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ORIGINAL ARTICLE

External review of procedure codes for intensive care, mechanical ventilation and extracorporeal membrane oxygenation for critically ill COVID-19 patients in the Swedish inpatient register

A nationwide observational cohort study

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BACKGROUND The quality of registry data is important for epidemiological research. The Swedish inpatient registry (IPR) is a national database with mandatory registration of all hospitalisations since 1987, and since 2007, the medical procedure codes which can be used for grading severity of infectious diseases. However, the completeness of procedure code registration has rarely been studied.

OBJECTIVES To determine the quality and completeness of procedure codes for ICU admission, mechanical ventilation and extra-corporeal membrane oxygenation (ECMO) in the Swedish IPR utilising the Swedish Intensive Care Registry (SIR) as the gold standard.

DESIGN A Swedish nationwide observational study.

SETTING Covid-19 patients in Sweden who required intensive care in Sweden between March 2020 and August 2022.

PATIENTS Covid-19 patients with a laboratory-verified SARS-CoV-2 infection who required ICU admission ($n = 8992$), mechanical ventilation ($n = 5262$) or ECMO ($n = 29$).

MAIN OUTCOME MEASURES The sensitivity and/or positive predictive values of procedure code registration for ICU, mechanical ventilation, ECMO and Covid-19 diagnosis code registration in the IPR were evaluated using SIR as the reference. Factors associated with low reporting were explored and the dates of ICU admission registration compared between IPR and SIR.

RESULTS For Covid-19 patients registered in SIR as needing intensive care, mechanical ventilation or ECMO, the completeness of procedure codes in the IPR was 39.7, 78.2 and 100%, respectively. Of the 39.7% with an ICU code in the IPR, the ICU date in the IPR corresponding to the actual ICU admission date was 52.3%. The completeness of ICU registration in the IPR varied from 0.6 to 96.9% between healthcare regions

CONCLUSIONS Procedure codes for intensive care in the Swedish IPR showed low sensitivity and varied greatly between healthcare regions. This negatively influences their usability for epidemiological research and calls for updated guidelines on coding.

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KEY POINTS

- Few studies have evaluated procedure codes in nationwide inpatient registries.
- This study highlights significant issues with regional variability in the accuracy of the Swedish inpatient registry for critically ill COVID-19 patients
- Our study underscores the global need for standardised guidelines to enhance data quality for epidemiological research and public health efforts.

Introduction

Healthcare registry data is a fundamental tool in public health research. It aids our understanding of disease patterns, allows evaluation of treatment outcomes and guides policymaking. However, its usefulness depends on data accuracy and completeness. The National Patient Registry in Sweden comprises two registries that contain information regarding patients who have been treated in specialised outpatient care [outpatient registry (OPR)] and/or admitted to inpatient care [inpatient registry (IPR)]. It is mandatory to report the main and contributing causes of contact, external causes of injury and poisoning, date of admittance and discharge, among other factors, for all outpatient and inpatient contacts. The main and contributing causes of contact are reported according to the Swedish International Classification of Diseases (ICD) system, developed from the WHO ICD classification system.[1] Although the IPR was created in 1964, it did not have full national coverage before 1987. The OPR was added in 2001 to create the current National Patient Registry. Since 2007, it has been mandatory to record healthcare interventions or procedures performed in an outpatient or inpatient context.[2] Current interventions/procedures and their codes are listed in the Swedish Classification of surgical and medical procedures, issued by the National Board of Health and Welfare (NBHW).[2] The National Patient Registry (OPR + IPR) has been assessed with regards to diagnosis codes with positive predictive values of 85 to 95%, with slight differences between medical conditions and diagnoses.[3] Internal evaluations of the National Patient Register by NBHW suggest a general underreporting of medical procedure codes with large regional differences.[4]

Diagnosis codes that reflect the main and contributing causes of contact with specialist healthcare (outpatient/inpatient contacts) provide a categorical representation of diseases or conditions; however, in most cases, they do not provide a measurement of the severity of disease other than that the patient needed specialised healthcare contact. To measure the severity of disease, other than needing, for example inpatient care, an option is to combine diagnoses registered in the IPR with medical procedure codes, such as ICU admission and mechanical ventilation. However, detailed studies evaluating the completeness of such procedure codes for patients requiring inpatient healthcare as identified in the Swedish IPR are lacking in the scientific literature.

