



Item no.: 2022-2-7767 Publication date 09/12/2022 Revised 20/01/2023

Department of Registers and Statistics Statistik 1

Statistical register's production and quality National Patient Register

What follows is a description of the Register of patients currently or previously registered for inpatient stay and outpatient encounters in specialised health care.

Reference period

The Register comprise inpatient care since 1964 (nationwide since 1987), day surgery since 1997, and other specialised outpatient care since 2001. Until 2021, the register was updated annually. Since June 2021, the Register is updated monthly. Corrections, including late or adjusted data, are also made after publication.

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Production of the statistical register

F1 Context of the statistical register

The National Board of Health and Welfare maintains a number of registers based on the Swedish personal ID number. The registers are used as a basis for statistics and research on health care and social services. The Patient Register (PAR) is one of the National Board of Health and Welfare's health data registers. PAR is a register that covers all types of inpatient admissions and outpatient encounters with physicians in specialised care in Sweden.

F2 Design

F2.1 Outline of register content

The Patient Register is a national register that contains information about patients who have been admitted to inpatient care and patients who have been treated by doctors in specialised outpatient care (outpatient encounters), and not in primary care. For each health care contact, information such as the patient's personal ID number, main diagnosis, relevant secondary diagnoses, care procedures, any external causes and other relevant medical and administrative information should be registered. The inpatient register was created 1964 but became a national register in 1987. Outpatient specialised care, was added in 2001. Since 2010, the Patient Register also comprise data on patients admitted to compulsory psychiatric care under the Compulsory Psychiatric Care Act, and, since 2016, waiting times in hospital emergency departments. The register does not contain any data from primary care.

F2.2 Data sources

The informant for the National Patient Register is the healthcare provider. Until 1997, only the county councils were obliged to report on inpatient admissions, but from 1998 all those involved in inpatient health care are covered by the obligation to report. In 1997, the collection of data from encounters involving surgical procedures, known as day surgery, began. From 2001 onwards, the obligation to report encounters with physicians applies to all providers of outpatient specialised care.

The data reported are extracted from the medical records (EMR) that health care providers are required to keep according to *Patientdatalagen* (the Patient Data Act) (2008:355). The health care providers are responsible for the basic systems (patient administration systems) from which the data are compiled and for the processes used to register the data. Patient administration systems may therefore differ between healthcare providers and even between different specialities of the same healthcare provider.

Population data are obtained from Statistics Sweden and the Swedish Tax Agency. Demographic information is added annually by linking to Statistics Sweden's Total Population Register (RTB). Before that, preliminary population registration data from the Swedish Tax Agency are used.

F2.3 Time frame

Before 2015, the data had to be reported to the National Board of Health and Welfare annually, by March 31 of the year following the end of the reference year. As of 2015, data are submitted to the National Board of Health and Welfare on a monthly basis, and must include information on health care contacts during the three months preceding the reporting month. The data must be submitted to the National Board of Health and Welfare by the last day of each month. This means that encounters during one month are reported in the following three months to the National Board of Health and Welfare. After three months, the data are considered to be finalised, but supplements can also be made later. The National Board of Health and Welfare carries out quality controls on data reported by informants, which may result in data being re-reported or supplemented by respondents.

Since 2017, annual data have usually been made available for the first time in June of the year following the reference year, and then the annual stock has been updated a few more times with supplementary or adjusted data from health care providers. Demographic data from Statistics Sweden is usually provided in the autumn.

From June 2021, the register will be made available on a monthly basis with the latest information, including ongoing inpatient stays. In the beginning there is an expected non-response rate due to delayed record-keeping and reporting (see K2.3), and the Register is corrected in retrospect when any supplementary information is received from the reporting organisations. It is not uncommon for information in the Register to be modified up to three years after the reference year, although the changes are usually minor. Corrections can also be made later.

In the context of the Covic-19 pandemic, a special temporary version of the Patient Register was created, with weekly reporting. Most Regions provide data on a weekly basis, but private health care providers send data on a monthly basis as usual. The content of the weekly reporting is not subject to the regular delivery controls.

F2.4 Collection procedure

F2.4.1 Data collection methods and data providers

As described under F2.2, the data collected are extracts from the medical records of the reporting health care providers, registered in patient administration systems that may differ between and within health care organisations. The data must be provided in a coherent manner for all healthcare units of a healthcare provider through the National Board of Health and Welfare's electronic file transfer services. The vast majority of all health care contacts are reported via 1 of the 21 Regions, which bring together all the activities financed by each Region. Some private healthcare providers report directly to the National Board of Health and Welfare (in 2020, this corresponded to just over 1.5% of all reported inpatient stays, but about 6% of all reported outpatient encounters).

F2.4.2 Measurement

The data that organisations are obliged to submit to the Patient Register are taken from medical records, which all health care providers are obliged to keep and update in accordance with the Patient Data Act (2008:355). What is ex-

tracted from the medical records is regulated by Förordningen om patientregister hos Socialstyrelsen (2001:707) (Ordinance on patient registers at the National Board of Health and Welfare), aka the PAR Ordinance, and Socialstyrelsens föreskrifter om uppgiftsskyldighet till Socialstyrelsens patientregister (The National Board of Health and Welfare's regulations on the obligation to provide information to the National Board of Health and Welfare's patient register), hereafter referred to as SOSFS 2013:35. The methods for this data extraction differ between healthcare providers based on the systems they are using.

According to the Patient Data Act, a medical record must contain diagnoses and reasons for more significant procedures. In reporting to the Patient Register, the diagnoses must be reported and coded as main and, where necessary, secondary diagnoses according to the National Board of Health and Welfare's instructions (as of now, ICD-10-SE is used for coding, see further under F2.5.1). Depending on health care provider, different functions may be responsible for coding diagnoses as this is not regulated. The coding is often performed by medical administrators with adequate coding training, based on the doctor's dictation, and not health care professionals. SOSFS 2013:35 also states that surgical (KKÅ) and medical procedures (KMÅ) must be coded according to the Classification of Procedures (KVÅ). For clinically relevant drug administration, an ATC code of the drug in question must be supplemented in accordance with the information in FASS. Specific external cause and diagnosis codes related to poisoning must be listed together with the ATC code of the medicinal drug in accordance with the information in FASS.

