**Data Resource Profile**

**Data Resource Profile: the Dutch National Intensive Care Evaluation (NICE) Registry of Admissions to Adult Intensive Care Units**

Nick van de Klundert,1,2 Rebecca Holman,1,2* Dave A. Dongelmans1,3 and Nicolette F. de Keizer1,2

1National Intensive Care Evaluation (NICE) Foundation, Amsterdam, The Netherlands, 2Department of Medical Informatics, Academic Medical Center, Amsterdam, The Netherlands, 3Department of Intensive Care, Academic Medical Center, Amsterdam, The Netherlands

*Corresponding author. Department of Medical Informatics, Academic Medical Center, PO Box 22660, 1100 DD Amsterdam, The Netherlands. E-mail: r.holman@amc.uva.nl.

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Why was the Netherlands Intensive Care Evaluation registry set up?

Patients admitted to intensive care units are seriously ill, require very frequent or continuous monitoring, generally have abnormal physiological parameters and are often in need of vital organ support and replacement. As a group, they have a substantial probability of dying during their hospital stay1-3 and within 12 months of discharge.4,5 There are substantial differences in duration of stay and in-hospital crude and standardized mortality rates between intensive care units,1,6 in patient groups based on diagnosis group2 and in referring specialism.6 This means it is important to appraise and seek to improve the quality of intensive care, to ensure that patients receive optimal intensive care.3

In 1996, a group of intensive care medical specialists launched the Dutch National Intensive Care Evaluation (NICE) foundation. The NICE foundation facilitates a registry to enable participating intensive care units to quantify and improve the quality of care they offer.7 The NICE foundation offers intensive care units feedback and benchmarking on patient outcomes, including mortality,6 and allows them to compare their outcomes with those achieved nationally and by groups of similar hospitals. The foundation provides each participating intensive care unit with biannual quality reports and access to an online tool enabling each intensive care unit to perform additional analyses on their data at any time.8 It also publishes two magazines each year with features based on analyses of registry data, and organizes a national conference to enable medical and nursing specialists to meet and discuss their own and national results. In addition, the foundation collects data to enable quality indicators developed by the Netherlands Society of Intensive Care to be calculated.

Each intensive care unit participating in the NICE registry pays the NICE foundation an annual fee. The Department of Medical Informatics of the Academic Medical Center, Amsterdam, processes data, monitors data quality, reports back to intensive care units on quality indicators and performs additional analyses on the data in the registry on behalf of the NICE foundation. The data in the NICE registry are collected in the course of normal clinical practice and no directly identifying variables are recorded. As such, according to Dutch national law, neither informed consent nor approval of a medical ethical review board are required when using these data to measure or improve the quality of care offered to patients. NICE researchers seek the approval of a medical ethical review board for studies not covered under this exemption. The data are officially registered in accordance with the Dutch Personal Data Protection Act.
Whose data is in the NICE registry?

The NICE registry contains data on all admissions to the intensive care units in the period in which the hospital participated. Participation is not mandatory, but the Dutch health care inspectorate strongly encourages hospitals to participate. The number of hospitals participating has risen and the profile of participating intensive care units has shifted since 1997. We present the number of hospitals participating and total number of admissions recorded in the registry each year from 1997 to 2014 in Figure 1 and their geographical spread in Figure 2. In 2014, 85 (94%) of the 90 hospitals in The Netherlands with intensive care units participated. We have no data on the small proportion of intensive care unit admissions to hospitals not participating in the registry. The annual number of admissions recorded in the registry rose from 5983 in 1997 to 90,115 in 2014. There are currently data on over 800,000 admissions in the registry. Hence, the NICE registry currently provides a geographically diverse and nearly complete picture of intensive care admissions in The Netherlands.

Most research using data from the NICE registry focuses on recent admissions; hence, we describe the demographic characteristics and comorbidities of the 537,629 admissions to intensive care units between 1 January 2008 and 31 December 2014 in Table 1. As many researchers use the Acute Physiology and Chronic Health Evaluation IV9 mortality prediction model inclusion criteria for their analyses on NICE registry data, we present the characteristics of admissions fulfilling and not fulfilling these criteria separately.

