Data-driven methods to improve quality assessment of intensive care units
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Chapter 2: Reliability of In-hospital Mortality as a Quality Indicator in Clinical Quality Registries. A Case Study in an Intensive Care Quality Register

Antonie Koetsier, Niels Peek, Evert de Jonge, Dave A. Dongelmans, Giel van Berkel, Nicolette F. de Keizer

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2.1 Abstract

2.1.1 Objectives: Errors in the registration or extraction of patient outcome data, such as in-hospital mortality, may lower the reliability of the quality indicator that uses this (partly) incorrect data. Our aim was to measure the reliability of in-hospital mortality registration in the Dutch National Intensive Care Evaluation (NICE) registry.

2.1.2 Methods: We linked data of the NICE registry with an insurance claims database, resulting in a list of discrepancies in in-hospital mortality. Eleven Intensive Care Units (ICUs) were visited where local data sources were investigated to find the true in-hospital mortality status of the discrepancies and to identify the causes of the data errors in the NICE registry. Original and corrected Standardized Mortality Ratios (SMRs) were calculated to determine if conclusions about quality of care changed compared to the national benchmark.

2.1.3 Results: In eleven ICUs, 23,855 records with 460 discrepancies were identified of which 255 discrepancies (1.1% of all linked records) were due to incorrect in-hospital mortality registration in the NICE registry. Two programming errors in computer software of six ICUs caused 78% of errors, the remainder was caused by manual transcription errors and failure to record patient outcomes. For one ICU the performance became concordant with the national benchmark after correction, instead of being better.

2.1.4 Conclusions: The reliability of in-hospital mortality registration in the NICE registry was good. This was reflected by the low number of data errors and by the fact that conclusions about the quality of care were only affected for one ICU due to systematic data errors. We recommend that registries frequently verify the software used in the registration process, and compare mortality data with an external source to assure consistent quality of data.
2.2 Introduction

Many clinical registries have been set up to assess and improve the quality of care. Clinical registries often encompass certain patient outcomes, such as in-hospital mortality of patients with a certain disease or from a specific department in a hospital. These registries [1-4] are often cross sectional, the patient outcome is measured at the end of the hospitalized period and not necessarily recorded by the department which treated the patient initially. Thus, the measured patient outcome can come from different (data) sources and departments. As a consequence, patient outcome registration is vulnerable to data errors. The recorded patient outcome data is used to construct a quality indicator, a measure to determine an institution’s or department’s quality of care. A prerequisite to use a quality indicator is that the quality of the data used is high [5]. High quality of data is defined as fit for their intended use in operations, decision making and planning [6]. Errors in the registration or extraction of patient outcome data may lower the reliability of the quality indicator that uses this (partly) incorrect data [7].

An example of a clinical registry using the patient outcome in-hospital mortality is the Dutch National Intensive Care Evaluation (NICE) registry [1]. This clinical registry was founded to provide insight into the effectiveness and efficiency of Dutch intensive care units (ICUs) where in-hospital mortality is the most important patient outcome. Currently, 81 ICUs covering 90% of all Dutch ICUs participate in the NICE registry. In the NICE registry, in-hospital mortality is, just as in other registries, the most frequently used quality indicator and incorporated in for example the Standardized Mortality Ratio (SMR), control charts, and the Variable Life Adjusted display. ICUs receive their SMR in annual reports and are used for benchmarking. If the SMR for an individual ICU is statistically significant higher than the national benchmark (above one), the ICU is triggered to take action to improve their quality. Therefore, we define the registration of in-hospital mortality as reliable when the conclusion of the SMR does not impose the opposite (statistically significant higher or lower than the national benchmark) after correction for errors in in-hospital mortality.

