drop in primary-care visits and outpatient visits in the oldest age groups.

### Data quality

When planning registry-based research, it is important to have detailed knowledge of organisational,

economic or technological changes in the health-care system relevant to the research topic. Such changes, including changes to the use of the coding systems for diagnoses and procedures, can potentially affect data quality and completeness and may influence the results.

An important element when considering registry data quality is the percentage of records with PIN numbers. Low PIN completeness reduces the possibility of linking data and will bias prevalence estimates. The reporting of the PIN to the NPR was nearly complete from the very beginning (somatic hospitals: 2008, 95.2%; 2017, 99.4%; unpublished results). The reporting of the PIN has, however, been less complete for certain patient groups in somatic hospitals such as newborns and for patients in private practices. The PIN was reported for 74% of newborns in 2016 [20] and for 93% of patients in private practices in 2015 [21]. The reporting of the PIN to the NRPHC is nearly complete (2018: 99.6% for primary health-care consultations; unpublished data).

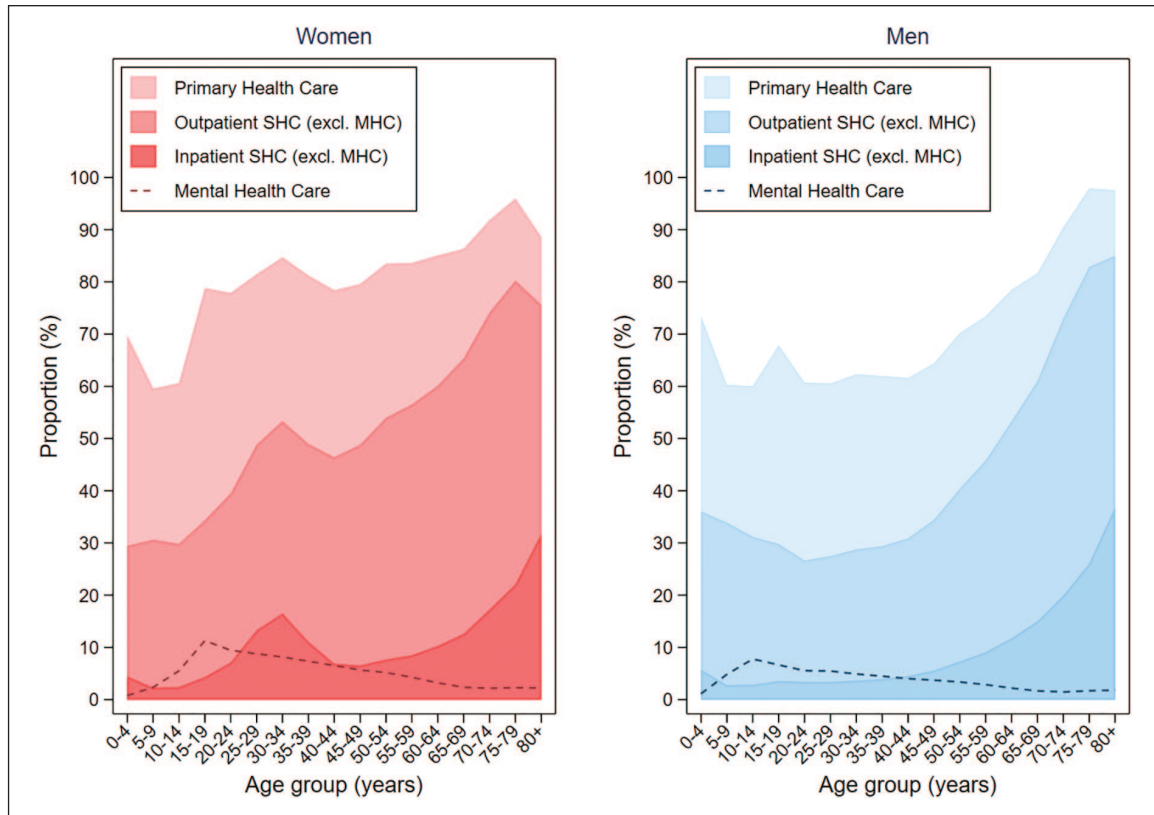


Figure 2. Proportion of the Norwegian population with primary health-care contact, outpatient specialist health-care (SHC) contact, inpatient SHC contact and mental health care in 2018 by sex and age group. Data from the NPR and the Norwegian Registry for Primary Health Care.