The reporting health care providers provide the patient's personal ID number, year of birth and gender. Using the personal ID number, additional registration data for the patient can be retrieved from the Swedish Tax Agency and later, for the annual version of the Register, from the Total Population Register (RTB) maintained by Statistics Sweden. These are collected annually and cover data on country of birth, last date of immigration, last date of emigration, municipality of residence, district, marital status and citizenship. For data before 2015, county, municipality and parish (LKF) data are also provided by the health care providers.

In order to report data to the National Patient Register, the health care provider must have a hospital code, which is assigned after contacting the National Board of Health and Welfare. The hospital codes are based on the National Board of Health and Welfare's health care list from 1992 with codes for hospitals and clinics (MVO).

F2.4.3 Defective deliveries

The most common known deficiencies are that an informant fails to make a delivery in a given month, or that the delivery is missing certain data. For example, external causes, waiting time or a particular medical field may be largely or completely missing for one or more months. Since 2015, automated data delivery controls have been carried out. There are different types of controls: technical, logical and non-response checks, for example, that all files are present, in the correct format and contain permitted values. Some delivery controls can trigger a stoppage, meaning that the entire delivery is stopped if it contains certain errors, while other controls generate a warning while permitting the delivery to be made. During the delivery controls, a feedback file is generated to summarise any discrepancies in the delivery. The feedback file is sent to the reporting health

care providers, who is notified of the encounters to which the discrepancies relate and the nature of the error. If a delivery is stopped, the health care providers must promptly correct the errors and submit a new delivery. Feedback files containing only "warnings", encourage health care providers to correct the submitted data

F2.5 Processing with review

F2.5.1 Coding

Information on the main diagnosis, secondary diagnosis, procedure, and external cause is coded by the health care organisation.

Diagnoses and external causes

The ICD-10-SE classification has been used since 1997 (Skåne 1998) for coding the main and secondary diagnosis and external cause. Below is a summary of the time periods during which different ICD versions have been in force. The coding must follow the instructions found at the website social styrelsen.se. Note that the Swedish version of the ICD contains some deviations from the international version, including the national specialisation codes (coded with a letter suffix).

Coding system used for diagnosis coding in the Patient Register:

Year	Version
1964-1967	ICD-7
1968	ICD-7 and ICD-8 in parallel
1969-1986 1987-1996	ICD-8 ICD-9
1997	ICD-9 for Skåne County Council, ICD-10-SE for all oth-
1998-	ers ICD-10-SE

Some codes are bundled in ICD-10-SE as one diagnosis, according to the so-called manifestation-etiology system, formerly known as the dagger-asterisk system. This means that two codes are used to describe both the underlying cause of the current complaint (etiology/dagger †) and the patient's current complaint (manifestation/asterisk *). An example is a patient with dementia due to late-on-set Alzheimer's disease. Alzheimer's dementia can then be indicated by the manifestation/etiology pair F00.1* (late-onset Alzheimer's dementia) and G30.1† (late-onset Alzheimer's).

Health care procedures

Health care procedures are coded according to the Classification of Health Care Procedures (KVÅ). KVÅ is a merger of KKÅ (Classification of Surgical Procedures), which is a Swedish translation of the *Nomesco Classification of Surgical Procedurers*, and KMÅ (Classification of Medical Procedures). The radiology codes from *Klassifikation av radiologiska åtgärder 1991* are included, in addition to the administrative codes, in the KVÅ.

Before 2007, only the reporting of surgical procedures (KKÅ) was required, not the medical procedures. Between 1997 and 2007, the Classification of Surgical Procedures 1997 was used, and, before 1997, the Classification of Operations (K06) – sixth edition (1963–1996).

F2.5.2 Duplicate check

The health care providers must report a health care encounter ID (vtf_id) for each patient health care encounter, which serves as the unique identifier of the encounter. The same encounter ID cannot occur more than once within the same delivery. There is currently no duplicate check for the same personal ID number, admission date, discharge date, hospital, medical field of activity, diagnosis, procedures or other variables.

F2.5.3 Reasonableness check

The data for each month is checked for the number of health care contacts by Region, in comparison with what was reported for the corresponding month a year earlier. To identify more subtle non-responses, comparative checks are made to some extent on the number of health care contacts grouped by diagnosis grouping, procedure grouping, external cause, and number per value/category for other variables. Before 2019, this type of comparison check was only done on an annual basis, comparing the last reference year's frequencies with previous ones for County councils/Regions and hospital codes. Specific annual checks are also still carried out upon delivery of a complete annual data. When major deviations are detected, healthcare providers are contacted, which often leads to the re-reporting or supplementation of data from the relevant healthcare provider. Updated reporting for the requested time period can sometimes take a very long time, which is one of the reasons why the Register is updated several years after the reference year.

F2.5.4 Imputations

No imputations are made in the register.

F2.5.5 Model-based calculations

Classification according to DRG

DRG (diagnosis-related groups) is a secondary patient classification system. Sweden uses NordDRG, which has been jointly developed by the Nordic countries. The National Board of Health and Welfare manages and develops NordDRG in Sweden. The principle behind the classification is that medically and roughly equally resource-intensive health care contacts are all grouped together. DRG is thus a way of presenting and making the case mix easier to grasp compared to describing thousands of diagnosis and procedure codes. DRG weight is a relative measure of the cost of care and treatment for an average patient in each DRG group. Greater weight means greater costs. A DRG code is derived for each health care contact in the Patient Register based on, among other things, diagnoses and procedures. Thus, the DRG code is not collected but developed based on the NordDRG.

Flat or multi-file format

Before the 2015 reference year, the Register was collected as a flat file from informants. This means that each health care contact was on one row and all associated variables were in columns. There was thus limited space for the number of diagnoses and procedures that could be listed. As of reference year 2015, the information is collected in multi-files. This means that each variable is collected line by line in a separate file, e.g., diagnoses and procedures separately. This has

made it possible to report more diagnoses and procedures per health care contact. In order to process all years in the same way, flat file versions of the new multi-files are created by the National Board of Health and Welfare. Doing this requires certain assumptions and rules. For example, only the first 30 diagnoses and procedures are included. In the flat-file format, which is the most commonly used, only one main diagnosis is allowed per health care contact. In this file format, the National Board of Health adds only the etiology/dagger† code (for description, see F2.5.1) as the main diagnosis. In the multi-file format, all entered principal diagnoses remain as principal diagnoses.