Recently, it became possible to link the NICE registry to a national administrative database which includes mortality of almost all Dutch citizens based on healthcare insurance claims. Therefore, we were able to answer our research question: What is the reliability of in-hospital mortality data in the NICE registry? The objectives of this study were to assess in the NICE registry (i) the types of errors in in-hospital mortality registration (ii) the causes of the errors made, and (iii) the influence of data errors (incorrect in-hospital mortality registration) on the reliability of in-hospital mortality as a quality indicator.
2.3 Methods

2.3.1 In-hospital mortality registration in NICE registry

The NICE registry collects severity of illness data from the first 24 hours that patients are admitted to the ICU, including physiological and diagnostic information. Furthermore, length of stay, and mortality data are collected. Participants of the NICE registry use either a Patient Data Management System (PDMS) which can be considered as an electronic medical record or they use a Paper based Medical Record (PMR) in which the data is manually transcribed from the PMR into the electronic data entry module (DEM) system. If there is no automatic linkage with a Hospital Information System (HIS) or laboratory system, staff also need to manually enter these data into the DEM. A specific data extraction algorithm (DEA) extracts the data from either a PDMS or DEM into a dataset, including discharge date and in-hospital mortality, which is to be sent to the NICE registry.

Figure 1 presents a flow chart showing an example of a patient who after ICU discharge died at the nursing department. The flow chart shows how the in-hospital mortality and discharge date is registered at an ICU using either a PDMS or DEM and subsequently registered at the NICE registry.
Figure 1. In-hospital mortality and discharge date registration of a patient who after ICU discharge died at the nursing department. A rounded rectangle means that the action is automatically performed by the system, regular rectangles are manual actions performed by the user of the system, and circles indicate what ICU/hospital discharge and mortality data is recorded in the corresponding system or registry. ICU, Intensive Care Unit; HIS, Hospital Information System; PDMS, Patient Data Management System; DEM, Data Entry Module; DEA, Data Extraction Algorithm; HL7, Health Level Seven messaging standard.

The hospital discharge date and destination (mortuary) forms the basis of the in-hospital mortality, which can differ from the ICU discharge date and destination. For ICUs, retrieving the correct hospital discharge date may prove difficult, but this is simplified by integration between the HIS and the ICU systems (such as the PDMS and DEA) through Health Level Seven v.3 (HL7) messaging standard connection [8]. In the case of no HL7 connection, the information retrieval of hospital discharge date and destination is handled manually. The ICU and hospital discharge destination ‘mortuary’ will result in the mortality data item being registered as ‘dead’, all other destinations including failure to record result in the value ‘alive’. As soon as a patient is discharged from the ICU, it exists in the dataset generated by the DEA using data from either the PDMS or DEM and is sent to the NICE registry. At the time of hospital discharge (either dead or alive) an update of the record is sent from the HIS to the PDMS or DEM and extracted into a new dataset.

<table>
<thead>
<tr>
<th>Patient flow</th>
<th>HIS</th>
<th>PDMS/DEM ICU</th>
<th>DEA</th>
<th>NICE Registry</th>
</tr>
</thead>
<tbody>
<tr>
<td>Admitted to hospital (nursing department)</td>
<td>1. Administrative staff enters patient in system</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Admitted to ICU (Discharged from nursing department)</td>
<td>2. ICU staff enter patient in system</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discharged from ICU (admitted to nursing department)</td>
<td>3. ICU staff enter ICU discharge destination</td>
<td>4. Dataset generation initiated by ICU staff</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital discharge destination = nursing department</td>
<td>ICU discharge destination = nursing department</td>
<td>ICU discharge destination = nursing department</td>
<td>5. If dataset is sent → ICU mortality = 0 , in-hospital mortality = 0 If dataset is not sent → record does not exist</td>
<td></td>
</tr>
<tr>
<td>Patient died at nursing department</td>
<td>6. Staff from treating department enter hospital discharge date and destination</td>
<td>7a. Hospital discharge date and destination copied into system by HL7 connection</td>
<td>7b. Hospital discharge date and destination entered manually into system</td>
<td>8. Dataset generation with update of record initiated by ICU staff</td>
</tr>
<tr>
<td>Hospital discharge destination = mortuary</td>
<td></td>
<td>Hospital discharge destination = mortuary, in-hospital mortality = 1</td>
<td>Hospital discharge destination = mortuary, in-hospital mortality = 1</td>
<td>9. If dataset is sent → in-hospital mortality = 1 If dataset is not sent → in-hospital mortality = 0</td>
</tr>
</tbody>
</table>
2.3.2 Mortality registration in the administrative database

We used an administrative insurance claims database that consists of health insurance companies’ client information covering 95% (in 2008) of the Dutch insured population and includes among others mortality and date of death. In the Netherlands, health care insurance is obligatory. Per quarter, for each insured patient, the number of active or insured days is registered in the insurance database as well as the period of hospitalization or ICU admission days for which reimbursement is claimed. The date of death is determined using the date and reason of cessation of the insurance. The pathway to register mortality and date of death differs from the NICE registry. Relatives of the deceased patient are obliged to send an official death confirmation letter (provided by the general practitioner) to the insurance company.

