

### **Bangor University**

### DOCTOR OF PHILOSOPHY

Strengthening international surveillance data on burn injury intent

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# Strengthening international surveillance data on burn injury intent

**Emily Bebbington** 

A thesis submitted to Bangor University in partial fulfilment of the requirements for the degree of Doctor of Philosophy

Centre for Mental Health and Society

**Bangor University** 

2023

### **Declaration and consent**

I hereby declare that this thesis is the results of my own investigations, except where otherwise stated. All other sources are acknowledged by bibliographic references. This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree unless, as agreed by the University, for approved dual awards.

Yr wyf drwy hyn yn datgan mai canlyniad fy ymchwil fy hun yw'r thesis hwn, ac eithrio lle nodir yn wahanol. Caiff ffynonellau eraill eu cydnabod gan droednodiadau yn rhoi cyfeiriadau eglur. Nid yw sylwedd y gwaith hwn wedi cael ei dderbyn o'r blaen ar gyfer unrhyw radd, ac nid yw'n cael ei gyflwyno ar yr un pryd mewn ymgeisiaeth am unrhyw radd oni bai ei fod, fel y cytunwyd gan y Brifysgol, am gymwysterau deuol cymeradwy.

I confirm that I am submitting this work with the agreement of my supervisors.

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### List of acronyms

ACEs	Adverse Childhood Experiences		
CDE	Common data element		
СМО	Casualty medical officer		
DALYs	Disability Adjusted Life Years		
GBD	Global Burden of Disease study		
GDPR	General Data Protection Regulation		
HIC	High-income countries		
ICD	International Classification of Disease		
ICECI	International Classification of External Causes of Injury		
LIC	Low-income countries		
LMIC	Lower-middle-income countries, or low- and middle-income countries. The correct use of the acronym will be made clear in the text.		
MLR	Medicolegal register		
ОР	Outpatient		
OPD	Outpatient department		
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses		
PRISMA-P	PRISMA extension for protocols		
PRISMA-ScR	PRISMA extension for scoping reviews		
RECORD	REporting of studies Conducted using Observational Routinely-collected Data		
SASHI	South Asia Self-Harm Initiative		
SHR	Self-harm register		
STROBE	Strengthening the Reporting of Observational studies in Epidemiology		
TBSA	Total body surface area of the body affected by the burn		
UMIC	Upper-middle-income countries		
WHO	World Health Organization		
WHO GBR	World Health Organization Global Burn Registry		
YLD	Years lived with disability		

### Acknowledgements

I feel incredibly privileged to have had the opportunity to complete this PhD. It is a product of a series of people putting their faith in me. All of them could have easily found someone else to work with who was more traditionally trained or already in their network. I have probably missed some important people from this acknowledgements section, but I am very grateful to everyone who has helped me.

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Much of the work in this thesis was conducted as part of the South Asia Self-Harm Initiative (SASHI). Dr Mohan first met with me at the SASHI meeting in Manchester in November 2018. We discussed the issues of misclassification of injury intent and how we might investigate this using data from his handwritten burn register. This PhD grew from that first conversation. Dr Mohan has supported this PhD throughout, and it is a testament to his belief in the importance of collecting high quality routinely collected data on burn injuries. The COVID-19 pandemic meant that we could not travel between India and the UK for much of my PhD. The SASHI project was able to keep going because of the strong relationships that had been forged over years. Murali, Sudeep, Sumanth, Rajesh,

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### **Thesis structure**

I have chosen to present my thesis in the alternative format allowed by Bangor University. The body of this thesis comprises of a series of papers that are either published or under review by a journal. This approach has allowed me to address a particular learning need within the overall doctoral programme, which was to gain more experience of paper writing, peer review, and publishing contemporaneously. Each paper and its protocol (where applicable) form a chapter. Each chapter is prefaced by a short explanation of how the paper relates to other chapters and the overall thesis question. The structure of published manuscripts necessitates some repetition of content between chapters to ensure there is sufficient background information to justify the research. The introductory chapter provides a general introduction to injury morbidity surveillance and the need for improved surveillance on burn injury intent. The introduction of each chapter justifies the need for that piece of research specifically.

Papers from chapters two to six have been published. Content from an upcoming book chapter has been adapted for chapter one. Further detail, including my contribution, can be found in the section 'Publications arising from this work and author contributions'. Preliminary results from most of the chapters have been presented at regional, national, or international conferences. Valuable feedback has been gained from these conferences that has shaped the resulting manuscripts. Further detail can be found in the section 'Presentations arising from this work'.

### Publications arising from this work and author contributions

### Introduction (chapter one) informed by book chapter

<u>Submitted for publication</u>: Bebbington E, Rezaeian M. Suicide and Violence. In: Poole R, Khan M, Robinson C, editors. Preventing Suicide: An evidence based approach: Cambridge University Press/ Royal College of Psychiatrists. Anticipated publication early 2024.

### Study roles and responsibilities

- Emily Bebbington: I was jointly responsible for conceptualisation of the book chapter. I completed analyses, visualisations, wrote the first draft of the chapter, and finalised the chapter.
- Mohsen Rezaeian was responsible for overseeing the book chapter, helped to conceive the work, and edited the chapter.

# Exploring the similarities and differences of burn registers globally: A data dictionary comparison study (Chapter two)

<u>Paper 1 – Published:</u> Bebbington E, Miles J, Peck M, Singer Y, Dunn K, Young A. Exploring the similarities and differences of variables collected by burn registers globally: protocol for a data dictionary review study. BMJ Open. 2023;13:e066512. doi: 10.1136/bmjopen-2022-066512. [1] Copyright information: © Author(s) (or their employer(s)) 2023. Re-use permitted under CC BY. Published by BMJ. This is an open access article distributed in accordance with the Creative Commons Attribution 4.0 Unported (CC BY 4.0) license, which permits others to copy, redistribute, remix, transform and build upon this work for any purpose, provided the original work is properly cited, a link to the licence is given, and indication of whether changes were made. See: https://creativecommons.org/licenses/by/4.0/.

### Study roles and responsibilities

- Emily Bebbington: I was jointly responsible for conception of the study and refinement of the methods. I was responsible for visualisations, writing the first draft of the manuscript, and finalising the manuscript.
- All authors helped to conceive the study, refine the methods, and review and agree on the final version of the manuscript.

<u>Paper 2 – Published:</u> Bebbington E, Miles J, Young A, van Baar ME, Bernal N, Brekke RL, van Dammen L, Elmasry M, Inoue Y, McMullen KA, Paton L, Thamm OC, Tracy LM, Zia N, Singer Y, Dunn K. Exploring the similarities and differences of burn registers globally: Results from a data dictionary comparison study. Burns. 2024. doi: 10.1016/j.burns.2024.01.004 [2] Copyright information: © 2024 The Authors. Published by Elsevier Ltd. This is an open access article distributed under the terms of the Creative Commons CC-BY license, which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

### Study roles and responsibilities

- Emily Bebbington: I was responsible for management of the project including coordination with all international partners. I helped to conceive the study and refine the methods with the aid of Joanna Miles, Amber Young, Yvonne Singer, and Ken Dunn. I extracted, verified, and analysed data with the help of Joanna Miles. I was responsible for visualisations, data management, writing the first draft of the manuscript, and finalising the manuscript.
- Margriet E. van Baar, Nicole Bernal, Ragnvald Ljones Brekke, Lotte van Dammen, Moustafa Elmasry, Yoshiaki Inoue, Kara A. McMullen, Lia Paton, Oliver C. Thamm, Lincoln M. Tracy, Nukhba Zia, and Ken Dunn provided contextual information about each register and verified information where required.
- Amber Young, Yvonne Singer, and Ken Dunn were responsible for supervision of the project.
- All authors reviewed and agreed on the final manuscript.

# Terminology and methods used to differentiate injury intent of hospital burn patients in South Asia: A systematic scoping review (Chapter three)

<u>Paper 3 – Published:</u> Bebbington E, Ramesh P, Kakola M, McPhillips R, Bibi F, Hanif A, Morris N, Khan M, Poole R, Robinson C. Terminology and methods used to differentiate injury intent of hospital burn patients in South Asia: a systematic scoping review protocol. Systematic Reviews. 2023;12:153. doi: 10.1186/s13643-023-02317-y [3]. Copyright information: This is an open access article distributed under the terms of the Creative Commons CC BY license, which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited. You are not required to obtain permission to reuse this article. CCO applies for supplementary material related to this article and attribution is not required.

- Emily Bebbington: I jointly devised the scoping review question with Mohan Kakola, Rob Poole, and Catherine Robinson. I developed the search strategy with the help of Nia Morris. I developed a table of terms and summary for non-specialist readers with the help of Fatima Bibi and Atiya Hanif. I was responsible for writing the first draft of the manuscript and finalising the manuscript.
- Fatima Bibi and Atiya Hanif checked the manuscript for accessibility for practitioners and non-specialists.
- Rob Poole and Catherine Robinson were responsible for supervising the project.
- All authors helped to refine the study methods, and comment on and approve the final manuscript.

Paper 4 – Published: Bebbington E, Ramesh P, McPhillips R, Bibi F, Khan M, Kakola M, Poole R, Robinson C. Terminology and methods used to differentiate injury intent of hospital burn patients South in Asia: Results from a systematic scoping review. Burns. 2023. doi: 10.1016/j.burns.2023.10.008. [4] Copyright information: © 2023 The Author(s). Published by Elsevier Ltd. This is an open access article distributed under the terms of the Creative Commons CC-BY license, which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

### Study roles and responsibilities

- Emily Bebbington: I was responsible for documenting changes from the protocol, completing searches, and data management. I completed screening with the help of Parvathy Ramesh.
   I was responsible for data extraction, analyses, visualisations, writing the first draft of the manuscript, and finalising the manuscript.
- Parvathy Ramesh completed verification of extracted data.
- Rebecca McPhillips was responsible for resolving conflicts during the screening process.
- Rob Poole and Catherine Robinson were responsible for supervising the project.
- All authors commented on and approved the final manuscript.