What has been measured?

The data in the NICE registry are collected in the course of normal clinical treatment in intensive care units. At least two employees of each participating intensive care unit have attended a training session on scoring the variables in the registry.10 Every month, hospital employees extract the required data from the electronic patient records or enter them by hand into a data file and securely upload the resulting file to a server. Most of the data are extracted from electronic patient records. NICE data managers run a series of automatic checks on the data and report on the quality of the data to the intensive care unit before reading the data into the registry database. In addition, they carry out periodic data quality audits in each hospital.11 Data processing and reporting are described in an ISO 9001:2008 certified quality management system.

The NICE registry contains the data in sections A to C of Box 1 on all admissions to participating intensive care units. In addition, each intensive care unit provides the organizational data in section D biannually. These data enable the registry to calculate: duration of the intensive care unit and associated hospital admission; expected mortality, using the Acute Physiology and Chronic Health Evaluation II,12 Simplified Acute Physiology Score II,13 Mortality Probability
Models II\textsuperscript{14} and Acute Physiology and Chronic Health Evaluation IV\textsuperscript{9} models; and the severity of illness, using the Acute Physiology and Chronic Health Evaluation III score.\textsuperscript{15} These four models form severity-of-disease classification systems. They are used to calculate the predicted probability of in-hospital mortality using data collected within the first 24 h of admission of a patient to an intensive care unit.

Some hospitals provide additional data on sequential organ failure assessment scores\textsuperscript{16,17} and quality indicators defined by the Netherlands Society of Intensive Care, such as blood glucose control,\textsuperscript{18} treatment complication, the duration of each period of ventilation and the adherence to guidelines on screening for and treating sepsis.\textsuperscript{19} Currently, researchers are examining the feasibility of adding variables in nursing workload on intensive care units, the use of blood products and antibiotics, timely measurement of pain, mechanical ventilation, feeding\textsuperscript{20} and the results of screening for physical, psychological and cognitive impairments following discharge from the intensive care unit\textsuperscript{21} to the registry. A Dutch language data dictionary is available on request and NICE staff will assist international researchers in using this if necessary.

The NICE registry obtains data on medium-term mortality following hospital discharge by linking records from the NICE registry with those in the Vektis national database on medical insurance claims, using a deterministic linkage algorithm using hospital of admission, gender, date of birth and intensive care admission and discharge dates.\textsuperscript{4,5}

**Key findings using data from the NICE registry**

Since the inception of the registry, researchers have examined the quality of existing quality indicators and proposed new ones. The standardized mortality rate, defined as the ratio of observed to expected mortality in a group of admissions, is an important NICE quality indicator. In the
The standardized mortality rate was calculated using the probabilities of mortality predicted by the Acute Physiology and Chronic Health Evaluation II and the Simplified Acute Physiology Score II prediction models. Currently, reporting focuses on the Acute Physiology and Chronic Health Evaluation IV mortality prediction model, since researchers have used data from the NICE registry to show that this model is currently the best model for The Netherlands. They have also shown that if the standardized mortality ratio is used as an indicator of quality of care, the rank positions of individual hospitals are substantially influenced by: whether in-hospital mortality or mortality at a fixed time point after intensive care unit admission is presented; whether the standardization model is based on administrative or clinical data; and which prognostic model is used to predict the probability of mortality. In addition, data from the NICE registry have been used as a basis for simulation studies to examine the usefulness of measures to improve quality of care and to examine whether temporal changes in the percentage of patients admitted to intensive care unit with a respiratory infection can predict the national incidence of influenza-like illness.

In Figure 3, we present the mortality rate, standardized according to the Acute Physiology and Chronic Health Evaluation IV mortality prediction model, for 58 hospitals. We choose these hospitals because they contributed at least 10 admissions in which the patient died, and at least 10 in which the patient was discharged from the hospital alive, in each year from 2008 to 2014. This selection criterion ensures the stability of parameter estimates. We analysed this rate using a linear mixed effects model with a random constant for each hospital. It has fallen by 0.034 (95% confidence interval 0.28 to 0.039, *P*-value < 0.0001) a year. These figures reflect previous results, which showed that standardized mortality rates in hospitals participating in the NICE registry fell, and hence quality of care rose, between 1997 and 2001 and between 1999 and 2007.

