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Exploring the similarities and differences of burn registers globally: Results from a data dictionary comparison study

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ABSTRACT

Introduction

Pooling and comparing data from the existing global network of burn registers represents a powerful, yet untapped, opportunity to improve burn prevention and care. There have been no studies investigating whether registers are sufficiently similar to allow data comparisons. It is also not known what differences exist that could bias analyses. Understanding this information is essential prior to any future data sharing. The aim of this project was to compare the variables collected in countrywide and intercountry burn registers to understand their similarities and differences.

Methods

Register custodians were invited to participate and share their data dictionaries. Inclusion and exclusion criteria were compared to understand each register population. Descriptive statistics were calculated for the number of unique variables. Variables were classified into themes. Definition, method, timing of measurement, and response options were compared for a sample of register concepts.

Results

13 burn registries participated in the study. Inclusion criteria varied between registers. Median number of variables per register was 94 (range 28 - 890), of which 24% (range 4.8 – 100%) were required to be collected. Six themes (patient information, admission details, injury, inpatient, outpatient, other) and 41 subthemes were identified. Register concepts of age and timing of injury show similarities in data collection. Intent, mechanism, inhalational injury, infection, and patient death show greater variation in measurement.

Conclusions

We found some commonalities between registers and some differences. Commonalities would assist in any future efforts to pool and compare data between registers. Differences between registers could introduce selection and measurement bias, which needs to be addressed in any strategy aiming to facilitate burn register data sharing. We recommend the development of common data elements used in an international minimum data set for burn injuries, including standard definitions and methods of measurement, as the next step in achieving burn register data sharing.

KEYWORDS

Burns, Registries, Routinely Collected Health Data, Common Data Elements, Data Science, Data Dictionary.

1. INTRODUCTION

Burn registers systematically collect pre-specified information about patients requiring medical care for their injury, known as routinely collected data [1]. The vast quantities of routinely collected health data that now exists have transformed the research landscape by enabling large scale, cost-effective, observational research studies. Superior computing power, the internet, and artificial intelligence is driving a new wave of interest in pooling data from different sources. An essential step in utilising these data for large scale network studies is to convert existing disparate data structures into a standardised comparable structure. There are two main approaches to achieving this: implementation of common data elements collected across all databases, or conversion of existing data using a common data model [2-4]. Common data elements have been successfully implemented for rare disease registers, and common data models have been used for national healthcare databases, oncology registers, and diabetes registers [5-7]. Pooling data not only allows clinical benchmarking, but also increases sample size to achieve higher power for embedded trials, study of rare outcomes, and tracking of emerging trends [8-10].

Increasing data quantity leads to increased precision in results but does not necessarily increase accuracy. This is known as the 'big data paradox' [11]. It is driven by lower data quality, increased patient heterogeneity, and bias as sample size increases unless avoidant measures are taken. The collection of large routine healthcare data sets is often many steps removed from those using the data. Reporting of such research has been found to lack key attributes required for appraisal of the strengths, limitations, and biases of large routinely collected data sets [12]. The Reporting of studies Conducted using Observational Routinely-collected Data (RECORD) guideline recommends inclusion of details such as study population selection, variable information, misclassification bias, and handling of missing data [12]. Technical advances mean that it is easier than ever to compare healthcare data, but data limitations must be carefully considered prior to analyses to avoid patient harm and ensure meaningful conclusions can be drawn from the results.

The Global Burden of Disease study estimates that over 16 million burn injuries from all causes were sustained globally in 2019 [13]. Burn care can lead to high out of pocket expenditure for patients [14, 15]. There has been a proliferation in burn registers since the mid-2000s in an effort to improve patient care [16]. Data are used for many purposes including research, service provision planning, and quality improvement [17-19]. Combining data collected across the global network of burn registers could be a powerful tool for primary prevention and improving patient outcomes, but few inter-

register comparisons have been completed [20]. There is no international standardised data set for burn registers. Current registers were established independently, each developing its own variables and data structure. A study of six regional burn register data dictionaries in the United States showed little overlap in data elements, limiting the ability to share data [21]. There is also no record of any burn register being converted to a common data model when checking prominent common data model websites [22-24].