While little is known on coding quality in the NRPHC, data from the NPR are routinely analysed by the National Service for Validation and Completeness Analyses [22]. This service provides analyses comparing data from medical quality registries to corresponding NPR data. Contributing data to such analyses is obligatory for the national medical quality registries. Results are published in annual reports, where completeness is defined as ‘the extent to which information about the patients within the target group is actually reported to the registry’ [23]. In general, the analyses show that the NPR data have a high level of completeness. For surgeries of cleft lip and palate, gynaecological endoscopy and hip fractures and for cases of childhood diabetes, cerebral palsy and hereditary and congenital neuromuscular disorders, the level of completeness is  $>95\%$ . The completeness is somewhat lower for paediatric hip patients, surgeries of cruciate ligaments and cases of spine surgery (85–92%) [23].

A registry linkage study of the six most frequently occurring cancer diagnoses showed that data from the NPR were largely in accordance with data from the Norwegian Cancer Registry, with the level of

accordance varying between 81% and 97% at the individual level, depending on diagnosis [24]. Another study, however, showed that only 43% of patients registered with a diagnosis of tuberculosis in the NPR were recorded with tuberculosis in the Norwegian Surveillance System for Communicable Diseases [25]. More specifically, cases of latent tuberculosis were often incorrectly reported as cases of active tuberculosis to the NPR. In response to results from this study, the Norwegian Directorate of Health provided new guidelines for coding of latent tuberculosis.

In a study of hip-replacement procedures in a single hospital in 1999–2002, it was found that 3.4% of operations were not registered in the NPR [26]. Another pre-PIN study (1996–1997) found a 19% overestimation of hip fractures in analyses based on data from the NPR [27]. However, a later study of hip fractures (2008–2009) showed an overestimation of 6.5% [28]. A recent study that compared stroke data from the NPR to a gold standard based on medical record review showed that the registry data were 97% complete [29]. The correctness was, however, lower, as only 80% of stroke cases in the NPR were

‘true cases’ by the gold standard. Restricting analyses to main diagnoses increased the correctness to 94%.

The Office of the Auditor General in Norway has reported that poor coding practices in the health trusts lead to substantial errors in diagnoses in the NPR [30]. However, many of the analyses of The Office of the Auditor General in Norway are at the lowest (most detailed) diagnostic code level (for instance, not ‘epilepsy’ but ‘type of epilepsy’). In epidemiological research, a more pragmatic approach is usually applied, defining outcomes by broader code groups. For instance, rather than investigating types of epilepsy, epilepsy is studied [31,32]. Similarly, rather than studying ‘subtype of cerebral palsy’, ‘cerebral palsy’ can be studied. The data quality of both epilepsy [33] and cerebral palsy [34] codes have been shown to have a data quality sufficient for epidemiological research.

### Data from NPR and the NRPHC in research

More than 200 published papers have so far been based on data from the NPR, with strongly increasing numbers over the past few years (2016:  $n=49$ ; 2017:  $n=68$ ; 2018:  $n=79$ ) [11]. Although NRPHC data as a whole have not yet been used in published studies, data from the primary health-care reimbursement database have been used for research [35–37]. In the following, we only give examples of research based on data from the NPR.

Before the PIN became an element in the NPR, research was usually limited to studies where patient trajectories were not crucial, such as studies on changes in the use of surgical techniques. One example is a study of female sterilisation 1999–2005, which showed that introduction of a large co-payment fee in 2002 led to a 75% decrease in sterilisation rates [38].

When studying chronic disorders (e.g. epilepsy) or conditions that often are treated in more than one hospital (e.g. myocardial infarction), the PIN is important, as takes into account that several treatment episodes are registered for the same patient. For example, a study based on NPR data with PIN estimated the prevalence of autism spectrum disorder (0.7%), attention-deficit/hyperactivity disorder (2.9%) and epilepsy (0.9%) in 11-year-old children [31]. Such studies would not be feasible without the PIN.