Some diagnoses, external causes and procedures are supplemented with information about medicines in the form of an ATC code. They are collected in the same field as the associated diagnosis, external cause or procedure. ATC codes are added in an own column in the creation of flat files. Medicines that are linked to a diagnosis or external cause are added to the ATC column and medicines that supplement the procedure code are added to ATCO. This separation of ATC codes from the respective fields is possible as these codes have a specific structure.

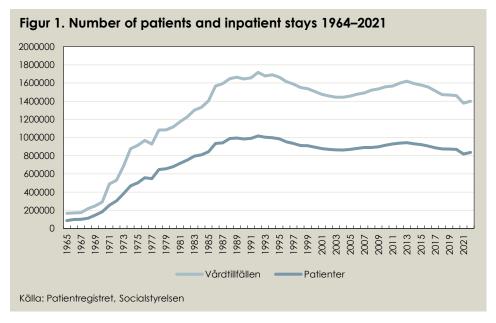
F2.5.6 Comparisons with other registers and data sources

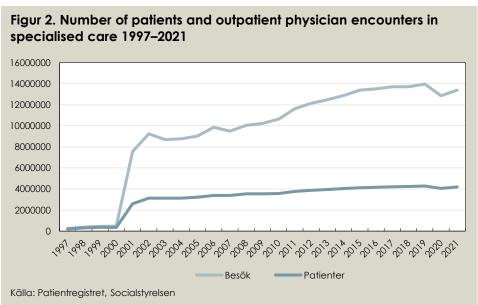
The content of the register can be compared with several other data sources, which gives an estimate of the extent of non-response in the Register (see K2.2.1). Comparisons with, for example, the Quality Registries are used to find non-response of health care contacts.

F3 Implementation

F3.1 Quantitative information

One observation in the National Patient Register corresponds to an inpatient stay or an outpatient encounter. Figure 1 shows the number of observations per year in inpatient care and the number of patients with a valid personal ID number for the Patient Register 1964-2021. Figure 2 shows the number of outpatient physician visits in specialised care per year and the number of patients with a valid personal ID number for the patient register 1997-2021.





3.2 Deviations from the design

Private health care providers have been exempted from the requirement to report the same data for three months, and need only report data in the month following the date of health care contact.

Statistical register quality

K1 Relevance

K1.1 Objectives and information requirements

K1.1.1 The Register's objective

Personal data in the Patient Register may be processed for the production of statistics, for monitoring, evaluation and quality assurance for inpatient care and specialised outpatient care, as well as for research and epidemiological studies.

K1.1.2 The information requirement of the register's users

The Patient Register forms the basis for official and other statistics on Swedish specialised care. The Register is also an important source for epidemiological research and for the documentation that the National Board of Health and Welfare produces for the Government. This can, for example, include evaluations, productivity comparisons and regional comparisons.

K1.2 The Register's content

K1.2.1 Object and population

The target population of the Register is all inpatient admissions and outpatient encounters with doctors in specialised care. The Patient Register is an event-based register, where the objects of observation are healthcare contacts delimited by fixed points in time. The objects of observation for inpatient care are inpatient stay delimited by dates of admission and discharge. The objects of observation for outpatient specialised care are encounters with doctors delimited by the date of the encounter.

The Register does not cover primary care, municipal health care, home nursing, school health care, occupational health care or any social services, or cosmetic procedures not covered by the Health and Medical Services Act. Nor does the Register include outpatient encounters with professionals other than doctors, such as midwives, nurses, dieticians, psychologists or physiotherapists.

K1.2.2 Variables

The observation variables relate to the conditions of the specific health care contact, and include information about the patient, the main diagnosis documented during the contact, relevant secondary diagnoses, care procedures that took place during the contact, any external causes of the diagnosis, the health care unit where the encounter took place, the medical field of activity of the care, etc. For the complete list of variables and metadata, see *Annex – Tables – The statistical register's production and quality – National Patient Register*. Personal ID numbers are used to link the Patient Register with other registers.

K1.2.3 Reference times

The Register includes inpatient care since 1964 (nationwide since 1987). Day surgery has been included since 1997, and other outpatient encounters with doctors (specialised care) have been included since 2001. Since 2010, the National Patient Register also includes information on different forms of compulsory psychiatric care and, since 2016, waiting times in hospital emergency departments. The Register was first updated once a year with data for the previous full year,

resulting in a new annual stock of the register. Since June 2021, a provisional, not fully quality-assured monthly version of the register is compiled, with a reference period from 2015 until two months before the current month, i.e., the whole month of October is available for the first time in December. The monthly version also includes the current hospitalised patients, while the annual files contain only discharged patients. The monthly version includes new supplementation of data going back as far as 2015, as well as data for all months reported since the last annual stock was created. New annual stocks for previous years are regularly created based on the monthly version, when data quality has been assured.

K2 Reliability

K2.1 Overall reliability

The reliability of the register is generally good, reflecting the data available in the regional patient administration systems. However, non-response has been observed, mainly from private health care providers and for certain variables, which may limit some uses. Quality has also varied over time, which can affect time series. Data on drugs (ATC code) to supplement certain diagnoses, external causes and procedures for administering medicines, as well as data on the admission date and discharge date in compulsory psychiatric care are particularly unreliable.

K2.2 Sources of uncertainty

K2.2.1 Coverage

The coverage is believed to be high for the Register, but in the absence of a suitably complete set of comparative data it is not possible to confirm. Anyone operating within specialised health care is obliged to report to the Patient Register, but the National Board of Health and Welfare is unable to command organisations to report to the National Patient Register. The lack of a comprehensive national register of all health care providers within specialised care, means that the National Board of Health and Welfare also lacks a complete list of those who are obliged to report information to the Register. There are variations in coverage rates between different health care areas. Private health care providers, particularly within specialised outpatient services, are estimated to account for a significant proportion of the non-responses. The non-response of telehealth encounters in specialised outpatient care is uncertain and the reported numbers varies between providers and regions.

From 1964, six county councils participated in the reporting, four of which reported from all hospitals. Reporting increased, and since 1987 all public health care providers have reported annually. For psychiatric care, the register is comprehensive from 1973 with the exception of individual years for some county councils. Before 1973, data from psychiatric clinics are largely missing. For more information on historical non-response, please refer to tackningsgrad-patientregistret.pdf.