2.3.3 Linking NICE registry to the administrative database

Data from the NICE registry were linked to the administrative database on a record-by-record basis for the years 2006-2009. The linkage was performed by a third party, which only does deterministic linkage. Record linkage was based on hospital admission date, ICU admission date, ICU discharge date, date of birth and gender using deterministic linkage. In deterministic linkage all linking variables have to agree to consider it as a true pair [8]. We distinguished three types of discrepancy categories between the mortality of both sources: (i) under registration of mortality in the NICE registry, according to the NICE registry the patient did not die but the administrative database stated that the patient died during the hospitalized period, (ii) different date of death, according to the NICE registry the patient died and the administrative database stated that the patient also died during the hospitalized period but on a different date, and (iii) excess registration of mortality in the NICE registry, according to the NICE registry the patient died but the administrative database stated that the patient did not die during the hospitalized period. For each ICU we generated a list of records with the above described discrepancies.

The NICE registry is officially registered according to the Dutch Personal Data Protection Act. All patient identification data, such as name and patient number, have been removed. In the Netherlands, there is no need to obtain consent to make use of registries without patient identifying information.

2.3.4 Discrepancies in in-hospital mortality

To determine the number, types and causes of errors in the NICE registry one of the researchers (AK) performed site visits at a selection of ICUs and checked together with the responsible physician the generated list of discrepancies on behalf of the treating physician. For each discrepancy found, if and when the corresponding patient died in the hospital was determined, re-abstracting mortality data from the following information sources: PDMS or DEM, HIS, and discharge letter(s). We also checked whether there were hospital visits after
hospital discharge, indicating that the patient was discharged alive. To be able to find different types of errors made in in-hospital mortality registration, we wanted at least one ICU in each strata: hospital type (university, teaching, general), data collection method (PMR, PDMS), and percentage of discrepancies (small, normal, high). For each strata we selected ICUs based on willingness to participate.

When a discrepancy between the NICE in-hospital mortality and one of the information sources was found, the in-hospital mortality of the source was regarded as the true in-hospital mortality, but only if the discharge letter recorded the same. If all sources in the hospital (PDMS or DEM, HIS, and discharge letters) showed that the NICE in-hospital mortality was correct, the discrepancy was attributed to the administrative database. However, due to privacy reasons we were not able to assess data errors of the administrative database. Additional ICUs were visited until no new types and causes of data errors in the current ICU compared to all previous ICUs were found.

### 2.3.5 Types of data errors

We distinguished three types of data errors regarding in-hospital mortality registration, using the same terminology as Arts et al.[9]: errors in computer software, manual transcription errors by care professionals, and failure to record outcome data by care professionals. Errors in computer software can be divided into: errors in the HL7 connection transferring data between different systems, and errors in the DEA extracting data into a dataset for the NICE registry. Manual transcription errors concern incorrect entry of the ICU/hospital discharge destination into the PDMS or DEM, or entering an incorrect hospital discharge date into the HIS. When ICU/hospital discharge destination was not entered into the PDMS, DEM, or HIS by the responsible staff we classified this as 'failure to record outcome data'.