To our knowledge, there have been no studies investigating key similarities and differences of burn registers on an international scale. This is an essential step prior to any data sharing. It will determine the suitability of burn registers for common data model conversion, or the need for common data elements as part of a global minimum data set [25]. The aim of this project, therefore, was to compare the variables collected in countrywide and intercountry burn registers to understand their similarities and differences.

The study objectives were to:

1) Compare characteristics that influence the register population

2) Determine which variables are collected by each register and if variables are required or optional

3) Identify variables collected by all registers and common variable themes

4) Compare a sample of register concepts to understand differences in definitions, measurement methods, and variable response options

2. METHODS

Methods described in the study protocol were followed [26]. Protocol changes and additional analysis details are reported for each objective. Ethical or institutional review board approval was not necessary because no human participant data were used. Permission to use the data dictionaries were sought from respective register custodians. All information was extracted from the data dictionaries. Where information was not available, it was sought from publications and the register custodian. Microsoft Excel and RStudio were used for analyses [27, 28].

Register recruitment

Active countrywide and intercountry burn registers were identified from a scoping review [16]. The rationale for this is described in greater detail in the study protocol [26]. Pilot registers were invited from countries where there is no active

countrywide register. Email invitations were sent to register custodians in May 2022. If no response had been received, a further invitation was sent in June 2022. All custodians provided an English language copy of their data dictionary for the study. The Burn Centres Outcomes Registry the Netherlands, Burn Unit Database Sweden, Dutch Burn Repository R3, German Burn Registry, and Japanese National Burn Registry translated their data dictionary to English prior to sharing.

Objective 1: Compare characteristics that influence the register population

Information was extracted into a spreadsheet about year data collection started, countries included, number of sites, and inclusion and exclusion criteria of the register. Data were verified by the respective register custodian. Inclusion criteria were compared across all registers and classified into common groups.

Objective 2: Determine which variables are collected by each register and if variables are required or optional.

All variable names were extracted into a spreadsheet file and verified by a second researcher. The number of variables collected by each register was calculated by counting the number of unique variable names. Variables that were collected repetitively were only counted once unless a new name was used. Calculated variables were excluded. Variables that were required to be collected for all patients were noted. Summary statistics were calculated for the number of variables and the number of required variables.

Objective 3: Identify variables collected by all registers and common variable themes.

Variables were classified into clinically meaningful themes and subthemes using a top-down approach. Initially variables from all registers were reviewed to develop a list of themes based upon a typical patient journey. This was then applied to all variables independently by two researchers. Themes that led to a high proportion of conflicts were discussed and refined to better capture register data collection timepoints. A theme was attributed to every variable. Variables in each theme were reviewed to develop subthemes. Subthemes were refined iteratively and then assigned to every variable. Resources were used to help ensure groupings were clinically meaningful and internationally comparable where possible. For the injury theme, we referred to the International Statistical Classification of Diseases and Related Health Problems (ICD) external causes of morbidity or mortality chapter [29]. For the inpatient and outpatient themes, the Core Outcome Set in Burn Care Research was used [30]. The number of variables in each theme and subtheme was calculated. Data

dictionary and information from register custodians was used to allocate the most appropriate theme and subtheme to each variable. Where a variable could apply to multiple subthemes, the most likely clinical group was chosen.

Objective 4: Compare a sample of register concepts to understand differences in definitions, measurement methods, and variable response options

Detailed variable information was extracted for a sample burn register concepts. These included placing the patient in time and space (examples chosen: patient age, timing of injury), primary injury prevention factors (examples chosen: injury intent, injury mechanism), predictors of patient outcome (example chosen: inhalational injury), and patient complications and outcomes (examples chosen: infection, patient death). Inhalational injury was added since protocol publication as an example of a key predictor of patient outcome. The protocol listed injury cause rather than injury mechanism. During detailed information extraction it was found that injury 'cause' was not used consistently across registers, so a more specific concept was required. Instead, we chose to extract information on injury mechanism, which ICD recommends as the next recommended level of classification of an injury after intent [29].