A sign of increasing coverage of specialised outpatient care is the sharp increase in the number of encounters recorded over time. The Swedish Association of Local Authorities and Regions (SALAR) publishes annual statistics on the number of encounters with a doctor in specialised outpatient care paid for by a

Region, and there is no corresponding increase. A comparison between SALAR's number and the total number of encounters in the outpatient part of the Patient Register showed that, in 2005, there were about 29% more encounters in SALAR's compilation. However, this has changed, and, in 2021, the Patient Register had 7% more reported encounters (see table). The improvement seems to have been continuous over time, but especially around 2011/12 the coverage rate increased. However, the comparison may be misleading, as the Patient Register also cover care which is fully privately financed, and should therefore have more encounters than SALAR's compilation; part of the apparent improvement may therefore be due to an increased proportion of privately financed care and/or an improvement in this particular reporting to the Register. In 2021, the share of outpatient encounters in specialised care submitted by private health care providers was 5% in the Patient Register.

Table 1. Number of outpatient encounters with a doctor in specialised care

Year	SALAR	PAR	Discrepancy	PAR compared to SALAR (%)
2005	12,676,808	9,030,675	-3,646,133	-29%
2006	12,723,180	9,870,829	-2,852,351	-22%
2007	12,687,284	9,498,346	-3,188,938	-25%
2008	12,655,772	10,041,609	-2,614,163	-21%
2009	12,916,920	10,237,763	-2,679,157	-21%
2010	12,976,361	10,647,634	-2,328,727	-18%
2011	13,164,001	11,634,362	-1,529,639	-12%
2012	13,220,984	12,146,890	-1,074,094	-8%
2013	13,396,017	12,482,037	-913,980	-7%
2014	13,634,401	12,875,996	-758,405	-6%
2015	13,719,668	13,395,039	-324,629	-2%
2016	13,981,332	13,514,089	-467,243	-3%
2017	13,874,525	13,719,381	-155,144	-1%
2018	13,574,868	13,707,253	132,385	1%
2019	13,640,711	13,975,617	334,906	2%
2020	11,816,322	12,866,468	1,050,146	9%
2021	12,560,266	13,388,762	828,495	7%

Total non-response of certain healthcare providers has also been identified upon comparison with the National Quality Registries in connection with the annual compilation by the National Board of Health and Welfare of the coverage of the quality registers. Of all diagnosed first-time cases of stroke reported to at least one of the registers in 2020, 96% were found in the Patient Register, 87% in the Swedish Stroke Register and 83% in both registers (National Board of Health and Welfare reg. no. 6.5-14102/2021). The corresponding comparison with the quality registry SWEDEHEART/RIKS-HIA, which is the Swedish quality registry for cardiac intensive care, showed a coverage rate of 94% in the Patient Register in 2020, 87% in RIKS-HIA and 81% in both registers in terms of reported cases with acute cardiac infarction as the main diagnosis (National Board of Health and Welfare reg. no. 6.5-20182/2021). These comparisons have certain limitations, as the quality registries may have their own quality deficiencies and

the coding of diagnosis may be done differently than in the National Patient Register. For some procedures, however, the non-response rate is very clear, such as in obesity surgery, where the National Patient Register lacks about 20% of the procedures registered in the quality register SOReg (Scandinavian Obesity Surgery Registry), and this from a limited number of health care providers who either do not report data at all to the National Board of Health and Welfare, or who report healthcare contacts but without procedure codes. Similarly, high levels of non-response are found for cataract surgery. The healthcare providers identified as missing, are small to medium-sized private care providers, and at least in part this appears to be privately funded care. Another area where there is a marked non-response is the treatment of varicose veins, where 58% of the registered treatments in 2018 were missing from the National Patient Register [Läkartidningen 2021;118:20218].

Monthly version

There is a delay reporting the data available in the monthly version of the Patient Register, where especially data for the most recently reported month may be missing care contacts and where registered care contacts have a higher non-response rate on, among other things, diagnosis. After one month, this delay in reporting is usually very small in terms of total care contacts, and after two months it is small in terms of the proportion contacts without diagnosis. However, the reporting delay can vary from month to month with occasionally large gaps, and there is a large variation between Regions, between inpatient and outpatient care, and between medical care areas. For example, a Region may have no data at all for one month. A rule of thumb is to always use the final reported data in the Patient Register, in order not to let this affect trends over time. There is a variable in the Register that indicates whether a care contact has been reported for the final time in accordance with the regulation; this is called final reporting.

Psychiatric care

In the government assignment Förbättrad datakvalitet avseende psykiatri i patientregistret (PAR) (Improved data quality regarding psychiatry in the patient register) (National Board of Health and Welfare reg. no. 21542/2019), the Regions' reporting of data concerning psychiatry to the Patient Register was investigated. The government assignment compared data in the Patient Register with data in the Regions' own patient administration systems. In most Regions, a proportion of outpatient encounters and inpatient stay had not been reported to PAR. In some cases, there were Regions that reported more outpatient encounters to PAR than were in their patient administration system. This may be due, for example, to Regions cancelling incorrect data and neglecting to send cancellation files to the National Board of Health and Welfare. The government assignment's target for the coverage rate for patients treated in regional psychiatric activities was at least 98%; the target was met by 66% of the Regions for psychiatric outpatient care and 81% of the Regions for psychiatric inpatient care.

Another target formulated in the government assignment was that reporting of main diagnoses according to ICD-10-SE would amount to at least 98% for patients in adult psychiatry, forensic psychiatry and child and adolescent psychiatry. Eight Regions did not meet the target for main diagnosis in psychiatric outpatient care, with non-response rates ranging from 0–20%. In psychiatric inpatient care, seven Regions did not meet the target for main diagnosis, with

non-response rates ranging from 0–19%. It was also found to be more common for the main diagnosis to be missing in outpatient care than in inpatient care. Child and adolescent psychiatry in both outpatient and inpatient care lacks a main diagnosis to a greater extent than adult psychiatry, forensic psychiatry is somewhat worse at reporting main diagnoses and a large proportion of telehealth contacts lack a main diagnosis. The target of improving the quality of the reporting of KVÅ codes could not be measured within the framework of the assignment as there were too many differences between the Regions regarding which KVÅ codes were used.

A comparison between SALAR's number of encounters in specialised psychiatry and the number of encounters in the patient register's outpatient care section MVO 900-998 showed that in 2005 there were about 28% more encounters in SALAR's compilation, while in 2021 it showed that the patient register had 19% more reported encounters (see table). However, as mentioned earlier in section K2.2.1 Coverage, the figures are not fully comparable.