# Establishing self-harm registers: The role of process mapping to improve quality of surveillance data globally (Chapter four)

<u>Paper 5 – Published:</u> Bebbington E, Poole R, Kumar SP, Krayer A, Krishna M, Taylor P, Hawton K, Raman R, Kakola M, Srinivasarangan M, Robinson C. Establishing Self-Harm Registers: The Role of Process Mapping to Improve Quality of Surveillance Data Globally. International Journal of Environmental Research and Public Health. 2023;20:2647. doi: 10.3390/ijerph20032647. [5] Copyright information: © 2023 by the authors. Licensee MDPI, Basel, Switzerland. This article is an open access article distributed under the terms and conditions of the Creative Commons Attribution (CC BY) license (https://creativecommons.org/licenses/by/4.0/).

### Study roles and responsibilities

- Emily Bebbington: I jointly conceived the project with Rob Poole and Catherine Robinson. I
  was responsible for initial data collection and was helped by Rajesh Raman, Mohan Kakola,
  and Madhu Srinivasarangan. I was responsible for data analysis, visualisations, writing the
  first draft of the manuscript, and finalising the manuscript.
- Sudeep P Kumar and Anne Krayer completed pilot work.
- Rob Poole and Catherine Robinson were responsible supervising the project. They
  completed repeat interviews with the help of Rajesh Raman, Mohan Kakola, and Madhu
  Srinivasarangan.
- All authors refined the study methodology, reviewed process maps, and commented on and approved the final manuscript.

# Development of an electronic burns register: Digitisation of routinely collected hospital data for global burns surveillance (Chapter five)

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- Emily Bebbington: I helped to refine the study methods with Mohan Kakola, Rob Poole, and Catherine Robinson. I completed the process mapping exercise with help from Mohan Kakola, Rajagopal Rajendra, Murali Krishna, Rob Poole, and Catherine Robinson. I designed the data entry form, completed data entry, and undertook first pass verification. I was responsible for data analysis, visualisations, writing the first draft of the manuscript, and finalising the manuscript.
- Mohan Kakola had the original idea.
- Mohan Kakola, Santhosh Nagaraj, Sathish Garuswamy, Sumanth Majgi, Rajagopal Rajendra, and Murali Krishna located and scanned the register books.
- Santhosh Nagaraj and Sathish Garuswamy completed quality checks.
- Rebecca McPhillips was responsible for second pass verification.
- Rob Poole and Catherine Robinson supervised the project.
- All authors commented on and approved the final manuscript.

### Exploring misclassification of injury intent: A burn register study (Chapter six)

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### Study roles and responsibilities

- Emily Bebbington: I refined the study idea with Mohan Kakola, Rob Poole, and Catherine Robinson. I was responsible for cleaning and analysing the data. I completed all visualisations, wrote the first draft of the manuscript, and finalised the manuscript.
- Rob Poole and Catherine Robinson supervised the project.
- All authors reviewed raw and analysed data, and provided contextual interpretations. All authors commented on and approved the final manuscript.

### Presentations arising from this work

# Exploring the similarities and differences of burn registers globally: A data dictionary comparison study (Chapter two)

<u>Invited national verbal presentation</u>: *Past, present and future role of registries in the prevention and care of burn injuries,* Scottish Burn Centre Inaugural Meeting on Burns Critical Care, Glasgow, September 2023.

<u>Invited regional verbal presentation</u>: *Exploring the similarities and differences of burn registers globally: Results from a data dictionary comparison study*. Offender Health research Network Conference, Wrexham, May 2023.

# Terminology and methods used to differentiate injury intent of hospital burn patients in South Asia: A systematic scoping review (Chapter three)

<u>Invited international verbal presentation</u>: *International differences in determination of burn injury intent*. 21st Congress of the International Society for Burns Injuries, Mexico, August 2022.

# Establishing self-harm registers: The role of process mapping to improve quality of surveillance data globally (Chapter four)

<u>International poster presentation</u>: Using process mapping to strengthen case ascertainment of a self-harm register in two hospitals in India. International Association for Suicide Prevention 31<sup>st</sup> World Congress, Hybrid meeting, September 2021.

<u>International verbal presentation</u>: Using process mapping to strengthen case ascertainment of a self-harm register including burns patients in two hospitals in India. 20<sup>th</sup> Congress of the International Society for Burns Injuries, Online meeting, June 2021.

# Development of an electronic burns register: Digitisation of routinely collected hospital data for global burns surveillance (Chapter five)

<u>National verbal presentation</u>: *Establishing burn registers: The role of digitisation of routinely collected data globally.* British Burn Association 55<sup>th</sup> Annual Meeting, Dublin, June 2023.

<u>International verbal presentation</u>: *Digitisation of a tertiary government hospital burn register in south India.* World Health Organisation 14th World Conference on Injury Prevention and Safety Promotion, Adelaide, November 2022.

### Exploring misclassification of injury intent: A burn register study (Chapter six)

<u>National poster presentation</u>: *Exploring differential misclassification bias of burn injury intent: A burn register study.* British Burn Association 55<sup>th</sup> Annual Meeting, Dublin, June 2023.

International verbal presentation: Exploring differential misclassification bias of injury intent in an Indian burn register. World Health Organisation 14th World Conference on Injury Prevention and Safety Promotion, Adelaide, November 2022.

<u>National verbal presentation</u>: *Misclassification in routinely collected health data: considerations for global health.* Data science in Health and Medicine, Pan Wales Alan Turing Institute Networking Meeting, Cardiff, September 2022.

### Abstract

#### Introduction

Burns are a major source of morbidity, accounting for over 16 million injuries annually. Approximately 8% of burns are intentional. Information about intent is essential to inform preventative interventions. Most intentional injuries occur in low- and middle-income countries, particularly in South Asia. There is a lack of high-quality data on injury intent in many parts of the world. Where data are collected, such data are prone to bias due to social and legal factors. The core research question that this thesis aimed to address was: "How can international burn injury morbidity surveillance data be strengthened to better differentiate burns that are: unintentional; due to self-harm; or due to interpersonal violence?".

#### Methods

The thesis research question was addressed through five studies. Each corresponds to a chapter of the thesis. In chapter two (papers 1 and 2), I investigated data that are collected about injury intent across 13 international burn registers. Data dictionaries were compared, and potential sources of bias were considered. In chapter three (papers 3 and 4), I used a systematic scoping review to investigate injury intent data from South Asia. Terminology and methods used to differentiate intent of hospital presenting burns were investigated. In chapter four (paper 5), I used process mapping to design a robust case ascertainment strategy for a new self-harm register that includes intent information at two hospitals in south India. In chapter five (paper 6), I describe how to assess the quality of existing hospital-based surveillance data on injury intent and then digitise these data from a hospital in south India. I analysed these data using exploratory data analysis techniques to investigate patient groups that may be at risk of misclassification of injury intent (chapter six – paper 7).

#### Results

A lot of information is being collected about burn injury intent internationally. Data dictionaries from national-level burn registers include 43 variables about intent across 12 registers. The systematic scoping review showed that 89 primary research studies from South Asia included information on injury intent. Lack of definitions for key terms limit data comparisons. Where method of assessment for intent is described, it is primarily based on clinician documentation. In South Asia, this is likely to be influenced by medicolegal processes where patient reported intent

must be documented. Process mapping showed that multiple routes to emergency care in hospitals in south India could introduce selection bias into data. I showed that a government hospital in south India collects high-quality handwritten burn injury information. Digitisation of these data was possible and yielded very low error rates (0.06% per field). Exploratory analyses of these data indicate that some groups (e.g. women with large total body surface area burns) may be misclassified, and that overwriting of intent data may be a useful predictor of misclassification.

### Conclusions

I have identified numerous ways that the international burns community can strengthen intent data. Firstly, digitisation of high-quality handwritten routinely collected data is a feasible way to begin to address data inequity in low- and middle-income countries. Secondly, there needs to be development of a common data element for injury intent to reduce the risk of misclassification. This should include standardised definitions and method of assessment, and be acceptable to clinicians and patients. It can be implemented in all burn registers and used as a reporting standard in publications. It is likely that an explicit reduction of the concept of intent in injury surveillance to 'Who did the act that resulted in the burn injury?' would minimise confusion amongst professional groups, but still provide valuable public health data. Thirdly, process mapping is a useful technique to explore and document potential sources of selection bias in registers that include intent information. Finally, exploratory data analyses are a promising method to identify misclassification in existing intent data, and should be encouraged in burn injury studies. **Chapter one – Introduction** 

### Development of injury morbidity surveillance

Surveillance is defined as:

### "The ongoing systematic collection, collation, analysis, and interpretation of data and the dissemination of the information to facilitate disease prevention." [8]

The historical origins of surveillance lie in the detection and control of communicable diseases that pose a threat to global public health. The first documented public health measure taken by a government in Europe to control a disease was by the Venetian Republic in 1348 [9]. Ships were excluded from port that had people aboard with pneumonic plague. The first population estimates of a disease were completed in 1662 by combining centrally collated mortality data for the plague with estimates of the population of London. This highlighted the utility of aggregating data to understand disease causes on a population level. Over the following centuries different types of surveillance data sources were developed. By the early 1900s there was mandatory reporting of communicable disease, death certification, an international list of causes of death, national health surveys, and disease registers. In the mid-20<sup>th</sup> Century, it became evident that representative and timely data was necessary to inform prevention and control activities beyond communicable diseases. This led to the development of surveillance systems for a broader range of health conditions including injuries [9].

The World Health Organization definition of an injury is:

"Injuries are caused by acute exposure to physical agents such as mechanical energy, heat, electricity, chemicals, and ionizing radiation interacting with the body in amounts or at rates that exceed the threshold of human tolerance. In some cases, (for example, drowning and frostbite), injuries result from the sudden lack of essential agents such as oxygen or heat" [10].

For many decades the preventable nature of injuries was underrecognised; most injuries were framed as unpreventable "accidents" [11]. The huge burden of morbidity and mortality from road traffic injuries eventually changed this misconception. It led to the development of injury surveillance and prevention practices that we recognise today. Widespread global motorisation from the 1930s onwards resulted in road traffic injuries. It is estimated that during the second world war 370,000 American citizens were injured as a result of war, whereas 588,000 were injured due to road traffic collisions [12]. The World Health Organization (WHO) was established in 1948 by the United Nations as a global organisation to control the spread of communicable diseases [13]. The first two decades of its existence were dominated by control of diseases such as tuberculosis,

malaria, and smallpox. In 1948 the WHO became the custodian of the sixth version of the International Classification of Diseases (ICD) [14]. ICD remains the standard text for categorisation of diseases to allow compilation and comparison of morbidity and mortality data internationally. Version six included, for the first time, a separate chapter to allow coding of the cause of injury (including intent). This is still known as the 'External causes of morbidity or mortality' chapter [15]. In 1951 the United States recorded their one millionth death from road traffic injuries. The WHO began to define road traffic injuries as a health issue, recognising that deaths from this cause outnumbered many communicable and non-communicable diseases. It was recognised that there was little data on the larger number of non-fatal road traffic injuries. These injuries resulted in significant morbidity for people of working age and negatively affected economic development [12].