The Swedish Intensive Care Registry (SIR), established in 2001 and managed by Region Värmland, is a national quality register dedicated to monitoring and improving intensive care in Sweden. Operating as a nonprofit organisation funded by fees paid by the local ICU and by grants from the central organisation for healthcare regions (SKR, Swedish Association of Local Authorities and Regions) – with no commercial financing – it collects detailed data on patients receiving advanced monitoring, diagnosis or treatment for imminent or manifest failure of vital bodily functions. This information includes medical and nursing care performance, enabling continuous quality improvement through the measurement of key variables. Every ICU in Sweden ($n = 82$) is a member of SIR. The data are collected from the ICU patient management systems, which are usually separate from the general medical journal systems. If an ICU does not have digital tools with automatic data transfer to SIR, these units instead utilise electronic questionnaires and web-based tools. Data pertaining to both nursing activities and medical data are registered, and an XML file is created and validated locally before being sent to SIR. It is the treating intensive care physicians who are responsible for coding diagnoses for the medical data transferred to SIR. Thereby, every ICU admission in Sweden, regardless of its location, is registered in the SIR quality database. SIR data quality is continuously monitored by SIR staff, who contact individual ICU clinics for problem-solving. To ensure adequate quality of SIR, there are dedicated personnel in each ICU who work with SIR data. In addition, individual ICUs are audited by site visits.

In this study, we utilised data from the Swedish Intensive Care Registry (SIR) to evaluate the use of IPR procedure codes relevant for disease severity grading in a cohort of critically ill patients with a laboratory-verified positive SARS-CoV-2 test, hospitalised between March 2020 to Aug 2022. The aim of this study was to validate the procedure codes for intensive care, mechanical ventilation and extracorporeal membrane oxygenation (ECMO) as registered in the IPR by using the complete data in SIR as the standard, and to determine factors that might influence potential under-reporting in the IPR

Materials and methods

Data sources

The unique personal identification numbers (PINs) assigned to all Swedish residents were used to cross-link data from registry data sources. Laboratory-verified positive tests for SARS-CoV-2 were identified through the

SmiNet database, managed by the Public Health Agency of Sweden. This has been collecting data on all individuals with a positive test since Covid-19 was declared a notifiable disease on 1 February 2020. The date of the SARS-CoV-2 infection was identified as the earliest possible date from the following: disease onset date, sample date, date of positive test or date of report to SmiNet. Data were obtained from SIR between 1 March 2020 and 27 August 2022 for individuals with a PIN and admitted with Covid-19 as a primary or secondary diagnosis (ICD10 codes U071 and U072). Concurrently, data from the IPR regarding hospitalisation and contact with outpatient clinics from the OPR were obtained. The PINs were replaced with a study ID for pseudonymisation before data was transferred to Umeå University for analysis.

Ethics

Ethical approval of this study was provided by the Swedish Ethical Review Authority in Sweden on 12 May 2020 (registration number 2020–02150). Ten ethical amendments were approved: registration number 2020–0266 (approval date 3 June 2020); 2020–034565 (2 July 2020); 2020–06713 (30 December 2020); 2021–00068 (29 January 2021); 2021–00552 (23 February 2021); 2021–01780 (9 April 2021); 2021–04687 (3 December 2021); 2022–03302-02 (6 July 2022); 2024-02491-01 (30 April 2024) and 2022-03776-02 (1 July 2024).

Study population

Using the pseudonymised study ID, we included SIR entries for patients with an ICU admission date within -5 to +30 days from their Covid-19 date. Furthermore, SIR entries with a laboratory verified SARS-CoV-2 infection were compared with the IPR, with the criteria that the ICU admission should overlap at least one day with the hospitalisation period (IPR date of admission or date of discharge). In the case that more than one IPR entry met the criteria, all of these were linked to their corresponding SIR entry, as a patient could be administratively transferred between different clinics whilst in the ICU. In Sweden, the ICU is not a separate entity, but provides life support whilst the care for the patient falls under the responsibility of the mother clinic. Thereby, discharge from the ICU is separate and data are not included in the Swedish Patient Registry.