Table 2. Number of outpatient encounters with a doctor in psychiatric care

Year	SALAR (special- ised psychiatry)	PAR (MVO 900-998)	Discrep- ancy	PAR compared to SALAR (%)
2008	978,061	707,791	-270,270	-28%
2009	1,015,605	776,424	-239,181	-24%
2010	1,046,236	779,341	-266,895	-26%
2011	1,087,956	898,795	-189,161	-17%
2012	1,095,486	944,623	-150,863	-14%
2013	1,097,467	975,278	-122,189	-11%
2014	1,119,414	1,013,206	-106,208	-9%
2015	1,134,915	1,117,908	-17,007	-1%
2016	1,148,552	1,123,093	-25,459	-2%
2017	1,164,979	1,161,341	-3,638	0%
2018	1,147,474	1,159,861	12,387	1%
2019	1,143,447	1,186,562	43,115	4%
2020	986,109	1,199,861	213,752	22%
2021	1,026,968	1,219,962	192,994	19%

K2.2.2 Measurement

Measurement errors, in the sense that the data in the Register do not match the information in the underlying administrative system for medical records at the time of reporting, are thought to be rare, at least in recent decades when extraction and data transmission have been predominantly automated. Measurement errors may nonetheless occur in the medical record systems, especially when any change or system update is made. How care is organised in different Regions, and how it is reported to the National Patient Register, can also affect the ability to compare care between Regions and over time. Operational reorganisations can also lead to deficient reporting. This is because changes in, for example, organisational codes may require changes in the programming that extracts data for transmission, which are not always made in time.

Diagnostic reliability

The fact that a certain diagnosis has been recorded in the medical record for a health care contact does not necessarily mean that the patient had this illness, as misdiagnosis is possible both through pure misattribution, or from what was considered reasonable based on the information available at the time but later dismissed. From the point of view of the Patient Register, this is not considered a measurement error, as long as the Register reflects the medical record at the date of the relevant encounter. Several published studies have attempted to validate different diagnoses in the National Patient Register, at different points in time, and to evaluate the accuracy of different algorithms in a medical record review (the algorithms are often variants of requiring repeated diagnoses at different numbers of care contacts, or with a particular specialist, or in combination with a particular procedure or drug dispensed). These studies have generally shown that diagnoses in the National Patient Register have a very high positive predictive value (usually above 90%, but with wide variation between conditions).

The use of more non-specific diagnosis codes (different variants of *.9, 'without further specification') has varied over time, and between Regions. The instructions for coding advise against using these, but in practice it is very common. One example is unspecified falls (W19), which account for approx. 25– 30% of all falls, leading to underestimation/underreporting of specified accident types. Another type of unspecified data that occurs is external cause codes, where location and/or activity can be indicated for most injury events. A possible explanation could be that the exact specification of the injury event is not relevant for health care. A large proportion of these have unspecified data regarding location, and an even larger proportion regarding activity. In the government assignment to review the conditions for the Register Injury Database (National Board of Health and Welfare reg. no. 6395/2021), the problem of collecting location and activity data has been highlighted. The final report, Förutsättningar för insamling av skadedata till Injury Database Minimum Data Set (IDB MDS), (Prerequisites for collecting injury data for the Injury Database Minimum Data Set) also includes statistics on the proportion of unspecified location and activity data.

Definition of an inpatient stay

Inpatient stay is limited by a date of admission and discharge in all Regions, but when a new admission occurs can differ between Regions. A new inpatient stay can be created when moving from one clinic (medical field of activity, MVO) to another clinic, but sometimes this is not the case. The number of inpatient stays may therefore be an inadequate measure for making comparisons between Regions. It also means that the length of care for a continuous hospitalisation may be underestimated if the length of stay is calculated based on only one admission and discharge date.

MVO (medical field of activity) and hospital codes

Each inpatient stay is reported as performed within a medical field of activity (MVO), and a specific hospital code. The MVO was previously referred to as a clinic (and is referred to as a clinic in SOSFS 2013:35). There are some deficiencies in the MVO coding used in the Register, and they do not fully reflect the current organisation of health care. In the absence of a clear regulatory framework, health care providers decide for themselves how MVO is interpreted for

their activities, and there are cases where health care providers indicate local MVO codes that do not follow the National Board of Health and Welfare's list.

As for hospital codes, they are to be listed according to the specific list maintained by the National Board of Health and Welfare, where the principle is that there is one hospital code per health care provider and geographical location. However, health care providers sometimes report unknown hospital codes, which are therefore missing from the National Board of Health and Welfare's list. This means that there is no information regarding where and by whom care was provided. The problem of unknown hospital codes is particularly evident in Region Stockholm. Another problem with hospital codes is duplication, as one healthcare provider may have several different hospital codes registered for the same activity. Conversely, the same hospital code can indicate several different healthcare providers and locations where care is provided. In recent years, some hospitals have restructured as larger healthcare organisations. For example, certain emergency departments have no geographical connection but are reported under the same hospital code. This concern, for example, Region Västra Götaland.

The problems with hospital codes are a result of shortcomings in the National Board of Health and Welfare's list of health care providers. If an organisation changes its activities or name, restructures or is acquired, there may be no information reflecting the change. The report *Rapport över nationella inrättnings-och klinikkodes* (Report on national facility and clinic codes) (National Board of Health and Welfare ref. no. 2.7-44105/2013) highlights the problems with MVOs and hospital codes.

The hospital codes are structured in away so the Region to which the healthcare provider belongs to can be identified based on the numbers at the beginning of the code. Due to the problem of unknown hospital codes and the deviation from this in some cases, it is not a reliable way to categorise Regions. The National Board of Health and Welfare groups hospital codes into Regions to try to link healthcare providers to the right Region. This gives a more accurate breakdown, but there may be shortcomings.

Compulsory psychiatric care

It has emerged that outpatient psychiatric services have difficulties in recording data on the type of psychiatric care. Several health care providers have also drawn the attention of the National Board of Health and Welfare to the fact that, for psychiatric inpatient care, it is technically difficult to link the data regarding the form of psychiatric care to a care contact ID. Another problem is that, when a patient moves from inpatient to outpatient compulsory psychiatric care, different care contact IDs are required for the outpatient and the inpatient compulsory care, for technical reasons. This makes it difficult to get an overall picture of the types of care a patient has received during a period of compulsory psychiatric care. Among other things, this problem has led to great uncertainty about data quality regarding the start and end dates for each form of compulsory care, which forms the basis for calculating the duration of care.