### 2.3.6 Reliability of in-hospital mortality as a quality indicator

The ICU population is heterogeneous, i.e. patients have different diagnostic and physiological characteristics. Therefore, to be able to use in-hospital mortality as an objective and valid quality indicator for quality of ICU care, case mix correction is necessary. With case mix correction, the SMR can be calculated: the ratio of the observed and expected number of deaths, where the expectation is based on the severity of illness of the admitted patients as quantified by a case mix adjustment model such as the Simplified Acute Physiology Score II (SAPS II) [10]. Variables used to calculate the expected mortality in the SAPS II model are: age, heart rate, systolic blood pressure, temperature, mechanically ventilated, PaO2, FiO2, urine output, blood urea nitrogen, white blood cells, potassium, sodium, bicarbonate, bilirubin, glasgow coma score, metastatic cancer, hematologic malignancy, AIDS, and type of admission. The SMR gives an indication of the quality of care but its usefulness depends on the validity of the case mix adjustment model [11] and the reliability of the registration of the observed mortality. If the model is well
recalibrated, an SMR with the 95% confidence interval (95% CI) above one indicates that, compared to the national benchmark, an ICU has more deaths than expected, whereas below one means that there are fewer deaths than expected.

To test the reliability of in-hospital mortality registration, we distinguished four scenarios that could occur after correcting for errors in in-hospital mortality based on the SMR and 95% CI in relation to the national benchmark: (i) the position of the SMR and its 95% CI changed when comparing it to the national benchmark in the sense that there was a statistically significant change in SMRs before and after correction and opposite conclusions about the quality of care, (ii) there was a significant change in SMRs before and after correction, and the difference with the national benchmark changed from statistically significant to not statistically significant or vice versa but not leading to opposite conclusions about care quality, (iii) there was a significant change in SMRs before and after correction but there was no change in the position of the SMR and its 95% CI when comparing it to the national benchmark and hence the same conclusions with respect to care quality apply, and (iv) there was no statistically significant change in SMRs before and after the correction.

We first recalibrated the SAPS II model using first level recalibration [12] so that the SMR of all data together (the national SMR) was equal to one. To perform first level recalibration, we refitted a new logistic regression model with the in-hospital mortality as dependent variable and the logit-transformed original expected mortality as the sole independent variable. The first and second scenario were answered by plotting the NICE registry SMR and the onsite visit corrected SMR, thereby visually investigating how many times each scenario occurred. To test if there was a significant change in SMRs before and after correction and to answer if the third scenario was applicable, we calculated NICE registry and onsite visit corrected SMRs for each ICU using 1000 bootstrap samples [13]. We calculated the difference between both SMRs and determined the corresponding 95% CI of these differences, represented by the 2.5 and 97.5 percentile of the differences. If the value zero (implying no difference) was not contained in the 95% CI, we concluded that there was a statistically significant difference between the NICE registry SMR and the onsite visit corrected SMR.

2.4 Results

2.4.1 Discrepancies in in-hospital mortality

In the period 2006-2009 the NICE registry consisted of 260,789 records from 72 ICUs. All ICUs were linked to the administrative database with a total of 205,621 records (78.8%), see figure 2.
The unlinked records had an ICU mortality of 5.7% (11.0% for linked records), in-hospital mortality of 9.0% (16.9% for linked records), 40.5% cardiac surgery patients (14.8% for linked records), and a median SAPS II score of 28 (31 for linked records, implying a higher severity of illness). These differences between the linked and unlinked records were statistically significant (based on a p-value <0.05). The linkage resulted in the detection of 2,746 records with discrepancies (1.9% of all linked records) for 72 ICUs, where the range of discrepancies was 0.4%-7.5% of the records. The difference between in-hospital mortality of the NICE registry and the administrative database ranged from 5.2% higher in-hospital mortality according to the administrative database and 6.7% higher in-hospital mortality according to the NICE registry, with a mean of 1.2% and a mean absolute difference of 1.6%.

Eleven ICUs were visited before saturation on newly found types and causes of data errors was reached. One ICU was in the transition phase from PMR to PDMS and used an in-house developed DEA. Eight ICUs used a PMR in combination with the DEA, two others used a fully implemented PDMS. All ICUs except one had an HL7 connection interface. For that ICU the HL7 connection interface was temporarily missing; the hospital discharge date and destination were manually entered into the PDMS. Six hospitals were university-affiliated/teaching, while the others were general non-teaching hospitals.