Public health prevention efforts in the 1950s focused on driver education, but this approach did little to curb the number of injuries [16]. The political climate of social change and increasing recognition of the structural determinants of health in the 1960s, eventually led to new policy for road and car safety. This included enforcement of seat belt laws, speed limits, and crash testing during car development. Publication of the Haddon Matrix by William Haddon in 1968 further dispelled the idea that injuries were not preventable [17]. The model considers all factors that cause a road traffic injury (host, agent, environment) during all phases of the event (before, during, after). It influenced understanding about the breadth of variables that should be measured in a surveillance system to inform prevention strategies. The Haddon matrix was initially applied to road traffic injuries, but has subsequently been used for a variety of injury types. It remains popular today to guide primary, secondary, and tertiary prevention programmes [18, 19]. Prevention strategies that focussed on vehicle and road safety, rather than individual agency, led to huge reductions in mortality from road traffic injuries in many high-income countries between 1975 and 1998 (e.g. 63.4% reduction in Canada) [12]. The same progress was not seen in low- and middle-income countries and this inequity remains today. Of the estimated 1.3 million annual deaths from road traffic collisions, 93% are believed to occur in low- and middle-income countries [20].

The epidemic number of road traffic injuries in the 20<sup>th</sup> century meant that the burden of injuries globally could not be ignored. Over the same time period other injury types were recognised to contribute to excess morbidity and mortality, particularly in children and working age people. Advancements were made in the surveillance and prevention of workplace, home, and childhood injuries [21]. Treatment of injuries progressed through the systematic expansion of hospital based emergency care. In 1968 the American College of Emergency Physicians was founded, and in 1972 the new speciality of Accident and Emergency Medicine was created in the UK [22]. These

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departments became pivotal in secondary and tertiary prevention of injuries, and became important sites for collection of morbidity surveillance data on injuries. Morbidity is defined as:

"The state of being symptomatic or unhealthy for a disease or condition. It is usually represented or estimated using prevalence or incidence. Prevalence describes the proportion of the population with a given symptom or quality...Incidence shows the frequency at which individuals within a specific population develop a given symptom or quality." [23]

The greatest strides in injury surveillance were seen in the 1980s and 1990s. In 1989 the first World Conference on Injury Prevention and Control was held in Sweden by the WHO. Delegates resolved to find ways to prevent injury, reduce harm, treat injury, and rehabilitate injury [11]. It was reiterated that the shortage of data, particularly on morbidity, was a major limiting factor to achieving these aims. Multiple revisions were made to the external causes of injuries chapter prior to the release of the 10th Revision International Classification of Diseases (ICD-10) in 1990. This allowed better coding of morbidity data in clinical settings [24]. It is believed that ICD-10 has been used to allocate 70% of the worlds health expenditure, and is used by 110 countries for cause of death data [25]. In 1998 a more detailed, supplementary, classification system for injury causation was released, known as the International Classification of External Causes of Injury (ICECI) [26]. This was designed to aid researchers and practitioners in the surveillance and prevention of injuries. ICD-10 and ICECI could only be used in settings with existing injury surveillance programmes, which were primarily found in high-income countries.

In 1993 the first Global Burden of Disease (GBD) study was published [27]. This landmark study allowed comparison of the incidence, prevalence, and long-term impact of disease and injuries between countries. These data were essential to allowing tracking of progress towards agreed global health targets. It was the first study to use a composite metric for mortality and morbidity known as disability-adjusted life year. Disability adjusted life year represents the loss of one year of full health. It combines years of life lost from premature death and years of healthy life lost. This metric helped to highlight the full impact of injuries (fatal and non-fatal), which had not been fully appreciated by many policy makers more familiar with mortality data (Figure 1) [27].

**Figure 1.** Total global disease burden by cause 1990 to 2019 [28]. Total disease burden measured as Disability-Adjusted Life Years (DALYs) per year. DALYs measure the total burden of disease – both from years of life lost due to premature death and years lived in less than full health. One DALY equals one lost year of healthy life. The proportion of DALYs due to injuries globally remains at approximately 10%.



The GBD study continues to provide the best available international morbidity estimates for injuries. It utilises a variety of data sources (Table 1). Imputation and modelling are necessary for many lowand middle-income countries that do not have representative data available for analysis [29]. Paradoxically, countries with the lowest availability of data are estimated to have the highest burden of disease (Figure 2). In 2001 the WHO published *Injury Surveillance Guidelines* to help fill the void in morbidity data on injuries. It includes information about how to establish, design, and maintain good injury surveillance systems where they do not already exist [11]. The guidelines remain relevant today as many low- and middle-income countries still do not have national injury surveillance systems.

Table 1. Morbidity	/ data sources	used by	y GBD	[30]
			/	

Data source	Definition
Hospital data	ICD coded data from public and private hospitals. It may include
	inpatient records, discharge data, and outpatient data.
Health insurance claims data	ICD coded data that describe patient-provider interactions
Household surveys	Information collected for a defined population on health behaviours
	and wellbeing.
Disease registers	Centralised databases that collect information on patients with a
	specific condition.
Morbidity notification data	Data collected about individual cases of notifiable diseases.
Published literature	Articles and papers from the published and grey literature that
	include health related data.

**Figure 2.** Disease burden from injuries, 1990 to 2019 [28]. Disease burden is measured in DALYs (Disability-Adjusted Life Years). DALYs are used to measure total burden of disease - both from years of life lost and years lived with a disability. One DALY equals one lost year of healthy life.



### **Differentiation of injury intent**

ICD is the international standard for classification of morbidity and mortality data. Its definitions and categorisation system, although not implemented universally, are the most widely accepted standard for injury causation in the health research and medical community. WHO regulations mandate that the most recent version of ICD is implemented by all member states. The 11<sup>th</sup> Revision came into effect in 2022, but many countries are still in the process of transitioning to ICD-11 [31]. ICECI was merged with the external causes of injury chapter in the 11<sup>th</sup> Revision of ICD [26]. There are multiple data elements used in the classification of injury causation [10]. The main elements are intent (e.g. self-harm) and mechanism (e.g. contact with hot object or liquid). Additional postcoordination elements become available in the ICD-11 electronic coding tool depending upon the chosen category of injury intent and mechanism (e.g. Intentional self-harm by contact with hot object or liquid). Postcoordination elements include, amongst others, activity when injured (e.g. paid work), object or substance producing injury (e.g. stove), place of occurrence (e.g. home – detached house), and alcohol and drug use in injury.

Intent is the first level of classification of the cause of an injury in ICD. It is recommended as the first level of classification in the Centres for Disease Control Injury Surveillance Training Manual and WHO injury Surveillance Guidelines [11, 32]. Intent takes precedent in the classification systems because it is recognised that monitoring these data is important to determine the effectiveness of interventions that involve changes in human behaviour [33]. This information can guide patient care and prevent injury recurrence. Categories used in the classification of intent are shown in Figure 3. "Unintentional" is preferred over "accidental" by the injury prevention community in order emphasise the preventable nature of all injuries [34]. Intentional injuries are subclassified into self-harm; interpersonal violence; legal interventions; and war, civil insurrection and disturbances.

**Figure 3.** Injury intent classification terms used in the International Classification of Diseases 11<sup>th</sup> Edition chapter 23 External causes of morbidity and mortality [10].



The GBD study estimates that in 2019 there were over 700 million injuries globally, of which 93.4% were classified as unintentional, 0.7% due to self-harm, 4.5% due to interpersonal violence, 0.1% due to execution or police conflict, and 1.4% due to conflict or terrorism (Table 2) [35]. The World

Bank estimates there are 7.95 billion people globally of whom 8.9% live in low-income countries, 40.3% in lower-middle income countries, 35.1% in upper-middle income countries, and 15.7% in high-income countries [36]. Global trends in the number of injuries varies by World Bank income group (Table 2). Most intentional injuries occur in low- and middle-income countries. High-income countries have a disproportionate age-standardised incidence rate of injuries due to self-harm. Injuries due to executions and police conflict, and conflict and terrorism mainly affect low- and lower-middle-income countries. Gender patterns are more uniform across World Bank income groups. Unintentional injuries occur slightly more often in men than women, injuries due to self-harm occur more in women, and a much greater number of injuries due to other forms of violence are recorded in men (Table 2).

**Table 2.** Incidence of injury disaggregated by cause of injury and World Bank income levels. Number of injuries (and column percentages) and age-standardised incidence per 100,000 people are shown for the year 2019. M:F ratio is the number of male injuries divided by female injuries, such that for every one male injury there would be the result number of female injuries. Abbreviations: LIC, low-income countries; LMIC, lower-middle-income countries; UMIC, upper-middle-income countries; HIC, high-income countries. Data downloaded from the Global Burden of Disease Study 2019 [35].