A pilot exercise was completed for extraction of detailed variable information to ensure a high level of agreement between researchers. Detailed information was extracted for patient age and timing of injury from three registers (Burn Care Quality Platform, Burns Registry of Australia and New Zealand, and Global Burn Registry). These registers were chosen because they included a lot of detailed information about variables. We theorised that this may lead to inter-rater differences between researchers when extracting detailed variable information. Percentage agreement and inter-rater reliability (Cohen's Kappa) was calculated on the pilot data. Level of agreement during the pilot exercise was excellent (kappa 0.85, percentage agreement 86.1%), so further data extraction was divided between two researchers. The researchers responsible for extraction of the information discussed each of the other data dictionaries in detail to ensure information was extracted in the same way as the pilot exercise. Variables for each concept were compared between registers to understand similarities and differences in the number of variables per concept, definitions, measurement methods, and variable response options.

3. RESULTS

Register recruitment

Study inclusion criteria were met by 17 registers, of which 13 agreed to participate (Appendix A). No response was received from three register custodians. The German and Austrian Paediatric Registry had combined with the German Burn Registry, so was not included as a separate register. The Burn Centres Outcomes Registry the Netherlands was identified following discussion with another register custodian and subsequently invited to participate.

Objective 1: Compare characteristics that influence the register population

Participating registers were primarily from high income countries (Table 1). Any healthcare facility providing inpatient burn care can submit data to the Global Burn Registry, but 97% of the data within the Global Burn Registry are from facilities in low- and middle-income countries [31]. There are four types of register custodians: burn associations or societies, academic organisations, health services, and non-profit organisations. Several registers have joint custodians. The oldest registers were established in Sweden in 1993, and the United States (Burn Care Quality Platform, and Burn Model System) in 1994. All other registers were established from the mid-2000's. Inclusion criteria were classified into diagnosis, length of stay, and consent (Table 1). Over half of the registers exclude acute dermatological conditions and other injuries affecting integrity of the skin. The focus of 11 registers is to collect inpatient data, of which three also collect outpatient and follow up data (Burn Unit Database, Dutch Burn Repository R3, International Burn Injury Database). Conversely, The Burn Centres Outcomes Registry the Netherlands and the Burn Model System were established to understand patient outcomes following hospital discharge. Patient consent is required from five registers for data to be entered into the burn register.

Objective 2: Determine which variables are collected by each register and if variables are required or optional

A total of 2759 variables are collected across all registers. The median number of variables collected by each register is 94 (IQR 65-235) (Table 2). The number of variables is affected by the approach to data collection. For example, use of multiple variables with binary responses increases the unique variable count compared to using a single variable with multiple categorical response options.

Almost a quarter (median 24.0%, IQR 18.9-64.9%) of all variables were required to be collected (Table 2). Approaches differed between registers with some mandating collection of a small number of administrative variables for tracking patient numbers (e.g. Burn Centres Outcomes Registry the Netherlands, Dutch Burn Repository R3, German Burn Registry),

or a detailed minimum data set for analysis of demographic and injury patterns (e.g. Burn Care Quality Platform, Burns Registry of Australia and New Zealand). The Burn Care Quality Platform has a minimum data set for all patients, but additional variables are required for more seriously injured patients (over 10% total body surface area, inhalational injury, death, or surgery). The minimum data set was included in our analysis of required variables. Alternative approaches include that of the International Burn injury Database which does not mandate the collection of any variables, but strongly recommends collection of variables used to calculate key performance indicators for monitoring healthcare quality. The Burn Model System does not define a minimum data set because participants are able to leave any question unanswered during interviews. Data collectors are, however, required to complete certain variables from patient medical records for all participants. Researchers were asked to collect all variables during the data collection phase of the South Asia Burn Registry pilot. These data will be used to determine which are feasible to collect when the register is scaled up.

Objective 3: Identify variables collected by all registers and common variable themes

No variables were identified that were identical across all registers. Some variables, such as patient age and timing of injury, were measured similarly across most registers. This is discussed further in objective four. Six themes and 41 subthemes were identified (Figure 1). Inpatient care was the most common theme, accounting for 40.4% of all variables (Table 3). Inpatient subthemes of complications, non-surgical management, and surgical management included the greatest number of variables. The proportion of required variables in these subthemes was lower than the subtheme median of 33.3%. The greatest proportion of required variables were in patient information and admission themes. Variables in the inpatient and outpatient themes closely aligned to the Core Outcome Set in Burn Care Research. Outcomes of serious complications and death were more likely to be recorded during inpatient care, whereas time to heal and time to return to work were more likely to be recorded during long term follow up. Of the 588 variables in the outpatient theme, 75.2% are collected by the Burn Model System. Standardised assessment tools are used for 397 variables in the outpatient theme. The Patient and Observer Scar Assessment Scale is the most commonly used assessment tool, which is collected by three registers [32].