Validation of procedure codes for ICU admission, mechanical ventilation and ECMO

For each SIR entry, the corresponding IPR entries were compared for presence of the procedure code corresponding to ICU admission (ZV049). False positive entries in the IPR were defined as having a procedure code for ICU in the IPR with an IPR admission date -5 to +30 days following a laboratory confirmation, without having a corresponding SIR entry. Where applicable, we calculated sensitivity (the proportion of SIR entries/codes correctly identified by IPR), positive predictive value (the proportion of ICU admissions identified in IPR that correspond to an entry in SIR).

To explore which factors might influence data completeness, the data were grouped based on parameters such as sex, treatment outcome, referring clinic (moderklinik), ICU type (avdelningstyp), admission SIR time of the day (h) and hospital region. The factors significantly associated with ICU code data completeness were determined using χ^2 test, applying P value adjustments using the Bonferroni method, and uni-variable logistic regression analysis using a significance threshold of P value less than 0.05. For analysis of dates, the corresponding procedure code date was extracted and compared to the time of ICU admittance in SIR. Similarly, for all SIR entries with a procedure code for mechanical ventilation (DG021) or ECMO (DV023 or FXD00) in SIR, the linked entry/entries in the IPR were analysed for the corresponding procedure code.

Statistical analysis

Data management and analysis were performed in R v.4.2.1. Sensitivity and positive predictive value with 95% confidence intervals (95% CIs) were calculated using GraphPad Prism (v10.2.2) using the Wilson-Brown method.

Results

Characteristics of study population

Between March 2020 and Aug 2022, a total of 12 323 ICU admissions with the diagnosis code for Covid-19 were registered in SIR, corresponding to 9415 individuals (Fig. 1). Of these, 94.3% (11 616) entries had a laboratory-verified infection with SARS-CoV-2 within the specified timeframe. Of the SIR entries, almost all (11 604, 99.9%) had a matching entry in the Swedish IPR. Among the 12 SIR entries lacking an IPR entry, seven of them had an entry in the OPR within 1 day of their ICU admission date. The remaining five cases did not appear in any of the two registries in connection with their ICU admission. For all further analysis, only SIR entries with a matching entry in the IPR were used, excluding these 12 entries. Individuals with entries from SIR that matched entries in the IPR corresponded to a total of 8992 individuals. Of these, the median age was 63 years and 68.8% were men (Table 1a). The highest number of ICU admissions was seen in 2020 (Table 1b), although Sweden did not experience its first case until March that year. Cases were from all main regions of Sweden, with Stockholm accounting for 27.2% of them. Of all admissions to the ICU, 7458 (64.2%) required mechanical ventilation only, and 90 (0.01%) were registered as receiving ECMO, of which 88 also had mechanical ventilation recorded (Table 1b).

Evaluation of diagnosis and procedure codes

Over the whole period January 2020 to August 2022, only 5248 of all SIR entries had the corresponding procedure code for ICU in the IPR, resulting in a sensitivity of 45.2 (95% CI, 44.3 to 46.1)%, (Table 2). We also investigated

Fig. 1 Workflow showing inclusion criteria, entries in the Swedish Intensive Care Registry (SIR) with a diagnosis code for Covid-19 were matched against laboratory verified diagnosis from SmiNet and time matched entries from the Swedish inpatient registry (IPR).