	Unintentional	Self-harm	Interpersonal violence	Executions and police conflict	Conflict and terrorism
Global					
n	666,151,749	4,963,597	32,240,049	404,729	9,790,702
Rate	8645.26	62.50	413.43	5.31	133.18
M:F ratio	1.43	0.70	2.95	3.43	1.54
LIC					
n (%)	46,521,214 (7.0%)	190,437 (3.8%)	1,672,863 (5.2%)	131,770 (32.6%)	4,262,704 (43.5%)
Rate	6247.76	31.18	239.50	18.15	610.07
M:F ratio	1.26	0.91	2.53	3.11	1.22
LMIC					
n (%)	258,489,871	2,019,344	14,412,444	256,264	4,905,998
	(38.8%)	(40.7%)	(44.7%)	(63.3%)	(50.1%)
Rate	8130.27	60.48	441.39	7.78	149.73
M:F ratio	1.36	0.52	3.01	3.58	1.82
UMIC					
n (%)	207,059,021	1,427,170	11,417,242	16,565	620,647
	(31.1%)	(28.8%)	(35.4%)	(4.1%)	(6.3%)
Rate	8029.75	50.93	435.12	0.69	28.65
M:F ratio	1.70	0.85	2.98	4.11	2.11
HIC					
n (%)	154,081,643	1,326,646	4,737,500	129	1,354
	(23.1%)	(26.7%)	(14.7%)	(0.03%)	(0.01%)
Rate	13383.98	108.81	454.33	0.01	0.15
M:F ratio	1.28	0.83	2.83	3.60	2.01

It is important to recognise that where nationally representative data is not available, estimates are generated using modelling techniques. Discrepancies have been found for estimates of mortality between the WHO, GBD, and national data in countries without high quality vital registration systems [37, 38]. 71% of high-income countries have death registration data of sufficient quality to be used for intercountry comparisons and time series analyses, compared to only 11% of low- and middle-income countries [39]. Mortality data have been reported in consistent ways internationally for many years. Conversely, morbidity reporting has developed in divergent ways based on local healthcare provision meaning reporting is not standardised internationally and data may not be disaggregated by intent [40]. It is likely, therefore, that estimates of non-fatal injuries are less accurate than fatal injuries. The lack of consistently collected and reported hospital-based surveillance data on injuries is the first major issue affecting the utility of morbidity surveillance data to differentiate injury intent.

The second major issue affecting the utility of morbidity surveillance data to differentiate injury intent is the risk of misclassification. Routinely collected hospital data such as admission records and disease registers are key sources of intent data for non-fatal injuries. Determination of intent is typically completed by the healthcare professional taking the history from the patient and then documenting the findings in the patient record [41]. The patient record is then used by a coder or data entrant to extract relevant information on injury intent [42]. It is recognised that accurate determination of intent is difficult because of the influence of personal, social, cultural, and legal sensitivities [31]. This can lead to misclassification of intent at multiple points in the collection of surveillance data (Figure 4).



Figure 4. Points where misclassification can occur (yellow arrows) in an individual patient record.

ICD defines the clinical concept of intent as:

#### "whether or not they [injuries] were deliberately inflicted and by whom" [10].

Definitions for classifier terms (e.g. unintentional, self-harm) are not provided in ICD documentation [42]. The ICD definition of intent combines two pieces of information: (i) whether the injury was deliberate; and (ii) who inflicted the injury. It can be difficult to collect data in acute clinical settings about whether an injury was deliberate because the patient may be unsure of underlying motives such as the intention to die (i.e. in cases of self-harm) or to inflict death (i.e. in cases of interpersonal violence) [43]. Use of broad neutral terms for subclassification of intentional injuries helps to mitigate this. For example, 'self-harm' can be used rather than 'suicidal' or 'non-suicidal' injury.

Classification of intent, therefore, hinges upon the second piece of information – determining who inflicted the injury. Patients may be reluctant to disclose self-harm due to stigma or fear of criminal investigation, particularly in countries where suicide has not been decriminalised [44, 45]. Domestic violence or assault may not be disclosed due to coercive control, "honour", fears over personal and financial safety, and police investigation [46]. Healthcare professionals may be affected by social and cultural norms, requirements to report information to the police, and conflict between understanding of capacity and consent [47, 48]. Accuracy of intent information in surveillance data tends to measure whether the external cause code assigned by the coder matches the patient notes [49]. Healthcare professionals have greater scope for recording insufficient or inaccurate information. This can lead coders to use default categories, typically "unintentional", where data is insufficient in medical records [32]. Intent is an important variable, but one in which the likelihood of misclassification bias is high.

### Importance of collecting surveillance data on intentional injuries

Intentional injuries are estimated to account for 6.6% (47 million) of all non-fatal injuries that occur globally each year (Table 2). There is a 14-fold greater burden of unintentional injuries compared to intentional injuries, which may lead some to question the importance of strengthening surveillance data on injury intent. There are two main reasons why this is important. Firstly, it is not known how biased our current estimates of each subclassification of intent are. Factors affecting this include selection bias due to lack of data collection in low- and middle-income countries, and the risk of misclassification where data is collected. Secondly, violence is an important wider determinant of health making its accurate surveillance a necessary public health function. Violence, whether self-

inflicted or directed against another person, has profound long-term effects on individuals, communities, and society.

The World Health Organization defines violence as:

"The intentional use of physical force or power, threatened or actual, against oneself, another person, or against a group or community, that either results in or has a high likelihood of resulting in injury, death, psychological harm, maldevelopment or deprivation" [50].

This definition captures all intentional injuries. Violence can be directed towards oneself (i.e. selfharm), against another (i.e. interpersonal violence), directed towards a citizen by the state (i.e. legal intervention), or collective (i.e. war). The definition makes it clear that violence, or the threat of violence, has further reaching consequences than physical injury or death. It can lead to psychological harm, developmental issues, poverty, and inequalities.

It is recognised that the antecedents and consequences of all forms are violence are interrelated, but all forms of violence are rarely considered under the same framework at a national level. The UK has a national suicide prevention strategy prepared by the Department of Health and Social Care, and a Serious Violence Strategy prepared by the Home Office that focuses on homicide and other forms of interpersonal violence [51-54]. The separation of self-harm from other forms of violence is seen in the United Nations Sustainable Development Goals. The Sustainable Development Goals were adopted by all United Nations Member States in 2015 [55]. Violence reduction goals are spread across multiple indicators using a variety of surveillance data (Table 3) [56]:

**Table 3.** Sustainable Development Goals relevant to the reduction of global violence.

Goal	Target	Surveillance data
Good health	By 2030, reduce by one third	(i) Mortality rate attributed to cardiovascular disease,
and	premature mortality from non-	cancer, diabetes or chronic respiratory disease; (ii)
wellbeing 3.4	communicable diseases through	Suicide mortality rate
	prevention and treatment and	
	promote mental health and	
	well- being.	
Gender	Eliminate all forms of violence	(i) Proportion of ever-partnered women and girls aged
equity 5.2	against all women and girls in	15 years and older subjected to physical, sexual or
	the public and private spheres,	psychological violence by a current or former intimate
	including trafficking and sexual	partner in the previous 12 months, by form of
	and other types of exploitation.	violence and by age; and (ii) Proportion of women and
		girls aged 15 years and older subjected to sexual
		violence by persons other than an intimate partner in
		the previous 12 months, by age and place of
Doaco	Significantly roduce all forms of	(i) Number of victime of intentional hemicide per
iustice and	violence and related death rates	100,000 population, by sex and age: (ii) Conflict-
strong	everywhere	related deaths per 100 000 population by sex age
institutions		and cause: (iii) Proportion of population subjected to
16.1		(a) physical violence (b) psychological violence and (c)
1011		sexual violence in the previous 12 months: (iv)
		Proportion of people that feel safe walking alone
		around the area they live.
Peace,	End abuse, exploitations,	(i) Percentage of children aged 1-17 years who
justice, and	trafficking and all forms of	experienced any physical punishment and/or
strong	violence against and torture of	psychological aggression by caregivers in the past
institutions	children.	month; (ii) Number of victims of human trafficking per
16.1		100,000 population, by sex, age group and form of
		exploitation; (iii) Proportion of young women and men
		aged 18-29 years who experienced sexual violence by
		age 18.

The Sustainable Development Goals were established based on the understanding that progress in one area of economic, social, or environmental equity influences all other areas. Responsibility for monitoring and submission of surveillance data used in each violence-related goal falls to different systems including health, coronial, police, and criminal justice [57]. Responsibility for acting upon these data may be siloed to respective systems, limiting the reach of interventions. Self-harm is the only typology of violence that is situated under health and wellbeing. It is not included in Sustainable Development Goal 16.1 (significantly reduce all forms of violence), which is instead situated with peace and justice. Relatively high rates of suicide and self-harm occur in high-income countries, whereas the highest number of other forms of violence are seen in low- and middle-income countries. This raises the question whether separating suicide from other forms of fatal violence is a manifestation of global health inequity.
Historically self-harm and interpersonal violence have been considered under the same theory, known as stream analogy [58]. Studies applying this theory have found that similar cultural, societal, and structural factors lead to the conditions that enable self-harm and interpersonal violence [59]. Decriminalisation of suicide is an important mechanism in recognising and addressing the individual, environmental, socioeconomic, and wider societal factors that lead to self-harm. Interpersonal violence is more likely to be treated as a law-and-order matter, which is unlikely to tackle the antecedents leading to the violent act. There are examples where improvements in outcomes have been achieved by utilising a public health approach to reduce interpersonal violence. Scotland's Violence Reduction Unit reframed knife crime as a public health problem calling it a "disease affecting communities" caused by structural inequities [60]. Upstream preventative approaches were co-produced with those with lived experience of violent crime. The resultant community engagement programmes promoted a culture of hope, respect, and trust. This led to a 55% reduction in emergency hospital admissions for assault over an 8 year period.

The antecedents and consequences of all forms are violence are interrelated and perpetuate other forms of violence. It is estimated that half of the world's children (1 billion) are exposed to violence annually [61]. Adverse childhood experiences (ACEs) are stressors experienced before the age of 18. These include abuse; domestic violence; and exposure to peer, community, or collective violence. Compared to children who have experienced no ACEs, children who have experienced four or more ACEs have five times the risk of problematic alcohol use, ten times the risk of problematic drug use, seven times the risk of being the victim or perpetrator of interpersonal violence, and 30 times the risk of making a suicide attempt [62]. Exposure to violence can occur at multiple points during the life course and from multiple sources. Injury morbidity and mortality statistics for the subcategory of "war, civil insurrection, and disturbances" provides a numerical estimate of the number of casualties sustained during combat. But this does not fully represent the extent of violence incurred during conflict. War facilitates the displacement of people, and the failure of policy and law enforcement. Women, children, and minority groups become more vulnerable to human trafficking, which is the mediator of modern slavery. 71% of those in modern slavery are women and girls [63]. Violence and physical harm are hallmarks of trafficking in women [64].

Violence against women and girls occurs at all levels of society: transnational (e.g. peacekeeper exploitation, human trafficking); state (e.g. conflict); community (e.g. rape, "honour" killings); and family (e.g. child marriage). 38% of homicides in women are caused by an intimate partner compared to only 6% in men [55]. Women and girls who experience violence are at increased risk of suicide and self-harm [52]. Victims may fail to recognise the compound effect of violent acts and

that it violates their human rights. During a trip to Kyrgyzstan, the UN appointed Special Rapporteur on *violence against women, its causes and consequences* found that women believed their husband had the right to beat them for reasons such as refusing sex, disagreeing with their husband, or burning food [65].