The proportion of variables in each theme varies between registers (Figure 2a). Inpatient care is the predominant theme of nine registers. Injury variables account for around half of the Global Burn Registry and Japanese National Burn Registry data set. Variables collected during follow up (outpatient theme) was the majority theme of the Burn Centres Outcomes

Registry the Netherlands and Burn Model System. Data linkage between the two registers means that the Burn Centres Outcomes Registry the Netherlands collects no injury or inpatient related variables, and Dutch Burn Repository R3 collects relatively few outpatient variables.

There is a change in the proportion of variables in each theme when analysing required variables only (Figure 2b). The greatest increase is in patient information and admission detail with a mean increase of 10.0% and 8.2% respectively. The greatest reduction is in the inpatient and outpatient with a mean reduction of 11.0% and 7.6% respectively. The injury and other themes show a mixed picture. Injury is more dominant in registers such as Burns Registry of Australia and New Zealand (+23.2%) and Burn Care Quality Platform (+13.4%), but less dominant in registers such as German Burn Registry (-18.7%) and Global Burn Registry (-18.1%).

Objective 4: Compare a sample of register concepts to understand differences in definitions, measurement methods, and variable response options

Data dictionaries consistently include variable name, conditionality information, and response options (Appendix B). Variable definitions and measurement information (e.g. method of measurement, timing of measurement) is less complete. Where variables definitions are provided, they often include the term that is being defined meaning that the reader is still required to use their own interpretation of the term. Measurement information mostly applied to the data entrant rather than those making the measurement. Each register has a different way of handling missing data and approximated entries.

Patient age

Variables related to patient age are collected by 12 registers (Appendix B: Patient age). Date of birth is collected by nine registers, of which three allow age to be collected where date of birth is unknown. Age is the sole age-related variable collected by three registers. Most specify that age at the time of injury should be recorded, whereas the German Burn Registry records age at the time of admission.

Timing of injury

Timing of the burn injury is collected by 12 registers (Appendix B: timing of injury). All include a date component, 10 include a time component. Date order varies between countries. Registers describe these variables as critical for analyses and ask that the data are as exact as possible or to provide an estimate where exact timing is unknown.

Injury intent

Information about injury intent is collected by 12 registers using 43 variables (1-8 variables per register) (Appendix B: Injury intent). "Intent" is the most commonly used term. Others include "circumstances", "category", and "accident context". Variable definitions, where provided, use the same term as the variable (e.g. intent, circumstances) meaning that variable response options (e.g. accident, self-inflicted, assault) had to be used to determine whether the variable related to injury intent. Measurement information extracted from the data dictionaries discusses that differentiation is challenging, and terms such as "suspected" are used to avoid legal problems with proof. Many register data dictionaries include a recommendation that the variable is completed based upon the clinicians' assessment, but little detail is given on how the clinician should make this assessment. Response options for accidental intent are often combined with activity (e.g. accident at work) as part of a single variable about injury intent. Whereas data about self-inflicted or injuries due to violence are more likely to be captured as individual variables (e.g. report of physical abuse, suicide attempt).

Injury mechanism

Injury mechanism (i.e. how the injury occurred) is collected by 12 registers using 61 variables (1-14 variables per register) (Appendix B: Injury mechanism). There are a variety of terms used for this concept including "aetiology", "cause", "type", and "nature" of injury. It can be inferred from the categorical response options (e.g. contact with fire or flame) that these variables relate to mechanism. All registers collect information on mechanism, though some response options also include options for the object or substance that conveyed the mechanism (e.g. hot drink). Six registers collect information about the object or substance separately. Information is also collected about contributing factors, particularly accelerants, clothing, vehicles, and structural fires.

Inhalational injury

A total of 66 variables about inhalational injury are collected by 11 registers (1-38 variables per register) (Appendix B: inhalational injury). There are two main approaches to collect these data. The most common is to document whether the

clinician has judged the patient to have an inhalational injury. The second is to collect clinical data indicative of inhalational injury, including clinical signs and bronchoscopic findings. Variable definitions and measurement information suggest that clinical signs are sufficient for a diagnosis of inhalational injury, but that bronchoscopy is the gold standard diagnostic method.