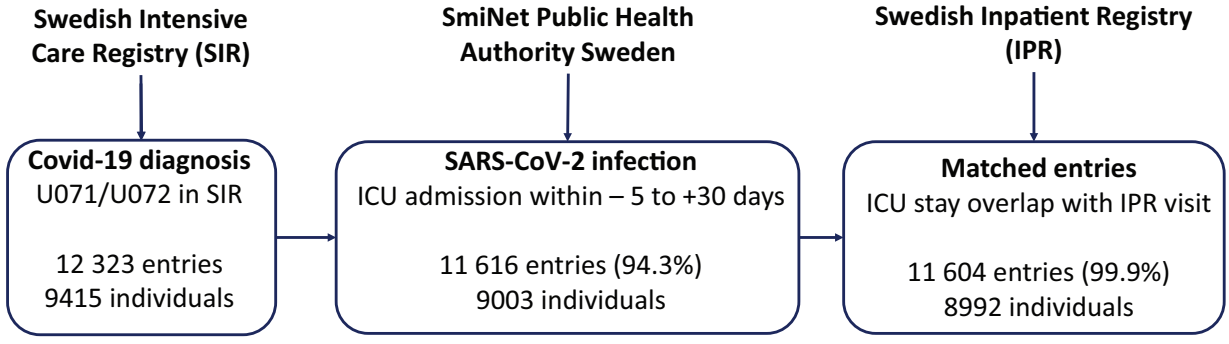


Table 1 **(a) Basic patient details and (b) characteristics of SIR entries**

a. Patients	All *n* = 8992	MV *n* = 5262	ECMO *n* = 29
Sex			
Female	2804 (31.2)	1513 (28.8)	10 (34.5)
Male	6188 (68.8)	3749 (71.2)	19 (65.5)
Age (years)	63 [52 to 72, 0 to 99]	63 [54 to 71, 0 to 92]	45 [38 to 50, 27 to 61]
b. SIR entries	**All *n* = 11 604**	**MV *n* = 7458**	**ECMO *n* = 90**
Year of ICU submission			
2020	5294 (45.6)	3605 (48.3)	53 (58.9)
2021	5136 (44.3)	3256 (43.7)	37 (41.1)[a]
2022	1174 (10.1)	597 (8)	
Hospital region			
Middle	2462 (21.2)	1606 (21.5)	7 (7.8)[a]
North	1007 (8.7)	647 (8.7)	
South	1446 (12.5)	929 (12.5)	
Southeast	1089 (9.4)	745 (10.0)	
Stockholm	3156 (27.2)	1799 (24.1)	79 (87.8)
West	2444 (21.2)	1732 (23.2)	4 (4.4)
Mechanical ventilation (MV)			
Yes	7546 (65.0)	7458 (100.0)	88 (97.8)

Data are presented as median [IQR, range] and number (%). MV represents SIR entries with a code for mechanical ventilation excluding those with a code for ECMO. [a] For sake of anonymity where there are less than three individuals, years or regions were combined.

the presence of false positive entries in the IPR (defined as having a procedure code for ICU in the IPR, without a SIR entry). We found only 90 such entries, resulting in a positive predictive value of 98.3 (95% CI, 97.9 to 98.6)%. Most of these (86/90, 95.5%) had a nonoverlapping SIR entry registered within a month before or after IP admission, suggesting that unintentional use of this procedure code is rare.

Table 2 **Presence of the corresponding IPR procedure codes for ICU admission mechanical ventilation and ECMO as well as IPR diagnosis code for Covid-19**

Code present in IPR	All SIR entries *n* = 11 604	MV *n* = 7458	ECMO *n* = 90
ICU code	5248 (45.2)	3672 (49.2)	20 (22.2)
MV code		5833 (78.2)	
ICU and MV code		3161 (42.4)	
ECMO code			90 (100.0)
ICU and ECMO code			20 (22.2)
Covid-19 diagnosis code	11 349 (97.8)	7318 (98.1)	90 (100.0)