Researchers have used data from the NICE registry to examine associations between the characteristics and policies of intensive care units and patient outcomes. In-hospital mortality in patients with severe sepsis was lower in intensive care units treating more of this type of patient each year and in intensive care units participating in and adhering to a surviving sepsis treatment bundle. However, intensive care unit level was not associated with mortality in hospital or within 90 days of discharge, and intensive care unit readmissions and in-hospital mortality following discharge from the intensive care unit were not associated with hospital practices around handover between intensive care unit and general ward staff. Furthermore, when compared with periodic quality reports, a multifaceted feedback strategy did not reduce patient duration of stay or mortality.

### Table 1. The demographic and clinical characteristics and comorbidities of the 537,629 admissions to intensive care units between 1 January 2008 and 31 December 2014

<table>
<thead>
<tr>
<th>Condition</th>
<th>Not fulfilling Acute Physiology and Chronic Health Evaluation IV mortality prediction model inclusion criteria</th>
<th>Fulfilling Acute Physiology and Chronic Health Evaluation IV mortality prediction model inclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>n</strong></td>
<td>101,069</td>
<td>436,560</td>
</tr>
<tr>
<td>Male</td>
<td>59,561 (59%)</td>
<td>259,730 (59%)</td>
</tr>
<tr>
<td>Median age in years (interquartile range)</td>
<td>66 (53 to 75)</td>
<td>66 (55 to 75)</td>
</tr>
<tr>
<td><strong>Type of intensive care unit admission</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical</td>
<td>54,252 (54%)</td>
<td>183,256 (42%)</td>
</tr>
<tr>
<td>Cardiac surgery</td>
<td>8223 (8%)</td>
<td>86,222 (20%)</td>
</tr>
<tr>
<td>Emergency other surgery</td>
<td>16,951 (17%)</td>
<td>54,525 (12%)</td>
</tr>
<tr>
<td>Planned other surgery</td>
<td>12,443 (12%)</td>
<td>112,557 (26%)</td>
</tr>
<tr>
<td>Missing or died before admission</td>
<td>9200 (9%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td><strong>Conditions diagnosed before current hospital admission</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chronic renal insufficiency or renal dialysis</td>
<td>6296 (6%)</td>
<td>22,666 (5%)</td>
</tr>
<tr>
<td>Chronic obstructive pulmonary disease or respiratory insufficiency</td>
<td>15,061 (15%)</td>
<td>68,914 (16%)</td>
</tr>
<tr>
<td>Chronic cardiovascular insufficiency</td>
<td>7588 (8%)</td>
<td>28,593 (7%)</td>
</tr>
<tr>
<td>Haematological malignancy or metastatic neoplasm</td>
<td>4886 (5%)</td>
<td>25,628 (6%)</td>
</tr>
<tr>
<td>Immunological insufficiency</td>
<td>6409 (6%)</td>
<td>29,205 (7%)</td>
</tr>
<tr>
<td>Diabetes</td>
<td>13,794 (14%)</td>
<td>69,798 (16%)</td>
</tr>
</tbody>
</table>

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Researchers have also used NICE data to examine: clinical outcomes for patients with a range of reasons for admission to the intensive care unit; patient characteristics; and types of treatment on the intensive care unit. Of patients admitted to the intensive care unit with an acute intoxication, 2% died before hospital discharge. Haematological patients had longer durations of stay in and higher rates of readmissions to the intensive care unit than non-haematological patients. Overall, 48% of haematological patients died before hospital discharge, which was significantly higher than for non-haematological patients. Between 2006 and 2011, 6% of cancer patients in The Netherlands were admitted to an intensive care unit and their survival time was significantly shorter than for patients not admitted to an intensive care unit. Of the cancer patients admitted to an intensive care unit following surgery, 25% required mechanical ventilation, 1% died before hospital discharge and the median duration of stay was 0.9 days. However, cancer patients only had a modestly higher severity of illness score and mortality than non-cancer patients admitted following surgery. When examining patients undergoing an unplanned medical admission to an intensive care unit, cancer patients were more severely ill and twice as likely to die as non-cancer patients. Following correction for patient characteristics and severity of illness, patients with a higher body mass index, lower blood glucose amplitude variability or who received hypothermia treatment following cardiac arrest had lower in-hospital mortality rates. Patients with a high administered fraction of oxygen in inspired air and particularly low or high achieved arterial partial pressure of oxygen in the first 24 h after admission had higher mortality rates. In-hospital mortality was significantly lower for patients admitted during weekday office hours than for...