As of 2021 and 2022, a supplementary assignment is underway within the framework of the government assignment *Uppdrag rörande den barn- och ungdomspsykiatriska heldygnsvården inklusive den psykiatriska tvångsvården* (Assignment concerning the child and adolescent psychiatric inpatient care, including compulsory psychiatric care) (National Board of Health and Welfare

reg. no. 11190/2019). The supplementary assignment aims to measure the quality of certain compulsory care data in the Patient Register. By comparing data in the Patient Register with data collected directly from the Regions, coverage rates are calculated for, for example, the number of patients, inpatient stays and involuntary treatments. Preliminary results show large differences in some Regions, while other Regions' figures are similar in the two data sources.

Planned care and emergency services

Extensive changes in how planned care is reported from one year to the next indicate quality problems. Especially for data from the 2000s, there is uncertainty in how this variable is coded. In outpatient specialised care, some Regions report all unplanned encounters as non-emergency encounters (*akutverksamhet*=0). This may be due to the limitations of medical record systems in terms of how data can be recorded.

For example, Västerbotten has previously not reported any visits to psychiatric emergency departments, but in the spring of 2021 this was changed so that these are also reported for the period 2017 and onwards. Other emergency activities (*akutverksamhet*=5) are largely reported from some Regions and almost not at all from others.

K2.2.3 Non-response

Non-response at the variable level occurs, but is low in recent years, for most variables.

Personal identity number

Of all inpatient stays the Patient Register during the period 1987–2021, approximately 1.5% lacked information on personal ID numbers. In specialised outpatient care, about 1% of the encounters lacked personal ID numbers during the period 2001–2021.

Diagnosis

Of all inpatient stays in the Patient Register during the period 1987–2021, about 1% had no main diagnosis, which is relatively constant over time. In specialised outpatient care, around 12% of the encounters were missing the main diagnosis in the period 2001—2021, but this has improved significantly over time. The proportion of missing principal diagnoses in outpatient care has been decreasing continuously since 2006, and, in 2021, just under 3% were missing principal diagnoses.

The table below presents the proportion of outpatient encounters (specialised care) with no main diagnosis by medical fields of activity (MVO) and year. Initially, the main diagnosis was missing for about a third of the encounters. Since 2016, the non-response rate has remained below 5%. In psychiatry, non-response was very high in the beginning, and did not fall below 10% until 2013.

Table 3. Proportion (%) with no main diagnosis in specialised outpatient care

				Child and Adolescent
YEAR	Total	Somatic	Psychiatry	Psychiatry
2001	34	30	81	77
2002	31	27	76	77
2003	24	21	69	64
2004	21	19	57	49
2005	18	15	55	58
2006	16	15	36	48
2007	12	11	20	37
2008	11	11	17	38
2009	10	9	18	37
2010	10	9	16	39
2011	10	9	15	22
2012	9	7	13	16
2013	7	5	8	8
2014	5	4	6	3
2015	6	5	7	3
2016	4	4	7	3
2017	3	3	6	3
2018	3	3	5	3
2019	3	3	5	3
2020	3	2	6	4
2021	2	2	5	4

External cause codes

For each diagnosis of injury or poisoning, the medical record shall include an indication of the external cause. Other conditions that are perceived to have an external cause, but are not classified as an injury or poisoning, can also be combined with a code for external causes. In some years and for some Regions, there have been significant non-response in regards to external causes when an injury or poisoning is listed as the main diagnosis. In 1997, there is no record of external causes of injury or poisoning in Skåne. In 2006, about 60% of inpatient cases of injury or poisoning in Sörmland had no external cause. At the national level, however, non-response has been less than 5% since 2000 for inpatient care and since 2010 for specialised outpatient care. In the Excel file https://sdb.socialstyrelsen.se/if_ska/filer/bortfall-yttre-orsaker-till-skador-och-forgiftningar-irespektive-lan.xls available in Swedish at the statistical database for external causes, the non-response rate is broken down by home county and year. If several external causes are involved at the same time, the cause related to the most serious injury, i.e., the main diagnosis, is listed first. Between 2001–2007, there is a suspiciously high number of reported encounters/inpatient stay with the external cause code V92 Drowning, drowning incidents during transport on water without direct involvement of watercraft. The suspected excessive number is thought to be due to misreporting of temporary non-operational procedures. For

Regions such as Stockholm and Gävleborg, the suspected misreporting is particularly noticeable. Comparisons at section level (V90–V94 – Transport accidents on water) and category level (V92 Drowning and drowning incidents during transport on water without direct involvement of watercraft) between 2001—2007 should be made with caution. For the years 2001 and 2002, the number reported with V92 is particularly high and also has some impact on the whole section transport accidents V01-V99.

Procedure codes and drugs

Reporting of medical procedures was mandatory as of 2007. They are reported to varying degrees and there can be large regional differences. There is a general underreporting of medical procedure codes.

There are major quality deficiencies for all three types of reporting of ATC codes for drugs. In many cases, Regions have not been able to report the ATC code either as a supplement to the diagnosis/external cause or as a supplement to the drug administration. There is also a high proportion of miscoding where the two types are mixed and the wrong variable has been reported. ATC codes are not currently recommended for analysis or for ordering data. The table below shows the number of inpatient stay and outpatient encounter lacking an ATC code when a medical procedure code on drug administration is specified (DT *Farmakologisk behandling*).

Table 4. Inpatient stays and outpatient encounters (specialised care) lacking an ATC code when a drug administration procedure code is indicated

Year	Number of in- patient stays with procedure code for drug administration	Proportion of in- patient stay with drug ad- ministration lacking an ATC code (%)	Number of out- patient en- counters with procedure code for drug administration	Proportion of out- patient encoun- ters with drug ad- ministration without ATC code (%)
2005	145	100.0	11	100.0
2006	38,425	100.0	112,233	100.0
2007	86,103	90.4	183,532	99.8
2008	103,800	89.5	231,816	94.0
2009	117,850	91.6	281,150	94.6
2010	132,968	94.2	293,431	94.0
2011	143,839	91.6	344,946	93.6
2012	155,366	89.8	406,112	93.2
2013	158,270	88.4	444,625	91.0
2014	151,474	86.3	482,137	89.1
2015	153,267	87.4	511,468	82.0
2016	149,598	89.0	518,924	80.0
2017	146,868	87.6	520,969	78.4
2018	152,642	87.0	518,089	76.7
2019	156,423	87.1	526,078	75.2
2020	181,327	71.9	556,511	63.6
2021	193,913	67.8	623,237	62.0

The table below shows, among other things, the proportion of inpatient admissions in 2021 that had a drug administration procedure code (specific medical

procedure codes starting with DT). In total, 14% of reported inpatient stay had such a code, but this varies regionally from 5% (Kronoberg) to 89% (Värmland). Värmland has been diligent in reporting ATC codes and stands out compared to other Regions. 5% of all reported inpatient stay in Sweden had an ATC code, compared to 89% for Värmland. This indicates a very significant underreporting of medical procedure codes (at least drug administration) and ATC codes. Procedure codes for drug administration during specialised outpatient encounters are less common, but the quality deficiencies follow the same pattern.