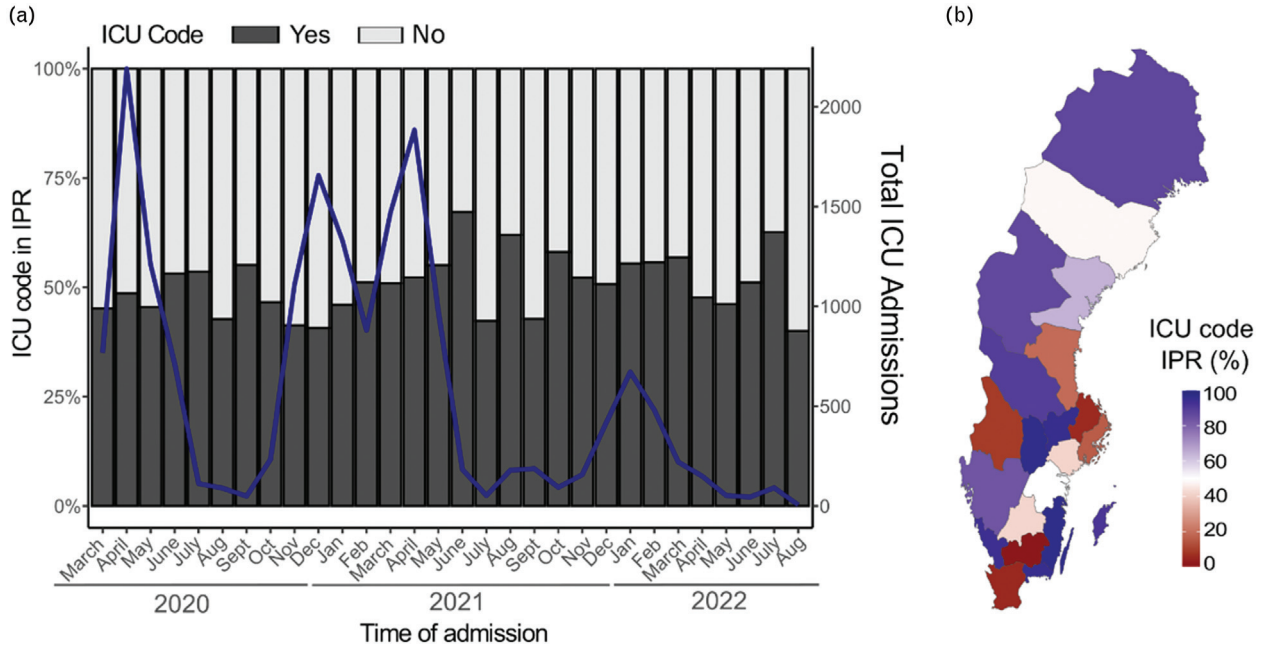
Data are *n* (%). MV represents SIR entries with a code for mechanical ventilation excluding those with a code for ECMO.

As for ICU admission, there are specific procedure codes corresponding to mechanical ventilation and ECMO. For the entries where the patient, according to SIR, received this treatment, 5833/7458 and 90/90 had the corresponding procedure codes in the IPR, resulting in a sensitivity of 78.2 (95%, CI 77.3 to 79.1)% and 100 (95% CI, 95.9 to 100)%, respectively. We also analysed the use of diagnosis codes in the IPR registry, and found that 11 349 SIR entries had the corresponding Covid-19 ICD-10 code in the IPR, resulting in a sensitivity of 97.8% (Table 2).

Factors influencing use of procedure codes

We hypothesised that the high strain on the healthcare system during pandemic peaks might have influenced

Fig. 2 Factors affecting completeness of ICU admission reporting in IPR.



(a) National completeness of ICU admission reporting in IPR per month of the analysed period (grey bars) along with the absolute number of ICU admissions registered in Sweden (blue line) and (b) map of Sweden coloured by completeness of ICU admission reporting in IPR per hospital region.

the use of procedure codes. However, our analysis shows that the overall use of procedure codes did not vary much over time, nor did it change with the peaks of ICU submissions during the pandemic (Fig. 2a). To further understand what factors might be influencing the registration of procedure codes, we analysed the association of various variables with data completeness, using both the χ^2 test and univariate logistic regression. Although several factors, such as treatment outcome, referral clinic, ICU unit type and time of admission, were associated with difference in data completeness (Table S1, http://links.lww.com/EJAIC/A109), different regions showed the most notable range of both data completeness and odds ratios (Fig. 2b, Table S1, http://links.lww.com/EJAIC/A109). Ten regions, Kalmar, Örebro, Västmanland, Blekinge, Halland, Gotland, Dalarna, Norrbotten, Jämtland Härjedalen och Västra Götaland, had an overall high completeness of ICU code registration (>80%). In six regions, Kronoberg, Skane, Uppsala, Värmland, Stockholm and Gävlebord, less than 20% of SIR entries had a matching ICU procedure code in the IPR. In regions with medium coverage of procedure codes (20 to 80%), the pandemic waves could still not explain the variation in missing ICU procedure codes (Fig. S1, http://links.lww.com/EJAIC/A109).

Regional differences in procedure codes

As the healthcare region was the main factor influencing the completeness of the procedure code for ICU admission, we also analysed regional differences in the use of procedure codes for mechanical ventilation and ECMO (Table 3). Overall, the use of mechanical ventilation codes were higher, and 13 of 21 regions had a high coherence rate (>80%). For ECMO, only five regions had cases registered and the majority of these (79/90) were from the Stockholm region, where 88.6% had the corresponding procedure code in the IPR.