Presentation to hospital following self-harm or assault is an important opportunity to recognise inequity and intervene. Creation of accurate surveillance data on injury intent requires all aspects of the system to work towards achieving social justice for victims. This includes creating an environment where the patient is willing to disclosure the cause of the injury, providing safe and effective interventions on an individual and community level, and utilising data to inform effective prevention policies.

## Burns as an important injury type for hospital-based surveillance

Surveillance guidance suggests that "in general, intent is primarily determined by the incident and not by the resulting injury" [66]. However, intentional injury is much more likely for some mechanisms such as hanging or ingestion of poison. Other injuries such as burns, falls, and transport events are more open to misclassification because the mechanism can be sustained in plausible unintentional and intentional circumstances. Differentiation of intent for these injuries is more complex. This thesis focuses on burn injuries as an exemplar of an injury type that requires strengthening of international surveillance data to better differentiate intent. The findings are likely to be applicable to other injury types as well.

#### ICD defines a burn injury as:

"an injury to the tissues caused by a pathological flux of energy which causes cellular destruction and irreversible denaturation of proteins and is primarily caused by thermal or other acute trauma. Inclusions: internal chemical burn or corrosion; external chemical burn or corrosion; burns from hot objects; burns from friction; burns from hot air and hot gases; burns from lightning." [67]

GBD estimates that 16.3 million burn injuries were sustained in 2019 [35]. Approximately 8% of all burns are intentional, but intentional injuries account for 14% of years lived in less than full health. This is likely to be because intentional burn injuries account for a greater proportion of larger surface area burns. Estimation of the number of burn injuries is complicated by the wide variety of mechanisms that can lead to a burn injury (Table 4). The most common cause of burn injuries is 'fire, heat, and hot substances', which accounts for 6.3 million annual burn injuries. But not all injuries from 'fire, heat, and hot substances' cause a burn. GBD estimates that in 2019 almost 9 million

injuries were caused by 'fire, heat, and hot substances'. It is easy to conflate injuries from 'fire, heat, and hot substances' with burn injuries [68, 69]. Defining inclusion criteria for a burn surveillance system is essential to ensure consistent case ascertainment and that data users understand the population under study.

**Table 4.** Incidence of all causes of burn injuries. Data extracted from the Global Burden of Disease studybased on the 'Injuries by nature' estimate [35].

Cause	Incidence	Lower Cl	Upper Cl
Total from all causes	16,339,833.41	13,835,467.61	19,332,508.83
Unintentional causes			
Fire, heat, and hot substances	6,270,915.07	4,669,393.83	8,022,790.26
Other unintentional injuries	2,801,084.03	1,769,367.26	4,112,790.84
Falls	2,183,451.42	1,308,533.22	3,558,870.67
Other exposure to mechanical forces	1,257,627.86	618,178.99	2,252,994.74
Environmental heat and cold exposure	421,502.60	245,286.59	701,833.35
Cyclist road injuries	348,182.92	184,139.11	606,608.16
Venomous animal contact	339,851.04	147,110.49	696,477.37
Pedestrian road injuries	301,219.82	172,448.98	537,368.38
Motorcyclist road injuries	296,974.23	173,112.12	488,446.25
Non-venomous animal contact	221,534.71	106,528.97	428,206.91
Motor vehicle road injuries	205,999.15	107,951.03	386,304.29
Foreign body in other body part	151,099.62	72,733.38	297,349.43
Other transport injuries	125,692.35	73,734.56	209,880.34
Unintentional firearm injuries	40,684.01	16,492.13	98,842.29
Other road injuries	30,641.59	8,706.44	79,900.40
Pulmonary aspiration and foreign body in airway	18,354.95	9,202.96	35,411.00
Poisoning by other means	17,387.54	9,647.27	29,743.58
Drowning	17,151.47	9,705.33	29,923.54
Exposure to forces of nature	16,243.45	9,538.41	25,779.05
Poisoning by carbon monoxide	7,323.13	3,711.62	13,224.63
Intentional causes			
Physical violence by other means	654,345.53	357,286.75	1,124,685.40
Conflict and terrorism	357,512.71	126,739.67	859,326.04
Self-harm by other specified means	160,517.30	103,674.71	244,091.31
Physical violence by sharp object	65,928.39	25,017.23	149,487.45
Physical violence by firearm	10,436.47	4,333.81	23,507.30
Executions and police conflict	9,245.20	3,720.17	21,291.48
Self-harm by firearm	8,926.83	3,710.12	17,860.73

There are income, geographical, and gendered patterns to burn injuries. 80% occur in low- and middle-income countries. Low- and lower-middle-income countries bear a disproportionate number of intentional burn injuries. South Asia has 24.1% of the world's population, but 47.4% of burn injuries due to self-harm and 33.1% due to interpersonal violence [36]. The vast majority of these occur in India. The GBD study estimates that females in South Asia have an age-standardised

incidence of 5.90 (CI 3.52-9.56) burn injuries due to self-harm per 100,000 people (Table 5) [35]. This is the highest of any region, and almost three times higher than the global age-standardised incidence of 2.2 per 100,000 people. South Asia is the only region where a higher incidence rate of unintentional injuries is reported in females than males. It is possible that the higher rate of unintentional burns in females is due to misclassification of intentional burns. These patterns are more pronounced in the India subset of data from South Asia.

**Table 5.** Age-standardised incidence of burn injuries disaggregated by injury intent per 100,000 population.Data shown for global, World Bank regions, and India. Data from the 2019 Global Burden of Disease study[35].

	Unintentional	Self-	Interpersonal	Executions and	Conflict and
		harm	violence	police conflict	terrorism
Global					
Male	219.91	1.59	12.19	0.16	5.15
Female	188.16	2.72	6.78	0.08	4.63
East Asia & Pacific					
Male	168.33	0.91	9.28	0.11	0.45
Female	145.96	1.20	5.74	0.05	0.33
Europe & Central Asia					
Male	408.77	4.30	13.61	0.02	0.52
Female	317.64	3.97	9.00	0.01	0.31
Latin America & Caribbean					
Male	336.98	0.81	20.73	0	0
Female	264.8	0.95	7.26	0	0
Middle East & North Africa					
Male	206.59	1.37	10.05	0.27	37.64
Female	180.45	2.07	6.31	0.20	30.19
North America					
Male	277.94	1.65	17.94	0	0
Female	240.45	2.31	9.13	0	0
South Asia					
Male	163.00	2.06	15.77	0.07	6.35
Female	180.64	5.90	8.69	0.05	7.71
Sub-Saharan Africa					
Male	148.14	0.53	6.03	0.65	6.40
Female	142.21	0.53	3.69	0.27	4.06
India					
Male	178.41	2.09	15.27	0.04	0.66
Female	198.75	7.08	9.58	0.02	0.34

A recent analysis by the GBD study provides a useful insight into the current limitations of GBD data and their vision for future areas of development [68]. The paper reiterates that data coverage is minimal in many low- and middle-income countries, which is likely to affect the accuracy of estimates. Where data is available, it is unclear whether patients uniformly seek medical care for minor burn injuries. This means there may be selection bias between international data sets. They suggest that more high-quality incidence data needs to be added to the GBD database and modelling framework, and that sources such as the World Health Organization Global Burn Registry may be a useful source of standardised data. They highlight that there is likely to be misclassification of burn injury intent in existing data, particularly from South Asia. They recommend that future research should include burns subclassified by intent, and that there should be a specific focus on burns due to self-harm and interpersonal violence in regions where this is a critical issue.

There are critically high rates of burn injuries in women due to self-harm and interpersonal violence in South Asia and neighbouring countries. The pervasiveness of the problem has led to the region being named the "geographical belt of self-immolation" [70]. Certain methods used to inflict burns have alternative names and associated cultural meaning. Their contribution to overall rates of burn injuries is difficult to quantify due to the likelihood of underreporting and misclassification:

- Sati means 'virtuous woman'. The term is typically associated with the practice of a woman dying by burning upon the funeral pyre of her husband either by voluntarily completing the act or through pressure from family [71]. A widow is by default 'asati' and can only achieve virtuousness through purification by burning. The practice received considerable attention by the British Victorian press. It was used as justification for continued colonial rule in order to enforce the 1829 law against sati. The most recent publicised case of sati was by Roop Kanwar in 1987. She is still worshipped in her hometown despite her death occurring 158 years after sati became illegal [72]. More modern interpretations of self-immolation suggest that loneliness due to abuse, poverty, and lack of autonomy may lead women to self-immolation [73].
- Dowry death is a category of death in the Indian Penal Code [74]. It applies to women who sustain a burn injury, have been married for under seven years, and who make an allegation of dowry related harassment. Dowry is the payment of money or goods from the bride's to the bridegroom's family upon marriage. The Dowry Prohibition Act was passed in India in 1961, but the practice remains commonplace today [75]. Harassment of the bride may occur if the dowry sum is deemed to be too little. This may lead to self-harm or assault. Women may be reluctant to make an allegation of abuse due to financial dependence, fear for their children, or coercion.
- *"Honour" related violence* is the practice of committing a crime to protect or defend the perceived "honour" of a family [46]. This may include the abuse or homicide of a woman

deemed to have brought shame on her family. "Honour" based violence is often associated with Islamic countries, but the practice existed before Islam was established. Suicide is condemned by the Koran and illegal in many Islamic countries. Despite this, there are high rates of self-immolation in young women in the WHO Eastern Mediterranean region where the primary religion is Islam [76, 77]. Burn injuries due to self-harm and "honour" based violence are perpetuated by patriarchal practices such as forced child marriage, and community acceptance of violence as a means to respond to conflict [78]. These same influences mean it is difficult for victims to accurately report the cause of burn injuries and seek help.