Table 5. Reporting of medical procedure codes for drug administration and ATC codes in inpatient care, 2021

Region/ informant	Proportion of all inpa- tient stay with a code for drug administra- tion	Proportion of inpatient stay with drug admin- istration lacking an ATC code	Percentage of all in- patient stay with an ATC code
Värmland	89	0	89
Västernorrland	17	38	11
Västerbotten	12	43	7
Västmanland	14	58	7
Kalmar	6	63	2
Sweden	14	68	5
Södermanland	22	71	7
Stockholm	9	76	2
Gotland	11	78	2
Kronoberg	5	79	2
Västra Götaland	12	84	2
Örebro	8	87	1
Uppsala	8	87	1
Gävleborg	18	94	1
Blekinge	26	98	1
Dalarna	11	100	0
Halland	13	100	0
Jämtland	11	100	0
Jönköping	6	100	0
Norrbotten	12	100	0
Skåne	12	100	0
Östergötland	18	100	0
Private care pro- viders	0	100	0

Emergency waiting times

Some Regions have had problems reporting time variables for emergency department encounters. The non-response is described per Region and year in the document *Kvalitet i statistikdatabasen "Väntetider och besök vid sjukhusbundna akutmottagningar"* (Quality in the statistical database "Time to treatment and encounters at hospital-based emergency departments"), only available in Swedish.

K2.2.4 Data processing

Some health care contacts are excluded as they should not be included in the Patient Register. These comprise, for example, health care contacts that only contain information about a healthy person as an accompanying person. Nor are healthy newborn babies to be registered separately as a contact.

Previously, there have been adjustments to the National Patient Register that may affect the data. Procedures for women performed on men and vice versa were previously removed, but are not deleted as of 2017. In the inpatient section of the National Patient Register for 2010, about half as many inpatient stays have a diagnosis code for the main diagnosis from the Z chapter compared to proximate years. This is probably the result of an attempt to improve diagnostic quality by moving Z-codes from the first position in the diagnostic row, but there is no documentation to verify this (National Board of Health and Welfare reg. no. 6.1-41915/2021).

The DRG coding for each inpatient stay is based on the data provided to the Register. Even if the same classification rules from NordDRG are used as when the organisations themselves create DRG's, the data on which the classification is based may differ. The patient administration systems contain many data that do not enter the National Patient Register, which in some cases may contribute to a different DRG code.

K2.2.5 Modelling assumptions

No modelling assumptions are applicable for the register.

K2.3 Provisional register compared to final register

Data for the months added since the last annual stock was created, are considered provisional. There may be updates to the annual stocks after 2015. Annual dataset before 2015 can be considered final.

A rule of thumb in regards to the monthly version of the Register, is to use final reported data in order to keep the delays in reporting so low that it does not affect time trends, but the delay is not constant over time, and non-response may arise even with this exclusion. All data in the annual datasets are finalised.

K3 Timeliness and punctuality

K3.1 Preparation time

Health care providers submit data by the last day of the month, covering health care contacts during the previous three months. Within a few weeks, these data are compiled into an updated provisional patient register. A quality-controlled annual dataset has, thus far, been produced in June of the following year.

K3.2 Frequency

The Register is updated every month with the latest available information.

K3.3 Punctuality

The annual dataset and the monthly version have been produced according to plan. Delays in reporting sometimes mean that the latest update is not complete, but the monthly version of the Register is still being updated with information on an ongoing basis.

K4 Accessibility and clarity

K4.1 Access to the register

Patient Register data may be used for research and statistical purposes. Each request to the National Board of Health and Welfare for disclosure of data is subject to a confidentiality assessment. The National Board of Health and Welfare's statistical registers are subject to statistical confidentiality according to Chapter 24, Section 8 of the Public Access to Information and Secrecy Act (2009:400).

Aggregated data from the register are also available in the official statistics, in the National Board of Health and Welfare's statistics database and through our commissioning activities. More information regarding how to order National Patient Register data can be found on the website of the National Board of Health and Welfare. Research projects reviewed by the Swedish Ethical Review Authority must include the application and decision.

K4.2 Dissemination of information

Information about the register can be found on the website socialstyrelsen.se. The official statistics are published annually, the date of which is indicated in the publication calendar of the National Board of Health and Welfare.

K4.3 Documentation

The Register is further documented on the website socialstyrelsen.se, including detailed descriptions of variables and value sets.

K5 Comparability and interoperability

K5.1 Comparability over time

In general, there are good opportunities for comparison over time. However, the Register has expanded over time, coding systems have been updated and coverage has increased, which may affect comparisons over longer time periods and around certain cut-off points. Changes in coding systems reduce comparability over time. The inpatient register has existed since 1964 but became national in 1987. The register for outpatient encounters (specialised care) was created in 2001, with extensive coverage gaps in the early years, especially for psychiatry. There has been a relatively high non-response rate of main diagnosis for outpatient encounters. This affects the numbers within each diagnostic category. Reporting for outpatient encounters has improved over the years, but comparisons between years should be interpreted with caution. Several quality aspects, such as coverage and non-response, have changed over time, which has consequences for time series from the register (see K2.2.1-K2.2.4).

In 1968, both ICD7 and 8 were used. This is problematic, as these versions are very similar, but there are still some differences in the codes. For this reason, it is not possible to know what a specific diagnosis or external cause code represents. Thus, this year is incomplete and often not suitable for use.

For the years 1984–86, the Register was retroactively updated with personal ID numbers, which were deleted at one stage but then reintroduced. Some of the principals who previously reported to the register were unable to recreate the personal data for individual years during this period. This means that the number

of county councils with long uninterrupted time series, is limited. Time series for somatic care going back to 1964 are available for two Regions.