Procedure code dates

Each procedure code in the IPR is registered with a corresponding date that the procedure/intervention was performed. For the entries with a matching ICU code in the IPR, we compared the dates of the ICU procedure code with the admission date in SIR. We found that for 2759 cases (55.5%) the date matched with the date for admission (Table 4). For the cases where the date of admission to ICU in the IPR did not match the procedure date in the IPR, the dates were instead most often the same as the date of admission to hospital (1458, 29.3%) or the date of discharge from the ICU (329, 6.6%).

Discussion

In our study, we identified major under-reporting of the procedure code for ICU admissions in the Swedish IPR, while the reporting of procedure codes for mechanical ventilation and ECMO had a higher degree of completeness. The differences in reporting the ICU admission procedure code varied greatly with hospital region, and was not dependent on different Covid-19 pandemic phases nor at what time of the day the patient was

Table 3 Number of admissions with the corresponding procedure code in IPR for ICU admission, mechanical ventilation and ECMO in each healthcare region

Hospital region	All $n = 11\,604$	MV $n = 7458$	ECMO $n = 90$
Blekinge	104 (95.4)	47 (95.9)	
Dalarna	233 (89.6)	198 (90.0)	
Gävleborg	66 (18.5)	47 (18.5)	
Gotland	44 (91.7)	6 (31.6)	
Halland	249 (94.3)	110 (81.5)	
Jämtland Härjedalen	84 (86.6)	46 (75.4)	
Jönköpings län	186 (41.2)	145 (42.5)	
Kalmar län	157 (96.9)	81 (97.6)	
Kronoberg	1 (0.6)	68 (93.2)	
Norrbotten	317 (87.3)	165 (67.1)	<3
Örebro län	356 (96.7)	239 (95.6)	
Östergötland	240 (50.4)	290 (90.3)	
Skåne	50 (4.9)	627 (84.2)	< 3
Sörmland	210 (41.0)	303 (85.4)	4 (100.0)
Stockholm	478 (15.4)	1438 (77.4)	79 (100.0)
Uppsala	30 (5.2)	109 (36.6)	< 3
Värmland	18 (8.5)	105 (85.4)	
Västerbotten	141 (48.0)	135 (73.8)	
Västernorrland	163 (64.4)	145 (91.8)	
Västmanland	174 (95.6)	102 (91.9)	
Västra Götaland	1947 (83.7)	1514 (91.0)	4 (100.0)

Data are presented as the percentage of all admissions with the correct code in each region provided in parentheses. MV represents SIR entries with a code for mechanical ventilation, excluding those with a code for ECMO.

Table 4 For ICU admissions with the corresponding procedure code in IPR, the registered date of the procedure code was evaluated

Date	ICU admissions with IPR procedure codes $n = 5248$
ICU admission	2759 (55.5)
ICU discharge	329 (6.6)
IPR admission	1458 (29.3)
IPR discharge	218 (4.4)
Other within ICU stay	60 (1.2)
Other within IPR stay	148 (3.0)
Other	2 (0.04)

Data are *n* (%). Priority was given in the order the dates as listed, e.g. if ICU admission and IPR admission occurred on the same day, ICU admission will be prioritised

registered in the ICU. These findings have important implications for the use of IPR procedure codes in research and suggests that data from additional registries, such as SIR, may be required when the aim includes judging the severity of a disease.

To our knowledge, there are no other whole-population nationwide studies validating the use of procedure codes regarding intensive care, mechanical ventilation and ECMO in Sweden or elsewhere. Two studies validating surgical procedure codes in the Swedish NPR for inflammatory bowel disease (IBD), and oesophageal cancer, reported both high sensitivity and PPVs (>90%).[5,6] However, it is worth noting that reporting of surgical procedure codes has been mandatory since 1993, while for nonsurgical procedure codes it has been mandatory only since 2007.