Infection

Infection information is collected by 11 registers with 143 variables (1-40 variables per register) (Appendix B: Infection). These include infection type, timing of diagnosis, microorganism details, and antibiotic usage. All collect information about infection type either using individual variables for specific types of infection (e.g. bronchopneumonia, sepsis, wound site), or as part of a wider list of inpatient complications. Little guidance is given on how to determine the diagnosis of infection except for sepsis in the German Burn Registry. Microorganism information is collected by nine registers and accounts for the greatest number of variables. Timing of infection primarily relate to when the microorganism was detected, rather than when a clinical diagnosis of infection was made. Antibiotic usage is collected by five registers.

Patient death

Information about patient death is collected by 12 registers using 106 variables (2-42 variables per register) (Appendix B: Patient death). These data include timing of death, discharge status, cause of death, and withdrawal of treatment. All collect information on timing of discharge or death. Collection of cause of death information varies between registers. Approaches include ICD codes, a single variable with a limited choice of responses (e.g. multiorgan failure, pulmonary embolus), or a series of variables listing several common causes or contributors of death. Discharge status variables include at least one categorical response option for death. Decision to withdraw treatment is recorded by six registers.

4. DISCUSSION

This is the first study to investigate similarities and differences of 13 countrywide and intercountry burn registers. We investigated factors influencing register population characteristics, number of variables collected, approaches to collection of required variables, variable themes, and inter-register compatibility of concepts. We found some commonalities between registers and some differences. Commonalities would assist in any future efforts to pool and

compare data between registers. Differences between registers could introduce selection and measurement bias, which needs to be addressed in any strategy aiming to facilitate burn register data sharing in the future.

Selection bias could be introduced at two levels - inter-register differences in inclusion and exclusion criteria, and national representativeness of the register population. Inclusion criteria differences for diagnosis, length of stay, and consent were found between registers. A recent study comparing Burn Model System and Burn Care Quality Platform showed Burn Model System patients had more severe burns on average [33]. This was attributed to different inclusion criteria. Patient consent is required for five registers. It is recognised that the consent process can lead to reduced case ascertainment and differences in baseline characteristics compared to those that have no consent process [34]. Data protection regulations may affect the requirement for patient consent. European Union General Data Protection Regulation (GDPR) requires informed patient consent for non-anonymous patient data to be used for research purposes [35]. Introduction of this legislation meant that centers in the German Burn Registry had to temporarily suspend data collection until all requirements for compliance with GDPR, including informed patient consent, could be met [36].

Countrywide and intercountry registers participated in this study, but national representativeness was not fully explored. The number of healthcare facilities that submit data ranges from 1 to 120 sites. This is affected by country population, healthcare infrastructure, fees to submit data to a register, and criteria used to determine which healthcare facilities participate. For example, any healthcare facility that provides inpatient burn care can submit data to the Global Burn Registry. Data has been submitted from 36 facilities across 20 countries [31]. Submission is voluntary and inconsistent, so it is unlikely that these data are representative of individual nation's burden of burn injuries requiring medical care [37]. In contrast, all NHS commissioned burn care services in England and Wales are mandated to submit data to the International Burn Injury Database. Sampling exercises show good case ascertainment when compared to burn admissions captured in routine national hospital administrative data, but the database would not include patients receiving care at non-specialist burn services [38]. Sampling exercises are a good way to ensure thorough case ascertainment but are difficult in jurisdictions without nationalised healthcare data collection. Inter-register differences in inclusion and exclusion criteria, and national representativeness of the register population would affect type of questions that could be investigated using pooled burn register data. They would require careful consideration to avoid problems with selection bias.

Missing data is another significant challenge for observational health research that can introduce bias into analyses [39]. Register approaches to collection of required and optional variables was explored. All registers included some variables that were required to be collected. This ranged from 4.8% - 100%. There was a huge breadth of variables collected by the registers. Analyses showed common variable subthemes, which is promising for future data harmonisation. The composition of themes in each register varied depending on whether variables were required or optional. Basic patient information and admission details were more likely to be required to be collected than inpatient or outpatient variables. It is likely optional variables would be a greater source of missing data than required variables, although registers with mandatory collection of variables still may not have complete records [40]. The likelihood of data to be missing would be an important consideration for the development of a global minimum data set, as a high degree of missing data would limit analyses.