These types of violence are closely related. Each is experienced in the family or community, victims are unlikely to accurately report who inflicted the injury, and the risk of burn injury increases if the victim is part of more than one marginalised identity category (e.g. female and poor) [79]. Daruwalla et al. [44] completed qualitative interviews at burn units in Delhi and Mumbai and used the findings to construct a model of risk factors for burns in women. It showed that the antecedents of burns due to self-harm and interpersonal violence often cluster so closely that it can be difficult to differentiate the cause. Their model consists of two arms: the "narrative precedent" and the "firestarter nexus". The narrative precedent is the sociocultural phenomena that increase the risk of women sustaining burn injuries by normalising, glamorising, or trivialising burns in women. This includes dowry or "honour" related burns, sati, media portrayal of burn injuries that leave no scars, and exposure to self-immolation of other women in their community. The firestarter nexus is the combination of access to means and life circumstances that increase the risk of burns in women. These include availability of kerosene in the home for cooking, lack of autonomy, poverty, genderbased discrimination, lack of education, unacceptability of divorce, and flammable synthetic clothing. This model closely aligns with qualitative work completed with women in Iran who had burn injuries due to self-harm [78].

Women described a common story in which the narrative precedent dominates initially. The woman would be regularly subjected to abuse from her husband. This may be precipitated by their husband's lack of employment and consumption of alcohol. This may lead the woman to threaten to set herself alight to try to provoke a sense of responsibility in her husband, or the husband may challenge her to do it. The firestarter nexus then dominates as the pair have access to means and a plausible alternative explanation of the injury being caused by cooking. Prevention of such injuries is hampered by the reluctance of women to disclose the cause of the injury, coercion, conflicting

narratives by the woman's natal and affinal family, lack of forensic investigation, and high legal costs.

For these reasons, misclassification and undercounting of burn injuries is thought to be a particular problem for women in South Asia. Sanghavi et al. [80] used a variety of mortality data from India to try to calculate more accurate estimates of the number of deaths due to burn injuries in men and women in India. Data was not disaggregated by intent, so they were unable to explore cause of death from suicide, homicide, and unintentional burns. There was insufficient hospital data to allow them to explore non-fatal outcomes. They estimated that there were 160,000 deaths from burns in 2001. 100,000 were in women, which is comparable to the number of maternal deaths. They found that the number of burn deaths in women closely resembled age-fertility curves suggesting that the factors that favour childbearing also increase the risk of burn injuries (e.g. marriage, move into affinal family home). These results were six times higher than national mortality statistics from India, but were similar to GBD results for 2013 [37]. In 2016, GBD methods were changed to use verbal autopsy as the main method of identifying cause of death. Verbal autopsy is well recognised to be prone to misclassification if the interviewee has reason to conceal the cause of death [81]. Following the change in method there was a 75% reduction in GBD estimates of deaths due to burns [37]. Indian Civil Registration System of Medically Certified Cause of Deaths provide a useful lower estimate of burn deaths. These data do not include all deaths and there are high levels of 'unspecified' cause. GBD estimates were found to be 50% lower than civil registration system data for the state of Karnataka, and 70% lower than data for Delhi [37]. Although these data relate to mortality rather than morbidity, it does highlight that there are issues with data availability, data representativeness, and disaggregation of data by intent for burn injuries in regions where violent burns are a critical issue.

## Strengthening surveillance data on burn injury intent

Collection of morbidity data is arguably harder than mortality data. Deaths are usually captured through civil registration and vital statistic systems. The spectrum of severity of non-fatal injuries means that a threshold for data capture must be set, which is usually the requirement for a patient to seek medical care. To gain a total overview of burn morbidity requires utilisation of routinely collected data from primary care, emergency departments, outpatient departments, and inpatient hospital care. This can be conceptualised as an injury pyramid. It has been shown that the incidence of burn injuries reduces with each level of the pyramid [82]. Burn registers are an important source of surveillance data on non-fatal burn outcomes. They usually provide better case ascertainment

and more variables than hospital admission data, discharge data, or insurance claim data [83]. Burn registers systematically and prospectively collect prespecified variables about patients presenting to hospital with a burn injury [84]. This allows continuous evaluation of a variety of exposures (e.g. injury intent) and outcomes important to primary, secondary, and tertiary prevention of burn injuries. Burn registers may be set up to only capture data about burn injuries, or burns injuries may be captured as part of a wider injury surveillance system [11]. There are a number of national level burn registers that collate data from multiple burn services in their country [83, 85, 86]. Clinical register data require constant input and analysis to provide timely data that can be used to improve clinical care and inform prevention strategies. There are resource implications to set up and maintain a burn register, which may account for why most active burn registers are found in high-income countries [87].

Data from burn registers can be a powerful tool for informing prevention strategies and improving patient care. Data can be used for traditional surveillance activities such as tracking of emerging trends, study of rare outcomes, clinical benchmarking, and embedding of clinical trials [88-90]. Results gained from observational data require careful consideration before being used to change services or policy. Hypotheses driven analyses of quantitative data rely upon a statistical model of the truth. There are various explanations for why an association may be found between an exposure and outcome (Figure 5) [8, 91]. If the model of the truth closely represents reality, then the association may be due to a true causal relationship. If the model does not closely resemble reality, then an association may be due to random error (also known as chance), systematic error (also known as bias), or the distribution of another variable (also known as a confounder).

Figure 5. Explanations for an association between an exposure and outcome.



Aggregation of data increases sample size, which leads to narrower confidence intervals (standard error is inversely proportional to the square root of sample size). This increases precision of the result, reducing random error. The large sample sizes achieved by using observational data sets is often seen as attractive. However, the disparate ways in which routinely collected data is gathered can mean that the increased precision is around an inaccurate estimate of the truth [92]. This is known as the "big data paradox" [93]. It is driven by selection and misclassification bias created by increased patient heterogeneity and poorer data quality as sample size increases, unless avoidant measures are taken. These factors can have a profound effect on new and established surveillance systems as they usually utilise routinely collected data.

The need to improve injury intent data has been recognised for many years, particularly for burn injuries. Inadequate quantity and quality of intent data is a limiting factor in reducing violence against women globally. Representative, high quality surveillance data on injury intent is essential to inform prevention strategies. The complex interplay of social, religious, economic, and legal factors that affect data collection processes means that there has been little concerted effort to improve morbidity surveillance data for burn injury intent. This thesis aims to address this research need by systematically considering the factors that affect the reliability of morbidity surveillance data about injury intent in order to determine how these data can be strengthened.

## Thesis aim and objectives

The research question that this thesis aims to address is:

How can international burn injury morbidity surveillance data be strengthened to better differentiate burns that are: unintentional; due to self-harm; or due to interpersonal violence?

Other forms of violence (executions and police conflict, and conflict and terrorism) are beyond the scope of this thesis. Although these forms of violence are an important cause of burn injuries, they are less likely to be encountered in the general hospital environment, so are not discussed further.

The thesis question will be addressed through the following study objectives:

- Understand current surveillance data collected internationally on burn injury intent and the likelihood of selection and misclassification bias in those data (Chapter two).
- Understand comparability and standardisation of variables currently used to record burn injury intent (Chapters two and three).
- Develop a method to improve case capture of new and existing hospital-based surveillance systems that include burn injury intent data (Chapter four).
- Develop a method to better utilise existing high quality hospital based surveillance data that includes burn injury intent data (Chapter five).
- Explore recording practices and patient groups that may be at risk of misclassification using existing injury intent data (Chapter six).

The thesis question and objectives are addressed in chapters two to six through review of current international practices and identifying where the gaps and errors are likely to be in those data; utilising existing data to its best possible potential; and, where good data does not already exist, establish new high quality recording systems. Some of these objectives are explored using case studies from South Asia where there is a need for high quality surveillance data that can be obtained in low resource settings.

Chapter two provides an international overview of the availability and representativeness of routinely collected burn injury data from national level burn registers. We investigate what variables, with specific reference to injury intent, are already collected, and how comparable they are between registers. We are then able to assess the likelihood of selection and misclassification bias of injury intent data gained from these sources. We address possible strategies to minimise bias if data were pooled. This is an important consideration as interest in 'big data' grows.

Chapter three evaluates whether published research studies could be used to fill the gap in surveillance data disaggregated by injury intent in South Asia. We review the terminology and methods used to differentiate injury intent of hospital patients with burn injuries. This is a key step before any epidemiological analyses can be completed. It must be understood how representative the data are, and the likely sources of bias within and between any compared data sets.

Chapters four to six were completed as part of the South Asia Self-Harm Initiative (SASHI). The SASHI research collaboration developed following identification of a local need to improve surveillance data on self-harm in India. Feasibility work did not include burn injuries [94]. It was recognised that this limitation must be addressed in the SASHI project. Professor Mohan Kakola, Head of the Department of Burns and Plastic Surgery at Krishna Rajendra Hospital, Mysore, and I worked to develop the burn injury workstreams of SASHI. Krishna Rajendra Hospital gained a government funded burn unit earlier than many other cities in India. It was built in response to a fire at Sandalwood film studio in Mysore in 1989 during the filming of 'Tipu Sultan' [95]. The death of 62 people, and burns sustained by the actor Sanjay Kahn, shone a light on morbidity and mortality caused by burn injuries [96].

Chapter four presents how a robust case ascertainment strategy for a newly established hospitalbased self-harm surveillance system (that includes burn injuries) was developed using process mapping in two hospitals in south India. Adequate data on all possible cases of self-harm did not exist, so a new system with broad inclusion criteria was developed. Ensuring robust and reliable case ascertainment in differing healthcare systems requires a tailored approach, but there is a gap in guidance on how to achieve this.

Chapter five presents a method to assess the suitability and reliability of existing routinely collected data for surveillance purposes, to digitise handwritten data, and to quantify error during the digitisation process. This is described using an example of a longstanding handwritten burn register from a tertiary government burn unit (Krishna Rajendra Hospital) in south India. Utilising existing data is a key component of any sustainable surveillance system, but minimal guidance exists on how to achieve this using modern digital methods in low resource environments.

Chapter six presents an analysis of data collected by the methods described in chapter five. We explore patterns in recording of intent and characteristics of patients according to intent classifications. Existing research often presents injury intent as a categorical variable, but there is likely to be misclassification in the data. This exploratory analysis allows groups to be identified that

may be misclassified and should be the focus of future research. It identifies ways to improve collection and modelling of injury causation data.

Chapter seven summarises the principal findings of the thesis with reference to the thesis question and objectives. It highlights the policy and practice implications of the work, the strengths of the studies, and the novel contribution this work makes to the field. Limitations of individual studies and the work as a whole are considered. This thesis will be the basis for future research, the scope of which is discussed in chapter seven.