Mechanical ventilation procedure codes were evaluated in our study, where we compared the reporting of mechanical ventilation with SIR vs. final reporting of mechanical ventilation by the mother clinic to the inpatient registry in the medical discharge record. Using SIR as the gold standard (100% of known cases), we found that 78% of cases that received mechanical ventilation were reported by the mother clinic to the inpatient registry. Thus, the majority (but not all known cases) would be identified by using mechanical ventilation procedure codes in the inpatient registry for laboratory-verified SARS-CoV-2 infected patients. Whether this holds true for the general population or other infectious disease cohorts is unknown. Studies aiming to validate procedure codes for mechanical ventilation have been conducted regionally in both Canada and the USA.[7,8] A study in Manitoba, Canada, compared the Discharge Abstract Database with the Winnipeg ICU database and found that the procedure code registration for mechanical ventilation corresponded to over 90% of ICU admissions where mechanical ventilation was performed.[7] In contrast, a study analysing two large cohorts in the US found that only 46 and 38% of cases, respectively, had procedure codes for mechanical ventilation correctly registered in their medical charts.[8]

We saw very little difference in the use of procedure codes over the course of the pandemic, which suggests that the high strain put on the healthcare system during the pandemic peaks did not significantly influence the use of procedure codes. This was slightly unexpected given the challenges that the pandemic posed for healthcare workers.[9,10] This may suggest that our findings here, although specific for Covid-19 patients, could be applicable to other infectious and possibly noninfectious diseases during this time period. Interestingly, entries where the patient recovered had a slightly higher proportion of ICU codes in IPR compared to entries where the patient died. Although other factors analysed such as the time of ICU admittance, the type of referring clinic or ICU unit type were associated with data completeness, the variation for these factors remained smaller than those observed between regions.

The use of procedure codes varied greatly with healthcare region, from almost none of the ICU admissions having the corresponding code in some regions, to almost perfect reporting in the IPR for other regions. Internal evaluations of the IPR by the NBHW from 2022 mentions regional differences.[4] Although coherence rate could be high regionally for one procedure code, this did not guarantee a corresponding coherence rate for a different code. This was exemplified by the healthcare region Gotland that had a high coherence rate for ICU procedure codes, but medium coherence rate for mechanical ventilation codes. In contrast, Uppsala, Skåne and Kronoberg had a low coherence for ICU codes but high for mechanical ventilation codes. This clearly

suggests that different factors could be involved in determining practices for specific codes in some regions. Of note is that the individual ICU clinics are allowed to choose how the procedures are reported to the SIR (i.e. presence yes/no, duration and so on). Of the 84 ICUs, one did not report any respiratory-related procedures during the study period. Further studies are required to determine the cause of under-reporting and what would be the best strategy to improve the registration of procedure codes.

Every IPR procedure code has a connected date when the procedure was performed (e.g. ICU admission date). These dates would be a valuable source of data when studying the timing of events necessitating procedures. For the IPR entries that had a procedure code for ICU (less than half), according to SIR, only half of these had the correct corresponding procedure date for ICU admission. Thus, only 25% of entries in the IPR had correct data regarding ICU and ICU admission date. The remaining dates for the ICU procedure date were most often the date of admission to hospital or date of discharge.

We focused specifically on Covid-19, including only laboratory-verified SARS-CoV-2 infections registered by the public health agency of Sweden through SmiNet, a registry for all notifiable diseases in Sweden. However, undiagnosed COVID-19 cases will not have been included, which represents a limitation of our study. Focusing exclusively on COVID-19 patients introduces another limitation when evaluating the presence of false positives in the IPR, that is entries with an ICU code in IPR but not registered in SIR. We restricted this to IPR entries with a laboratory-confirmed SARS-CoV-2 infection around the time of their IP admission. However, this approach may overlook entries where the patient contracted the infection during a prolonged hospital stay. In addition, it could lead to misclassification of an entry as a false positive if extended time passed between the laboratory confirmation/IP admission and SIR admission. Lastly, the quality of data in our reference registry, SIR, poses another potential limitation. However, SIR is a comprehensive national quality registry that provides detailed clinical information on patients admitted to ICUs across Sweden,[11] and serves as a relevant reference for comparisons.

In this study, we conclude that the completeness of procedure codes in the IPR as a source of data regarding ICU is low, but higher for the procedure codes for mechanical ventilation and ECMO. Although several factors were associated with data completeness, the geographic region showed the largest impact on low reporting of ICU procedure codes, indicating that regional practices at the clinics determines what is reported. When performing studies including ICU admission as an indicator of severity for Covid-19 outcomes, or possibly other diseases, the IPR is inadequate and requires supplementation of data from the SIR.

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