For the eleven ICUs visited, 23,855 records were linked (73.3%) including 460 (1.9%) discrepancies (see Table 1). The range of discrepancies was 0.8%-7.5%. A minority (3.0%, n=14) of the 460 discrepancies could be explained by the fact that the patients were discharged from the hospital to another hospital/location and died that same day. According to the NICE registry these patients did not die that day in the hospital, while the administrative database stated that they died that day. Both registries were correct although a discrepancy was found.
Table 1. Quantitative overview of the sources and error categories of the discrepancies (n=460).

<table>
<thead>
<tr>
<th>Source of error</th>
<th>Error category</th>
<th>N (% of linked records)</th>
<th>% of all errors</th>
</tr>
</thead>
<tbody>
<tr>
<td>NICE Registry</td>
<td>Under registration of mortality</td>
<td>237 (1.0%)</td>
<td>51.5%</td>
</tr>
<tr>
<td>NICE Registry</td>
<td>Different date of death</td>
<td>4 (&lt;0.1%)</td>
<td>0.9%</td>
</tr>
<tr>
<td>NICE Registry</td>
<td>Excess registration of mortality</td>
<td>14 (&lt;0.1%)</td>
<td>3.0%</td>
</tr>
<tr>
<td>Patient died same day in other hospital</td>
<td>Not applicable</td>
<td>14 (&lt;0.1%)</td>
<td>3.0%</td>
</tr>
<tr>
<td>Insurance claims database</td>
<td>Under registration of mortality</td>
<td>126 (0.5%)</td>
<td>27.4%</td>
</tr>
<tr>
<td>Insurance claims database</td>
<td>Different date of death</td>
<td>63 (0.3%)</td>
<td>13.7%</td>
</tr>
<tr>
<td>Insurance claims database</td>
<td>Excess registration of mortality</td>
<td>2 (&lt;0.1%)</td>
<td>0.4%</td>
</tr>
</tbody>
</table>

2.4.2 Types of data errors

The remainder of the discrepancies (n=446) were data errors of the NICE registry (57.2%, n=255, 1.1% of 23,855 records) or of the administrative database (42.8%, n=191) as is shown in Table 1. Most data errors in the NICE registry concerned under registration of mortality (92.9%, n=237).

Table 2 shows the different types of data errors found, where most data errors were due to two types of errors in computer software, residing in six different ICUs (78.1%, n=199). The error in the DEA preventing correct linkage between the HL7 messages from the HIS to the PDMS or DEM caused most errors (n=172). The HL7 discharge destination ‘mortuary’ was not recognized by the DEA and consequently the hospital discharge destination was not registered in the dataset that is sent to the NICE registry, see step 7a to step 8 in figure 1. All patients that died in the hospital after ICU stay were thus falsely registered as discharged alive, consequently the post ICU in-hospital mortality was 0%. The 27 remaining errors in computer software were caused by a second error in the DEA causing revised hospital discharge destinations not being exported to new datasets, see step 7b to step 8 in figure 1. The post ICU in-hospital mortality was also 0%. Both errors in computer software were caused by a software update.

A total of 34 (13.3%) manual transcription errors were found. For 19 of the manual transcription errors the ICU discharge destination was incorrectly coded by ICU staff in the DEM (step 3 in figure 1) and eleven manual transcription errors were caused by incorrect manual entry of hospital discharge destination into the PDMS due to absence of an HL7 connection to the HIS (step 7b in figure 1). In all cases, the discharge destination...
selected from a dropdown list was above or below the correct value. The four remaining manual transcription errors were due to an incorrect date of death entered into the HIS, the date of dying was set after the hospitalized period and these patients were falsely registered as alive (step 6 in figure 1).

Failure to record outcome data occurred the least. ICUs did not enter the ICU discharge destination into either the DEM or PDMS in 22 cases (8.6%), which resulted in patients registered as alive even though their discharge destination should have been ‘mortuary’ (step 3 figure 1).
Table 2. Qualitative overview of the types of data errors made in the NICE registry. ICU, Intensive Care Unit; HIS, Hospital Information System; DEM, Data Entry Module; DEA, Data Extraction Algorithm; HL7, Health Level Seven messaging standard.