With sufficient washout periods and careful design, incidence rates can also be estimated for chronic conditions. A study combined data from the national registry, the NPR, the primary health-care reimbursement database and the Norwegian

Prescription Database to identify new-onset type 1 diabetes [39]. The study also included data from the Norwegian Immunisation Registry on the influenza vaccine which was extensively distributed in Norway during the 2009 pandemic, and showed no association between the vaccine and subsequent type 1 diabetes.

Following children from birth or a defined age onwards allows for precise estimation of cumulative incidence of childhood conditions usually treated in specialist health care. For instance, by using data from the national registry on month of birth and data from the NPR on dates of diagnoses, it was shown that children born later in the year were at higher risk for being diagnosed with ADHD [40].

Data from the NPR have been used in several multinational studies. One multinational study concluded that increased nurse staffing and higher levels of education among nurses are associated with decreased risk of patient death [41]. Another multinational study showed that Norway has a relatively high level of hospitalisation of terminal cancer patients and high public expenditures when compared to six other developed countries [42].

In multiple studies based on the Norwegian Mother and Child Cohort Study (MoBa), data from the NPR have been used to identify cases. MoBa is a large cohort study that includes survey data and biological samples from pregnant women, their partners and their children [43,44]. In one MoBa–NPR linkage study, it was found that folic acid supplements are associated with a decreased risk of autism spectrum disorder [45]. A similar study has showed that gastrointestinal symptoms during infancy were associated with an increased risk of autism spectrum disorder [46]. Further, linkage between the MoBa and the NPR has also shown that weight gain during the first year of life was associated with increased risk for diabetes type 1 [47].

Data from the NPR can also be used to follow patients participating in randomised controlled trials. For instance, in the Norwegian Coronary Stent Trial (NORSTENT), 9013 patients undergoing percutaneous coronary interventions were randomly assigned to drug-eluting stents or bare-metal stents [48]. Data for participants were first retrieved from the NPR and the Causes of Death Registry. When potential outcomes were identified in the registry data, additional information was retrieved from hospitals for verification of end points. No significant differences in mortality rates or myocardial infarction rates were found, but repeat revascularisation occurred less frequently among patients who had received drug-eluting stents. In another example, elderly patients with hip fractures were randomly assigned to either

comprehensive care or standard orthopaedic care [49]. Information retrieved from hospital records was linked to data on rehabilitation from the NPR. The study concluded that comprehensive geriatric care led to improved mobility.

We expect that when the NRPHC becomes more known and the time period for data availability expands, numerous research studies will be designed where data from the registry are to be included. Combining data from the NPR with data from the NRPHC will open up new research possibilities. For instance, having access to specialist health-care data only excludes the possibility of studying conditions that are usually treated in primary care. We expect that the study of patient trajectories between primary and secondary health-care services will be a new important area of research in the near future [50].

### Access to registry data

The NPR and the NRPHC are subject to the Health Registry Act [51]. Studies using data have to be in accordance with the aims of the registries. The requested data have to be relevant and necessary for fulfilling the purpose of the research project, and should be at the lowest possible detailing level.

The terms and conditions for access to NPR and NRPHC data are described in the registry regulations [18,52]. Application procedures for aggregated statistics and anonymous data are simpler than procedures for access to data that provide details about individuals. The regulations state that the maximum time from application to data delivery is 30 days for statistics and anonymous data and 60 days for non-anonymous or linked data. After implementation of the EU General Data Protection Regulation in July 2018, access to individual-level data for health research requires approval from a Regional Committee for Medical and Health Research Ethics and a data protection impact assessment. Researchers at non-Norwegian institutions have the same right to access to statistics and anonymous data as researchers at Norwegian institutions, but access to non-anonymous data including linked data requires that a Norwegian institute holds the responsibility for data management. More information about the application procedures are provided at the website of The Norwegian Directorate of Health [11].

### Conclusion

The access to linkable, individual-level data from the NPR has been followed by a significant increased use of data for research from 2008 onwards. With the

establishment of the NRPHC in 2017, research possibilities have expanded even further.

### Declaration of conflicting interests

The authors declare that there is no conflict of interest.

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