Exploration of variables collected in our sample of burn register concepts showed some similarities, but there were also limitations that could lead to misclassification bias and unmeasured confounding if data were pooled. Mapping of current variables to a set of common variables would be required. This approach has been used in trauma registries for international data comparisons [41]. Mapping would be straightforward for burn register concepts such as patient age and timing of injury, but more complex and prone to bias for variables such as intent, inhalational injury, and infection.

Information provided in the data dictionaries suggests that variables for patient age and timing of injury are collected in a similar enough way to be compared (Appendix B: Patient age comparison, Timing of injury comparison). It is unlikely that date of birth information could be shared due to risk of patient identification. The Burn Model System data dictionary explicitly states date of birth will not be shared. All registers that collect date of birth can calculate age at the time of injury. This could then be pooled with data for registers that only collect age information. Age disaggregated analyses are common in burns research as it is a key predictor of outcomes [42]. Self-reported age is prone to responder bias and less reliable than date of birth, particularly in communities where birth registration is not mandated [43]. This could affect reliability in registers such as the Global Burn Registry where estimated age can be recorded. Timing of injury data are collected differently across registers, particularly missing and approximated values. These data would require transformation into a standard format prior to pooling. This could be achieved using the International Organization for Standardization's standard for sharing of numerical representations of date and time (ISO 8601) [44]. It recommends date

is represented in the format YYYY-MM-DD, and time is represented as HH:MM:SS. Missing data can be represented by XX (e.g. 2016-XX-XX where only the year 2016 is known), and the symbol ~ where data are estimated.

Mapping variables for the concept of injury intent is more complex. ICD External Cause codes are standardised internationally but require considerable training to use accurately [45]. These data are only collected by the Burn Care Quality Platform and Burns Registry of Australia and New Zealand, so could not be used across all registers. Variables could be harmonised by creating a new injury intent variable and mapping current categorical response options to new response options (Figure 3, Appendix B: Injury intent comparison). There are 53 unique response options that appear sufficiently similar based on the information provided in the data dictionaries to be mapped to six response options. However, the reliability and comparability of these data is not fully known. There is no internationally agreed method for clinical differentiation of injury intent. Intent is an inherently medico-legal term and its determination in clinical settings can have legal consequences [46, 47]. It is also prone to responder (e.g. patient) and observer (e.g. clinician, data entrant) differential misclassification bias [48, 49]. It is not possible to know the degree of misclassification in these data within and between registers. Internationally agreed definitions and methods of assessment for injury intent would help to address this issue.

Inhalational injury variables could be harmonised using two new variables and mapping current response options to the new options (Appendix B: inhalational injury comparison). Firstly, 'clinical suspicion of inhalational injury', which would allow all registers that collect information on inhalational injury to be compared. Secondly, 'bronchoscopic signs of inhalational injury'. Only three registers currently include variables for clinical data on bronchoscopic signs of inhalational injury, however because this is the gold standard of measurement it is likely that comparison of these data would be of value to the burns community [50]. It is challenging to compare data between registers that collect clinical data and those that record clinical judgement of inhalational injury because it is not possible to know how the clinician has determined the presence of inhalational injury. Some centres may routinely use bronchoscopy whereas others may only use clinical signs. An internationally agreed method of assessment would help to reduce the risk of misclassification bias in these data.

Harmonising variables for other concepts is equally challenging. For example, registers showed variation in how information about infection is captured. Burn patients are at high risk of wound and systematic infections [51]. Diagnosis and management of infection is complicated by deranged physiological parameters, immunosuppression, invasive

monitoring, procedures, and prolonged hospital stays [52]. The variety of information recorded by registers emphasises the breadth of potential uses of these data. Deciding upon which concept should be compared is essential prior to any harmonisation process. These comparisons highlight that although data pooling could be achieved technically between registers, the compatibility of the data are not fully known due to differing definitions, methods of measurement, and response options. Common data elements improve the sharing of data if they are used in a standardised way across all databases [53]. They include a prompt, data type, unit of measure, and set of permissible values. No examples of burn specific common data elements were found when searching the NIH Common Data Elements Repository [54]. Development of burn-specific common data elements would vastly improve the reliability of analyses if burn register data sharing were to occur. Additionally, inclusion of non-circular definitions and agreed method of measurement/assessment for both the clinician and person completing data entry would reduce measurement bias. These could be used as part of a global minimum data set for burn registers.