<table>
<thead>
<tr>
<th>Type of data error</th>
<th>Cause of data error</th>
<th>no. (%)</th>
<th>Source with other value</th>
<th>no. of ICUs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Error in computer software</td>
<td>DEA: HL7 message not recognized: hospital discharge destination not registered, should be mortuary</td>
<td>172 (67.4%)</td>
<td>HIS</td>
<td>5</td>
</tr>
<tr>
<td>Error in computer software</td>
<td>DEA: Update of hospital discharge destination not entered in dataset, should be mortuary</td>
<td>27 (10.6%)</td>
<td>DEM</td>
<td>2</td>
</tr>
<tr>
<td>Manual transcription error</td>
<td>Incorrect ICU discharge destination: not mortuary while died</td>
<td>9 (3.5%)</td>
<td>HIS</td>
<td>6</td>
</tr>
<tr>
<td>Manual transcription error</td>
<td>Incorrect ICU discharge destination: mortuary while alive</td>
<td>10 (3.9%)</td>
<td>HIS</td>
<td>6</td>
</tr>
<tr>
<td>Manual transcription error</td>
<td>Incorrect hospital discharge destination: mortuary while alive</td>
<td>4 (1.6%)</td>
<td>HIS</td>
<td>1</td>
</tr>
<tr>
<td>Manual transcription error</td>
<td>Incorrect hospital discharge destination: not mortuary while died</td>
<td>7 (2.7%)</td>
<td>HIS</td>
<td>1</td>
</tr>
<tr>
<td>Manual transcription error</td>
<td>Incorrect date of death in HIS: registered as alive while died</td>
<td>4 (1.6%)</td>
<td>Discharge letters</td>
<td>2</td>
</tr>
<tr>
<td>Failure to record outcome data</td>
<td>ICU discharge destination not registered, should be mortuary</td>
<td>22 (8.6%)</td>
<td>HIS</td>
<td>4</td>
</tr>
</tbody>
</table>
2.4.3 Reliability of in-hospital mortality as a quality indicator

Figure 3 shows the recalibrated SAPS II SMRs according to the NICE registry and the onsite visit corrected SMR and table 3 shows the number of times each of the three possible scenarios occurred. The first scenario, a statistically significant difference of the SMR before and after correction when comparing it to the national benchmark, and opposite conclusions about the quality of care, never occurred. For ICU 9, the second scenario occurred: while there was a statistically significant difference with the national benchmark before the correction, this difference became smaller and was no longer significant thereafter. The third scenario occurred for four ICUs: ICU 2, ICU 5, ICU 6, and ICU 11. In this scenario, the SMRs before and after correction differ significantly according to the bootstrap method but the conclusions about care quality remain exactly the same. For the six other ICUs, the fourth scenario was applicable, meaning that there was no significant change in the SMRs before and after correction.

![SAPS II SMR of the NICE registry and onsite visit corrected](image)

Figure 3. NICE Registry recalibrated SAPS II SMR and the onsite visit corrected recalibrated SAPS II SMR. ICU, Intensive Care Unit; SMR, Standardized Mortality Ratio; SAPS II, Simplified Acute Physiology Score II.
Table 3. Different scenarios of how the conclusion of the Standardized Mortality Ratio (SMR) about quality of care compared to the national benchmark changed after correction for errors in in-hospital mortality.

<table>
<thead>
<tr>
<th>Scenario</th>
<th>Number of ICUs where scenario occurred</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scenario i – statistically significant different conclusion</td>
<td>0</td>
</tr>
<tr>
<td>Scenario ii – conclusion not statistically significant different anymore</td>
<td>1</td>
</tr>
<tr>
<td>Scenario iii – SMRs differ statistically significant but not a different conclusion (bootstrap method)</td>
<td>4</td>
</tr>
<tr>
<td>Scenario iv – no statistically significant change in SMRs before and after the correction</td>
<td>6</td>
</tr>
</tbody>
</table>

2.5 Discussion

2.5.1 Summary of main findings

Incorrect in-hospital mortality registration occurred in 1.1% of the records in the NICE registry. Almost 80% of the errors in in-hospital mortality registration in the NICE registry concerned two programming errors in the DEA caused by a software update, which could easily be resolved once detected. There was a statistically significant difference between the NICE registry SMR and onsite visit corrected SMR for five ICUs. For one of these ICUs the conclusion about the quality of care changed from statistically significant different from the national benchmark to not statistically significant. For the six remaining ICUs, there was no difference between the NICE registry SMR and onsite visit corrected SMR and consequently no other conclusion about the quality of care.