## Chapter two - Exploring the similarities and differences of burn registers globally: A data dictionary comparison study

## Preface to chapter two

Burn registers collect data about patients presenting to hospital with a burn injury. They are an important source of morbidity data in the surveillance of burn injuries. These data can be used for a variety of clinical and epidemiological purposes. There is an increasing interest in pooling routinely collected data sources to gain greater insights into global burn injury patterns and care. Systems to complete data comparisons across burn registers do not currently exist.

This chapter presents a project that was established to understand the feasibility of comparing data between burn registers, particularly the likely sources of selection and misclassification bias within and between registers. It was a large international project working with custodians from 13 national level burn registers. Comparison of elements in the classification of burn injuries (e.g. intent) was included as part of the project. Injury intent is used as an exemplar of the potential for misclassification if data were compared in its current form, and the need to strengthen our approach to surveillance through the development of common data elements for use in an international minimum data set for burn injuries.

## Paper 1: Protocol

A published version of this paper is available: Bebbington E, Miles J, Peck M, Singer Y, Dunn K, Young A. Exploring the similarities and differences of variables collected by burn registers globally: protocol for a data dictionary review study. BMJ Open. 2023;13:e066512. doi: 10.1136/bmjopen-2022-066512.

## Abstract

#### Introduction

Burn registers can provide high quality clinical data that can be used for surveillance, research, planning service provision, and clinical quality assessment. Many country-wide and inter-country burn registers now exist. The variables collected by burn registers are not standardised internationally. Few international burn register data comparisons are completed beyond basic morbidity and mortality statistics. Data comparisons across registers require analysis of homogenous variables. Little work has been done to understand if burn registers have sufficiently similar variables to enable useful comparisons. The aim of this project is to compare the variables collected in country-wide and inter-country burn registers internationally to understand their similarities and differences.

#### Methods and analysis

Register custodians will be invited to participate in the study and to share their register data dictionaries. Study objectives are to compare patient inclusion and exclusion criteria of each participating burn register; determine which variables are collected by each register and if variables are required or optional, identify common variable themes; and compare a sample of data variables to understand how they are defined and measured. All variable names will be extracted from each register and common themes identified. Detailed information will be extracted for a sample of variables to give a deeper insight into similarities and differences between registers.

## **Ethics and dissemination**

No patient data will be used in this project. Permission to use each register's data dictionary will be sought from respective register custodians. Results will be presented at international meetings and published in open access journals. These results will be of interest to register custodians and researchers wishing to explore international data comparisons, and countries wishing to establish their own burn register.

## Introduction

Approximately 9 million people globally sustain burn injuries each year requiring medical treatment, of whom 120 000 die [68]. Over 80% of these injuries and deaths occur in low and middle-income countries [68]. Lower-income countries often have poor coverage of surveillance data, meaning that the true burden of disease in these countries is not fully known [29, 68]. Where data is collected, it frequently does not include information required to inform prevention and intervention strategies, such as disaggregation of data by injury intent in regions where there are high rates of deliberate burns [37, 68, 70, 80, 97]. Burn mortality surveillance statistics are compiled from civil registration and vital statistic data, whereas burn morbidity statistics are calculated from hospital-based data [29].

Burn registers provide clinical data that can be used for international morbidity surveillance. However, few international burn data comparisons are completed beyond basic morbidity and mortality statistics. Registers can be used for outcomes assessment, research, planning service provision, clinical governance, quality improvement, service accreditation or, as clinical quality registers, to identify variation in practice [84]. The utility of burn registers is such that there are now numerous country-wide registers (e.g. Dutch Burn Repository) as well as inter-country registers (e.g. Burn registry of Australia and New Zealand collects data from Australia and New Zealand, International Burn Injury Database collects data from England and Wales, German Burn Registry collects data from German speaking countries, and National Burn Repository collects data from US centres and some international burn centres) [85, 86, 98-100]. Established burn registers are strongly concentrated in high income countries, most likely due to ethical, regulatory, technological, and economic issues [101]. A notable exception is the World Health Organization Global Burn Registry (WHO GBR) [102]. This register allows any healthcare facility globally to submit and analyse their data for free. Twenty countries submit data to the WHO GBR, the majority of which are middleincome countries [103]. Most countries that submit data do not have a country-wide burn register. The success of the WHO GBR in countries without an active burn register likely reflects the enthusiasm of the international burn community for rigorously collected and collated burn injury data.

The variables collected by burn registers are not standardised internationally, thereby limiting international data comparisons. The development of a set of variables that are collected across all registers in a standardised way (an international minimum dataset) would allow the comparison of data on issues of international significance. Pooling data from registers effectively achieves a larger

sample size allowing investigation of rarer exposures and outcomes, tracking of emerging trends, investigation of how disease processes are affected by sociocultural factors, and embedding trials [88-90, 104-106]. Custodians of a country-wide or inter-country register might choose to incorporate an international minimum dataset into existing data collection processes to help facilitate international data comparisons, but are likely to continue to collect country specific variables required to tailor prevention strategies, service provision, and quality improvement to the long-term needs of their population.

It is not known whether burn registers already collect any variables in a way that would allow international data comparisons. If data is not comparable, an international minimum dataset would need to be developed as differences between registers may represent sources of bias during analyses. To achieve this will require internationally agreed variable definitions and methods of measurement. It is necessary to understand which variables are commonly collected across all registers prior to the development of an international minimum dataset as it is likely that important common themes at present may not be collected in comparable ways. Agreed definitions would be helpful to countries wishing to establish their own burn registers. Little work has been done to understand the similarities and differences across burn registers internationally. The aim of this project is to compare the variables collected in country-wide and inter-country burn registers internationally to understand their similarities and differences.

## Methods

The study objectives are to:

- 1. Compare patient inclusion and exclusion criteria of each participating burn register
- 2. Determine what variables are collected by each register and if variables are required or optional
- 3. Identify if any variables are collected by all registers and identify common variable themes
- Undertake a detailed comparison of a sample of variables to understand differences in definitions and measurement methods.

The steps of the study are shown in Figure 6. No reporting guidelines for protocols or studies of this nature were found on the Equator Network website (www.equator-network.org). Any deviations from the study protocol will be reported in the results manuscript.

## Figure 6. The process of register recruitment, data extraction and data analyses that the study will follow.



## Terminology

Common terms applicable to the study have been defined to ensure uniformity of understanding across international collaborators (Table 6). Standard definitions have been used where possible. These definitions will be used in all research material and manuscripts.

**Table 6.** Definitions of key terms used in this study.

Term	Definition	Example
Registry	An organisation and associated systems	World Health Organization Global
	that support the upkeep of a register [84].	Burn Registry
Register custodian	Organisation responsible for maintaining reliability and security of a register's data [107].	World Health Organization
Register	A physical or electronic collection of pre- specified and systematically recorded details [84].	Details about burn presentations to a hospital
Data dictionary	Document that defines each variable in a register, their limits, and validation parameters [108-110]. It does not include any patient data.	Specific to each register. May use standard definitions for a variable such as International Classification of Diseases 11 <sup>th</sup> Revision.
Variable	One feature of interest in a register.	'Date of birth', 'total body surface area of burn' (TBSA), 'discharge disposition'.
Variable response options	Potential choices to answer a variable.	Response options for 'discharge disposition' may include 'discharged home', 'transferred', 'discharged against medical advice', 'died'.
Required variable	A variable that must be inputted by the person completing data entry.	These are specific to each register and are dependent on the analyses that are deemed essential. Essential variables might include 'date of birth', 'TBSA'.
Optional variable	A variable that is not collected about every patient.	These are specific to each register and are dependent on the analyses that are deemed important but not essential. For example, 'income', 'occupation'.
Minimum data set	The list of required variables collected by the register	Specific to each register.
Electronic	Collection of data organised for rapid	SQL
	A piece of information that is computed	
Calculated field	using variable data.	variable 'date of birth'.
Outcome	Variable measured at a specific time point to assess the efficacy or harm of an intervention [112].	Quality of life
Outcome measure	Method of quantifying an outcome of interest.	EQ-5D instrument

## Eligibility criteria for burn register participation in the study

Country-wide and inter-country burn registers will be invited to participate in the study. Registers will be identified from a scoping review of active burn registers [87, 113]. A register will be classed as country-wide or inter-country if there is the potential for healthcare facilities across a single country or multiple countries to submit data. The WHO GBR meets these inclusion criteria despite data submission being locally rather than nationally coordinated. The variables included in the WHO GBR are of particular importance because of the wide uptake of the WHO GBR in low- and middleincome countries, which are underrepresented in burn register studies. Registers that are restricted to a single state or region of a country will be excluded in countries with an active country-wide or inter-country register. Burn register pilot studies will be included for countries that do not have an active burn register to attempt to further increase representation of low and middle-income countries. Contact information from the register website will be used to invite register custodians to participate in the study. In cases where there is no register website, corresponding authors of recent register publications will be contacted to provide up to date information about the register custodian. Each custodian will be asked to provide a copy of their most recent data dictionary or equivalent document that explains which variables are collected by the burn register. Registers that have freely available data dictionaries will be automatically included in the study.

### Data handling and storage

No patient data will be collected. Data dictionaries and project documents will be held on an encrypted cloud storage system to allow international collaboration across institutional boundaries. Access to the cloud storage system will be agreed by the authors and permissions set accordingly.

### Register design data extraction rationale and process

## *Objective 1. Compare patient inclusion and exclusion criteria of each participating burn register.*

Each register uses a set of inclusion and exclusion criteria to determine which patients will have their information recorded in the burn register. For example, a register may include only patients with a burn injury requiring admission for more than 24 hours and exclude patients receiving care on an outpatient basis. Inclusion and exclusion criteria will be compared between registers to understand the patient populations under study. Inclusion criteria heterogeneity could represent a source of selection bias if data were compared without allowing for this. One author (EB) will extract patient inclusion and exclusion criteria from each register's data dictionary into a spreadsheet file. Where this information is not included in the data dictionary, it will be sought from the register website or custodian (order of preference). 100% of the data will be verified by a second author (JM).

Objectives 2 and 3. Determine what variables are collected by each register and if variables are required or optional. Identify if any variables are collected by all registers and identify common variable themes.