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**Box 1 Summary of variables recorded for all admissions to intensive care units in participating hospitals.**

**Section A. Demographic, administrative information and patient outcome.**

Patient age, gender, height, weight and referring medical specialism; time and date of admission to and discharge from the intensive care unit; date of admission to and discharge from hospital; whether the intensive care unit admission is the first in the current hospital admission; whether the admission is classed as medical, planned surgical or emergency surgery; and whether the patient was alive at discharge from the intensive care unit and hospital.

**Section B. Clinical diagnoses.**

Whether the patient had been diagnosed with chronic renal insufficiency, chronic obstructive pulmonary disease, chronic respiratory insufficiency, chronic cardiovascular insufficiency, cirrhosis, neoplasm metastasis, haematological malignancy, acquired immune deficiency syndrome, immunological insufficiency or diabetes, or was receiving chronic renal dialysis before the current admission.

Whether the patient experienced cardiopulmonary resuscitation, substantial burns, cardiac dysrhythmia, gastrointestinal bleeding, cerebrovascular accident, intracranial mass effect or myocardial infarction immediately prior to intensive care unit admission.

Whether the patient develops acute renal failure or is diagnosed with a proven infection or receives mechanical ventilation or vasoactive medication during the first 24 h on the intensive care unit; and the Acute Physiology and Chronic Health Evaluation II and IV reasons for intensive care unit admission.

**Section C. Glasgow Coma Scale and physiology and lab data from the first 24 h on the unit.**

Eye, motor and verbal reactions as assessed by the Glasgow Coma Score; heart and respiration rates; blood pressure; body temperature; urine output; partial thromboplastin time; international normalized ratio; blood gasses and pH; white blood cell count; thrombocytes; haematocrit; serum creatinine, potassium, nitrate, bicarbonate, urea, bilirubin, albumin and glucose.

**Section D. Biannually reported organizational characteristics of intensive care units.**

Hospital type; intensive care unit level; total numbers of hospital, intensive care unit, coronary care unit, medium care unit and post anaesthesia care unit beds in the hospital; whether the unit offers specialized care following cardiovascular surgery, intracranial neurosurgery, organ transplantation or serious burns, or if the hospital is a supra-regional trauma or oncology centre; full-time equivalent of intensive care nurse specialists, medical specialists and other physicians working on the intensive care unit; and the times that the day, evening and night shifts begin.
those admitted at other times. There is a complete list of publications using data from the NICE registry on the foundation website: [http://www.stichting-nice.nl/publications.jsp].

Strengths and weaknesses

Strengths of the NICE registry include the facts that: it has been in existence for nearly 20 years; there is currently nearly complete national coverage of intensive care unit admissions; it is possible to predict mortality using multiple internationally accepted models; and the data management is of a high quality. A number of factors have contributed to the success of the NICE registry. The NICE registry was set up by intensive care medical specialists and most of the NICE foundation board members are intensive care medical specialists. This means that there are good channels of communication with intensive care medical specialists nationwide and that they can be consulted on changes in the data collected, including the choice of quality indicators. Regular feedback and additional support for intensive care units with questions on the quality of care they provide have strengthened this communication. In addition, the registry is embedded in the Department of Medical Informatics. This enables registry staff to learn from and work with other medical information specialists. Furthermore, since its inception, the NICE registry has concentrated on ways to extract as many variables as possible from hospital information systems automatically. This minimizes the amount of time medical and nursing staff need to spend collecting and entering data specifically for the registry.