2.5.2 Reflection of findings toward existing literature

Other studies have investigated the percentage of errors in (in-hospital) mortality registration using two different strategies to obtain the researched data, either with linkage or a (random) subset of the data. Three studies [14-16] linked data of a registry with another database consisting of the mortality status and date. Two studies [14;15] used a national (death) database and one [16] linked the data with the administrative database of the hospital where registration for the registry also occurred. The studies had a linkage percentage between 70.2% and 95.8%. Linkage using a national identification number was done by Ji. Et al [14], while deterministic linkage has been performed by Koek et al. [15], and probabilistic linkage by Wynn et al. [16]. The percentage of errors in mortality registration was 20.2% and 15.5% for the Swedish cancer registry [14], 0.2%-0.6% for
acute myocardial infarction patients in the Dutch national hospital discharge registry [15], and 0.5% for a United States hospital trauma registry [16]. Only one study reported the type of error, which was underreporting of mortality in the registry [16].

Four studies [17-20] did not link their data but performed onsite visits or a variation of that, of which one checked all the records of one specific year, the others checked a (random) subset of the data. Three studies performed onsite visits [17;19;20] and one study [18] selected all alive patients at a certain date and verified this by contacting the municipal offices of the patients. The percentage of errors in mortality was 0.9% for the Tyrol (Austria) cancer registry [18], 2.0% for the Swedish heart surgery registry [19], and 8.0% for the United Kingdom cystic fibrosis registry [20]. In the study of Datta et al. [17] no errors were found in the Alberta trauma registry (Canada). Only the study of Oberaigner et al. [18] described the type of error, nine deaths were underreported and for five these the cause of underreporting was mentioned. When compared to the previously mentioned studies, we found 1.1% error in in-hospital mortality. Our study was the only one that performed linkage with a third party insurance claims database to investigate in an efficient way the types and causes of all errors, and to assess the effect on the reliability of mortality as a quality indicator. The percentage of errors was very different for all aforementioned studies, possibly due to the different methods used or types of registries. Future research should investigate what is causing these large differences.

2.5.3 Strength/limitations of study

A strength of our study is that we were able to link a national administrative insurance claims database to a critical care registry. With this linkage, we generated a list of discrepancies in in-hospital mortality, i.e. records that had a high chance of having incorrect mortality registration, allowing us, compared to a random-sample selection of the records, to more efficiently detect almost all errors in the registry by performing onsite visits and find causes for these errors. Since health insurance is compulsory in the Netherlands, almost every Dutch citizen is present in the administrative database. However, a few insurance companies are not yet present in this registry and uninsured citizens (less than 0.8%) are not present in the insurance database. Another strength is that we performed site visits and were able to thoroughly assess all used information sources in the hospital. As a result we could determine whether a data error occurred in the NICE registry and what the exact type and cause of the error was. This can help in improving the process of data collection in the future. Furthermore, we used the SMR as a measure to assess whether the data errors present in the NICE registry influenced the reliability of in-hospital mortality as a quality indicator. A limitation of our study is that only 78.8% of ICU admission records in the NICE registry could be linked to the records in the administrative database, and that there were significant differences in clinical characteristics of linked and unlinked admissions. Linked admissions were more often medical ICU patients as opposed to non-linked admissions and therefore more severely ill at the time of ICU admission, as reflected by higher SAPS II scores. We believe that our results are not influenced by our linkage rate, because the same
ICUs existed in both the linked and unlinked dataset implying no organizational differences between both datasets. Furthermore, we believe that most unlinked records were not due to registration errors in the NICE registry but a result of organizational aspects of the administrative registry. Some insurance company did not take part in the administrative registry, or had startup problems with the registration itself. Additionally, for the ICU transplant and cardiac surgery population declaration to the insurance companies is not by number of days stayed at an ICU, but by the type of intervention. Therefore, deterministic linkage of these patients using the period that they were at the ICU is more difficult and has a higher chance of non-linkage.