For the period 1987–1994, the Register has been supplemented with birth data from the National Medical Birth Register. From 1995 onwards, birth data is once more reported to the National Patient Register, as it was before 1987.

Since 2015, data for the National Patient Register have been collected on a monthly basis. At the same time, a multi-file data submission system was introduced, allowing more secondary diagnoses and procedures to be reported per inpatient stay than before.

On 1 October 2016, the Government decided to remove the exemption for abortions in the PAR Ordinance. This enabled the National Board of Health and Welfare to include personal ID numbers in connection with abortions in the National Patient Register; conversely, there are no personal ID numbers for healthcare contacts in connection with abortions prior to this. As of 1 February 2017, it became mandatory for health care providers covered by the PAR Ordinance to report these data to the National Patient Register.

Since 2015, emergency encounters that lead to admission must be reported as an outpatient encounter in specialised care, while the admission is reported as an inpatient stay. Before 2015, emergency encounters leading to admission were only recorded as inpatient stay. Emergency department encounters that did not lead to admission before 2015 are included in the outpatient part of the National Patient Register, but it is not possible to distinguish them from other outpatient encounters. This change naturally led to a large increase in the reporting of some outpatient encounters in 2015. For example, almost all femur fractures in the emergency department, lead to admission, and from 2015 these encounters are also included as outpatient encounters in the Register. Due to reporting difficulties at the time of implementation in 2015, there are no specific data on emergency activities that took place in 2015.

Since 2017, the PAR Ordinance enables the inclusion in the Patient Register of patients treated by healthcare professionals other than doctors in psychiatric outpatient care, but this has not yet been implemented.

In the first quarter of 2020, COVID-19 began to spread in Sweden and around the world. The pandemic had an impact on society and health care, which is reflected in the Register.

K5.2 Interoperability with other registers

The data in the Patient Register can be connected with other registers based on personal ID numbers. When using them together, it should be kept in mind that there are some minor differences between the established national ICD10-SE used in the Patient Register and the international ICD10 used in the Cause of Death Register. When using the National Medical Birth Register (MFR), it should be recognised that diagnoses in the MFR may differ, as they follow SFOG's¹ guidelines for the use of diagnosis and procedure codes and related descriptions. When using the Patient Register with the MFR, it should be added that in international statistics, newborn babies are considered patients and are diagnosed with the code *Z38 Liveborn infant*. This code is not used in Sweden, and healthy newborns are not considered patients in the Patient Register. The Cancer

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¹ Swedish Society for Obstetrics and Gynecology (SFOG).

Register covers confirmed incident cancer cases, and should generally be considered more reliable than a cancer diagnosis registered for a health care contact in the Patient Register. However, the update frequency of the National Patient Register is significantly higher than these registers, which are currently only made available on an annual basis with a delay of at least six months, which may limit their interoperability.

The Prescribed Drug Register covers drugs prescribed and dispensed in pharmacies in Sweden, and in theory the Patient Register is a supplement providing information about drugs administered during health care contacts. However, with the exception of a few hospitals and medical care areas, and Värmland as of 2021, high non-response in the variable ATCO (ATC as a supplement to the procedure code) means that it is not possible at present to follow which drugs are administered during a health care contact.

General information

U1 Confidentiality and personal data processing

In the special activities of public agencies for the production of statistics, confidentiality applies in accordance with Chapter 24, Section 8 of the Public Access to Information and Secrecy Act (2009:400). However, information needed for research and statistical purposes, as well as information that is not directly attributable to an individual through his or her name, other identity codes or similar relationship, may be disclosed if it is clear that the information can be disclosed without causing damage or harm to the individual or someone close to him or her.

When processing personal data, i.e., information that can be directly or indirectly attributed to a living person, it should be noted that the General Data Protection Regulation 2016/679² and the Regulation (2018:218) containing supplementary provisions to the EU General Data Protection Regulation apply.

In addition, the Act regarding official statistics (2001:99) (*Lagen om den officiella statistiken*), the Ordinance regarding official statistics (2001:100) (*Förordningen om den officiella statistiken*) and the Act regarding the health data register, aka the Health Data Register Act (1998:543), as well as the Ordinance on patient registers at the National Board of Health and Welfare, aka the PAR Ordinance (2001:707), apply to the processing of personal data.

U2 Retention and data erasure

The National Patient Register is a register where personal data must be exempt from data erasure. The Register is covered by the Swedish National Archives' Regulations regarding exemptions from data erasure at the National Board of Health and Welfare (RA-MS 2020:22) (*Föreskrifter om undantag från gallring och gallring hos Socialstyrelsen*). Primary data, i.e., the basis for the register, may be erased five years after the basis has been received by the public agency.

The register is a so-called living register, which means that continuous updates can change data even historically. Immediate erasure of incorrect data is

² Regulation (EU) 2016/679 of the European Parliament and the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation).

permitted under RA-MS 2020:22, which means that earlier versions of the register are generally not saved by the National Board of Health and Welfare.

U3 Obligation to give information

Anyone conducting activities in the healthcare sector is obligated to give information to the National Board of Health and Welfare in accordance with the Health Data Register Act and the PAR Regulation. The submission of data must take place in accordance with SOSFS 2013:35 and the amending regulations HSLF-FS 2016:91.

U4 International reporting

Statistics from the National Patient Register are reported to EuroSafe, Eurostat, Nomesko, OECD and WHO.

U5 History

The National Patient Register is to provide data on healthcare utilisation for research, evaluation, planning and general information. Inpatient data have been collected since 1964. A comprehensive national register for all public, inpatient healthcare services exists since 1987. Outpatient encounters (specialised care) was added in 2001, day surgery in 1997. Data on the provision of compulsory psychiatric care were included from 2010 onwards; prior to that, these inpatient stays were included in the Register without indicating that the care was compulsory. The last major change to the Register came into effect on 1 January 2015, when the data submission process was changed, monthly reporting was introduced, and the file structure of the National Board of Health and Welfare's data warehouse was fundamentally changed. This also permitted collection of data on emergency activities and time to treatment in emergency departments. Since February 2017, data on abortions performed by healthcare providers covered by the PAR Ordinance must be reported to the National Patient Register. There are provisions for reporting of patients treated by healthcare professionals other than doctors in psychiatric outpatient care, but these have not yet been implemented.

U6 Contact details

Questions about the National Patient Register can be sent to the mailbox of the Patient Register team:

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Version history

Version	Change	Date
1.0	The document is new	08/02/2022
1.1	The document is updated	09/12/2022