There are some limitations to this study. We did not identify any active countrywide burn registers in many parts of the world. The majority of burn registers included in this study were from high-income countries meaning that variables pertinent to prevention and care of burn injuries in low- and middle-income countries may have been underrepresented. We tried to address this issue through inclusion of the Global Burn Registry and invitation of pilot registers from countries without an active countrywide register. Custodians from all participating registers were invited to be authors in the results manuscript to try to maximise diversity and provide contextual understanding to the findings. Operational differences such as method of data collection that could affect the national representativeness of registers were not explored. These factors can also introduce bias were data to be compared. Exploration of differences in data coverage and completeness would likely require qualitative enquiry with register custodians and analysis of register patient data, thus were beyond the scope of this project. Only unique variables were included in the thematic analyses. A register may record a variable repeatedly at different timepoints, but it was only counted once in our analyses. Therefore, the proportional composition of the variable themes described in this paper may not replicate the composition of each registers data set.

Recommendations

We recommend that the global burn community continues to work together to determine which concepts in burn epidemiology, prevention, care, and patient outcomes should be measured internationally. We are aware that our current collaboration is dominated by specialists from high-income countries. The greatest burden of burn injuries is experienced

in low- and middle-income countries. It will be important to include more stakeholders from low- and middle-income countries to ensure that the variables serve all partners equally and do not contribute to widening of health inequalities globally. Our preliminary work can be used as the basis to develop a set of common data elements including definitions and methods of measurement targeted at both those completing the measurement (e.g. clinician) and those entering the data. Common data elements can be used as part of a minimum data set in burn registers to facilitate future pooling of data, as well as in burn research studies to minimise measurement bias.

CONCLUSIONS

Burn registers are an important resource for burn surveillance, prevention, and improvement of care. Pooling register data could provide additional power to answer important clinical questions. We have shown that there are similarities in inclusion of patients, variable themes, and variable response options that would facilitate this process. We have also demonstrated how variables could be harmonised using a mapping process. There are, however, differences between registers that could introduce bias and need to be adequately addressed in any strategy aiming to facilitate burn register data sharing. We recommend the development of common data elements, including standard definitions and methods of measurement, to create an international minimum data set for burn injuries. This is the next step in realising burn register data sharing to enable international benchmarking, larger sample populations for study of rare trends and outcomes, and more robust observational research studies.

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APPENDIX

Appendix A: Register responses to invitation to participate in the study. Registers listed alphabetically.

Appendix B: Detailed variable information for a sample of important register concepts.

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LEGENDS FOR TABLES AND FIGURES (in order of appearance in text)

Table 1. Burn register characteristics including register custodian, year register established, countries included in the register, number of sites submitting data, inclusion criteria, and exclusion criteria. Registers listed alphabetically.

Table 2. The number of unique and required variables collected by each burn register. The number of required variables as a percentage of the total number of variables is shown for each register.

Figure 1. Bar plot showing the number of variables in each theme and subtheme. Abbreviations: Pre, pre-existing; IP, inpatient; OP, outpatient.

Table 3. Table showing the total and required number of variables in each theme and subtheme. Examples of variables included in each subtheme are given. Abbreviations: IP, inpatient; OP, outpatient.

Figure 2. The proportion of all variables in each register classified by theme (Figure 2a). The proportion of required variables in each register classified by theme (Figure 2b). Abbreviations: BCQP, Burn Care Quality Platform; BORN, Burn Centres Outcomes Registry the Netherlands; BMS, Burn Model System; BRANZ, Burns Registry of Australia and New Zealand; BUD, Burn Unit Database Sweden; COBIS, Care of Burns in Scotland; DBR-R3, Dutch Burn Repository R3; GBR (VR-DGV), German Burn Registry; GBR (WHO), Global Burn Registry; iBID, International Burn Injury Database of England and Wales; JNBR, Japanese National Burn Registry; NBR, Norwegian Burn Registry; SABR, South Asia Burn Registry.

Figure 3. Example from two registers of extract, transform, load process that could be used to harmonise burn injury intent data. This process could be used for all registers to pool data. Abbreviations: BCQP, Burn Care Quality Platform; GBR, Global Burn Registry.