Our linkage rate may have improved if we would have performed probabilistic linkage instead of deterministic. However, the linkage could only be performed by a third party, which only does deterministic linkage. Furthermore, we did not investigate if discrepancies that were attributed to the administrative database were real data errors, but this was also not possible due to privacy regulations. We did not check the unlinked records of the NICE registry for incorrect mortality registration, and assumed that the absence of a discrepancy implied that there was no incorrect in-hospital mortality registration in the NICE registry. Additionally, we were not able to discover if ICU records were missing in the NICE registry with our methods and also could not estimate the likelihood. These missing records could have an impact on an ICU’s SMR.

Our scope was limited to the data quality of only in-hospital mortality in the NICE registry. Arts et al. [9] investigated the number of errors in all variables registered for the NICE registry by performing site visits, but only for a random selection of the data which is a less effective and efficient method than ours. A last limitation is that our selected ICUs were non-randomly selected, possibly biasing our results.

2.5.4 Implications of the study

Our results show that clinical registries registering cross sectional patient outcomes, such as (in-hospital) mortality, should be aware of the existing data errors and how they occur. Data from participants stemming from automated systems does not imply good quality of data per se. If errors in computer software are present, a high number of data errors can occur. These errors are, once detected, more easily preventable as opposed to manual transcription errors.

Remarkably, most data errors (78.1%) were due to malfunctioning of software causing incorrect data extraction and consequently a post ICU in-hospital mortality of 0% over a given time period. We therefore advise registries aiming to prevent errors in (in-hospital) mortality registration to regularly test possible malfunctioning of software used by participants. The field of Software Engineering [21;22] provides several methods to investigate software quality by systematically testing whether pieces of computer code perform what they were specified to do. Additionally, one can monitor whether post ICU in-hospital mortality is zero for a given time period. Currently, at the involved ICUs causes of the errors in the computer software have been solved by a new software update. As a
result, these errors in computer software do not occur again. Recently performed linkage with the administrative database of the year 2010 showed that the number of discrepancies reduced from 1.9% during the study period (2006-2009) to 1.4% discrepancies in 2010. We expect that this difference is due to a decrease in the number of errors is in the NICE registry.

As we showed in this study, some participants did not notice that they actually registered a patient as deceased due to wrongly selecting the discharge destination ‘mortuary’ or registering a patient as alive by not entering a discharge destination. Therefore, we propose that besides the discharge destination, participants need to explicitly register the mortality. Within the registry, these two variables can be checked for discrepancies.

In the NICE registry general site visits are regularly performed, thereby assessing the data quality of all registered variables, by re-abstracting a random sample of the records. Between 2010 and 2011 site visits were performed at 48 different ICUs thereby checking 903 records. Only four errors in mortality registration were found (<0.01%) without investigating the possible causes, indicating that this method alone is not effective in finding errors in mortality.

In only a few countries it is possible to link clinical registries to a national death registry using a national identification number [23-26]. Having this linkage would allow a higher percentage of linked records and even a better investigation of errors in in-hospital mortality. Other registries not having the possibility to link their data to a national death registry ought to consider using an independent data source such as an insurance claims database.

2.6 Conclusion

In-hospital mortality registration in the NICE registry is reliable, represented by the low number of discrepancies with the administrative database, and the low number of data errors presented after performing the site visits. The corrected mortalities resulted in significant differences with regard to the SMR for five ICUs. This lead to a different conclusion about the quality of care in relation to the national benchmark for one ICU. Errors of that specific ICU were systematic due to a failure in the interoperability between the DEA and the HIS. Therefore, caution is necessary when interpreting mortality data from registries where there is not sufficient quality assurance. Registries need frequent data assurance efforts to keep adequate data quality and to identify systematic errors. The data assurance efforts should not consist of only random checking of the data, as this is insufficient to find all errors in in-hospital mortality. Preferably, automatic checks should be developed in both the hospitals’ and registries’ software which test that the mortality in a given time period cannot be zero in order to timely identify possible problems in interoperability between software applications.

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2.7 References