There are three main weaknesses of the registry. First, there is no record linkage of intensive care unit admissions across multiple hospital admissions. This means that data from the, presumably very small, proportion of patients with multiple intensive care unit admissions may have undue weight in results obtained from registry data. Second, currently most of the data in the registry are collected in the first 24 h of an intensive care unit admission and contain limited data on patients’ clinical history, the rest of the admission period or health status following discharge from the intensive care unit. Third, the data in the registry are recorded in each intensive care unit by local staff. This means that despite an extensive data dictionary, training, site visits and data quality checks, there may be local

Figure 3. The mortality rate standardized according to the Acute Physiology and Chronic Health Evaluation IV mortality prediction model for 53 hospitals participating in the NICE registry each year from 2008 to 2014.
differences and systematic inaccuracies in the way the data are collected and entered.

In the future, the NICE foundation hopes to move towards real-time data extraction from electronic health record systems in participating hospitals. However, this will only be possible if the systems in participating hospitals conform to standard information, exchange and terminology standards. The foundation would also like to stimulate intensive care medical specialists to continue to use the NICE registry data for clinical research. In addition, it would be helpful if it were possible to routinely match patient-level data from the NICE registry with those in other registries and national databases to obtain more in-depth clinical information, such as tumour stage in cancer patients, or demographic information, such as date and cause of death, education and income. However, it is difficult to do this while remaining within the constraints of the data protection laws in The Netherlands. With interest in critical care outcomes moving from mortality to patient-reported outcomes, such as quality of life and functional status, we expect that data on this type of outcome would be valuable for researchers in the future. However, it is logistically and legally difficult to collect these data, as patients usually do not have any contact with intensive care unit (ICU) staff following discharge. Currently initiatives to follow patients after ICU discharge are successfully emerging throughout The Netherlands.

Using NICE registry data

Apart from clinical research, the data in the NICE registry have the potential to yield knowledge on longitudinal changes in the characteristics of patients admitted to intensive care units and the aetiology of medium-term mortality following an episode of severe acute illness. NICE welcomes collaboration with researchers on the quality of care in and outcomes of admission to intensive care units. In the past, NICE researchers have successfully collaborated with other Dutch and international research groups. To ensure that potential collaborations are feasible; in accordance with the goals of the NICE foundation; of a high scientific quality; and do not violate privacy regulations, members of the board of directors of the NICE Foundation assess each request. Aggregated data and the results of statistical analyses are reviewed to ensure the anonymity of both patients and hospitals before publication. Due to contractual boundaries, all analyses on admission and hospital-level data are performed by employees of the Department of Medical Informatics, Academic Medical Center, Amsterdam, The Netherlands. The application form for using data from the NICE registry is available as an online appendix to this paper (available at IJE online), and titles of previously approved applications can be found at: [http://www.stichting-nice.nl/extractieverzoek.jsp]. Questions on using NICE registry data can be addressed to: [info@stichting-nice.nl].

The NICE registry in a nutshell

- The NICE registry was set up to enable intensive care units in The Netherlands to quantify and improve the quality of care they offer.
- The number of intensive care units participating in the registry rose from six in 1997 to 90 in 2014. The annual number of admissions recorded in the registry rose from 5983 in 1997 to 90115 in 2014. The total number of admissions recorded in the database is currently over 800000.
- The NICE registry contains primary data collected in the course of clinical care provided in and following discharge from intensive care units.
- Hospitals supply the following data to the registry: demographic and administrative information; whether the patient was alive at intensive care unit and hospital discharge; clinical diagnoses before and on admission to the intensive care unit; and Glasgow Coma Scale and physiology and laboratory data from each patient’s first 24 h on the intensive care unit. In addition, hospitals report on organizational characteristics of the intensive care units biannually.
- NICE welcomes collaboration with researchers on the quality of care in and outcomes of admission to intensive care units. Questions on using NICE registry data can be addressed to the head of research at the NICE Foundation (Nicolette de Keizer) via: [info@stichting-nice.nl].

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Conflict of interest: Dave Dongelmans and Nicolette F. de Keizer are members of the board of directors of NICE.
References