A diverse range of required and optional information is collected about patients in burn registers. We will collate and compare required and optionally collected variables noting differences between them. Calculated fields will not be included because they are a form of analysis reflecting the expertise of the data analyst rather than the raw data collected by the register. All variable names from the data dictionaries will be extracted by a researcher (JM) and 100% verified by a second researcher (EB). Data will be extracted into a spreadsheet file. The same extracted data will be used for objective 2 and 3.

# *Objective 4. Undertake a detailed comparison of a sample of variables to understand differences in definitions and measurement methods.*

Data about the same topic may be collected by each register in different ways. For example, information on the intent of the burn injury may include multiple variables such as patient reported injury intent, physician suspicion of injury intent, and International Classification of Diseases external causes of morbidity codes. Each register may use different definitions for the variable and include different response options. Comparison of data that has been collected using different definitions, methods, or timing of measurement would represent a potential source of misclassification bias.

Detailed information will be extracted from the data dictionaries for a sample of topics. These will include 'patient age', 'timing of injury', 'injury cause', 'injury intent', 'infection', and 'survival'. The topics are chosen because they are likely to be collected by all registers. All variables related to each topic will be extracted. This will allow more comprehensive comparisons of variables across registers.

A pilot exercise will be completed in two phases to ensure the detailed variable information is extracted accurately. Firstly, two researchers (EB/JM) will extract detailed information on a sample of 20 variables from two freely available data dictionaries. This will allow the development and refinement of the data dictionary extraction form – a spreadsheet file with predefined column headings (e.g. variable name, variable definition, method of measurement). Codes will be developed

to ensure that a reason is assigned for missing fields in the extraction form. Secondly, detailed variable extraction for the topics 'patient age' and 'timing of injury' will be completed independently by two researchers (EB/JM) using the extraction form. Interrater reliability will be calculated. Providing a good level of agreement is reached (Kappa statistic >0.60), data dictionary extraction will then be split equally between the two researchers (EB – injury cause and injury intent, JM – infection and survival). Regular discussion will be held to ensure any method developments are documented and applied universally. These will be reported in the final paper.

#### Analysis, synthesis, and presentation

A custodian from each register will be invited to be part of the study team to ensure accurate interpretation of the data dictionaries, analyses, and write up.

*Objective 1. Compare patient inclusion and exclusion criteria of each participating burn register* 

A table will be presented in the main manuscript that includes the register name, countries contributing to the register, and patient inclusion and exclusion criteria.

*Objective 2. Determine what variables are collected by each register and if variables are required or optional* 

A full list of variables will be presented for each register with required and optional variables reported differently. Summary data on the number of variables (required and optional) collected by each register will be presented in tabular format in the main manuscript to understand the differences in volume of data collection occurring internationally.

*Objective 3. Identify if any variables are collected by all registers and identify common variable themes* 

Variables will be divided into iteratively developed clinically meaningful thematic groups (e.g. injury causation and severity) and subgroups (e.g. injury intent, size of burn) by two researchers (EB/JM) and checked by a third (YS). Variables in each group and subgroup will be compared to identify the most commonly collected variable themes across registers and if any are variables are collected by all registers in the same way. These will be listed in the manuscript. Common themes across registers will be presented as a figure.

*Objective 4. Undertake a detailed comparison of a sample of variables to understand differences in definitions and measurement methods.* 

Detailed information collected by each register for variables relating to the topics 'patient age', 'timing of injury', 'injury cause', 'injury intent', 'infection', and 'survival' will be compared across registers and presented in tables. Comparisons will be made about the variable definitions, response options, timing of measurement, and method of measurement.

## Patient and public involvement

A member of the public with experience of burns service planning and commissioning has reviewed this manuscript for readability and to ensure the needs of the service user are represented.

## **Ethics and Dissemination**

This project involves the analysis of burn register data dictionaries and freely available burn register related documents (e.g. website, research papers) only. No human participant data will be used in this project, therefore ethical approval is not required in accordance with UK Research and Innovation, and the Declaration of Helsinki [114, 115]. Permissions will be requested from each register custodian to analyse data dictionaries where these dictionaries are not freely available. Only data dictionaries that we have express permission to use will be included in the project. Data will be anonymised and aggregated as required. The identity of the register will only be given with permission of the custodian. Prospective registration has not been completed as there is no appropriate register for this study type.

Results will be presented at international academic meetings to reach interested stakeholder groups (e.g. International Society for Burn Injuries World Congress). Peer reviewed publications of results will be published open access where possible to ensure accessibility. Custodians will be encouraged to disseminate the results in their country or territory. The collaboration formed for this study will be the basis for working together to address any recommendations for future work from the results manuscript.

## Paper 2: Results

A published version of this paper is available: Bebbington E, Miles J, Young A, van Baar ME, Bernal N, Brekke RL, van Dammen L, Elmasry M, Inoue Y, McMullen KA, Paton L, Thamm OC, Tracy LM, Zia

N, Singer Y, Dunn K. Exploring the similarities and differences of burn registers globally: Results from a data dictionary comparison study. Burns. 20234. doi: 10.1016/j.burns.2024.01.004

## 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 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.

## Introduction

Burn registers systematically collect pre-specified information about patients requiring medical care for their injury, known as routinely collected data [116]. The vast quantities of routinely collected health data that now exists have transformed the research landscape by enabling large scale, costeffective, 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 [105, 106, 117]. 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 [118-120]. 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 [88, 104, 121].

Increasing data quantity leads to increased precision in results but does not necessarily increase accuracy. This is known as the 'big data paradox' [93]. 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 [122]. 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 [122]. 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 [35]. Burn care can lead to high out of pocket expenditure for patients [123, 124]. There has been a proliferation in burn registers since the mid-2000s in an effort to improve patient care [87]. Data are used for many purposes including research, service provision planning, and quality improvement [100, 125, 126]. 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 [127]. 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 [128]. There is no record of any burn register being converted to a common data model when checking prominent common data model websites [129-131].

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 [132]. 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
- 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

## Methods

Methods described in the study protocol were followed [1]. 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 [133, 134].

## **Register recruitment**

Active countrywide and intercountry burn registers were identified from a scoping review [87]. The rationale for this is described in greater detail in the study protocol [1]. 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 [10]. For the inpatient and outpatient themes, the Core Outcome Set in Burn Care Research was used [135]. 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 [10].

A pilot exercise was completed 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. 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.

#### 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 7). 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 [103]. 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 7). 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.

**Table 7.** 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.

Register	Register custodian	Year est.	Countries included	Sites	Inclusion criteria (A criteria must be met from each of the bold headings for patient inclusion)	Exclusion criteria
Burn Care Quality Platform	American Burn Association	1994	United States; Canada*	100	<b>Diagnosis:</b> Any patient with a burn injury, acute dermatological condition, or other injury affecting the integrity of the skin. <b>Length of stay:</b> Inpatient admission of any duration, death in hospital, or operation in hospital.	Patients treated on an outpatient basis only.
Burn Centres Outcomes Registry the Netherlands	Dutch Burns Foundation; Association of Dutch Burn Centres	2018	Netherlands	3	<b>Diagnosis:</b> Any patient with a burn injury, acute dermatological condition, or other injury affecting the integrity of the skin. <b>Length of stay:</b> Discharged alive following admission over 24 hours, operation in hospital, or those who may benefit from the system.	No formal exclusion criteria. In practice, those who cannot speak Dutch cannot participate.
Burn Model System	Burn Model System National Data and Statistical Center	1994	United States	4*	<b>Diagnosis:</b> Patient required burn surgery for wound closure and has one of the following diagnoses: Burn TBSA 20% or greater (0-64 years), burn TBSA 10% or greater (65+ years), electrical high voltage burn, lightning burn, or burn to hand/face/feet. <b>Consent:</b> Patient consents to participate in the study within 30 days of discharge from the burn model system clinical unit.	Acute dermatological conditions; cold injuries; abrasion. Burn surgery that only includes xenografting or allografting. Patients or participants in law enforcement custody. Patients who do not consent to participate.
Burns Registry of Australia and New Zealand	Australian and New Zealand Burn Association; Monash University	2009	Australia; New Zealand	17	<b>Diagnosis:</b> Any patient with a burn injury. <b>Length of stay:</b> Admission for over 24 hours, death within 24 hours, or burn management procedure in hospital (even if length of stay under 24 hours). <b>Timing of care:</b> Admission within 28 days of injury, burn unit consultation, or transfers to a burn unit from other hospitals.	Acute dermatological conditions; extravasation injuries. Patients treated on an outpatient basis only.

Burn Unit Database	Linköping University, Sweden	1993	Sweden	2	<b>Diagnosis:</b> Any patient with a burn injury, acute dermatological condition, or other injury affecting the integrity of the skin. <b>Length of stay:</b> Admission of any duration, referrals and follow up seen in outpatient department. <b>Consent:</b> Patient consents to participate.	Patients who do not consent to participate.
Care of Burns in Scotland	National Managed Clinical Network, NHS Scotland	2012	Scotland	6	<b>Diagnosis:</b> Any patient with a burn injury. <b>Length of stay:</b> Admission of any duration.	Acute dermatological conditions. Patients treated on an outpatient basis only.
Dutch Burn Repository R3	Association of Dutch Burn Centres	2009	Netherlands	3	<b>Diagnosis:</b> Any patient with a burn injury, acute dermatological condition, or other injury affecting the integrity of the skin. <b>Length of stay:</b> Admission over 2 hours, or referral or follow up seen in the outpatient department.	No formal exclusion criteria.
German Burn Registry	German Society for Burn Treatment	2014	Germany; Austria; Switzerland	64	<b>Diagnosis:</b> Any patient with a burn injury, acute dermatological condition, or other injury affecting the integrity of the skin. <b>Length of stay:</b> Admission to hospital (0-15 years), or admission to the burns intensive care unit (16+ years). <b>Consent:</b> Patient consents to participate.	Patients treated on an outpatient basis only. Patients who do not consent to participate.
Global Burn Registry	World Health Organization	2018	20*	36*	<b>Diagnosis:</b> Any patient with a burn injury. <b>Length of stay:</b> Admission to a healthcare facility for over 24 hours.	Patients treated on an outpatient basis only.
International Burn Injury Database	NHS England and Wales	2005	England; Wales	25	<b>Diagnosis:</b> Any patient with a burn injury, acute dermatological condition, or other injury affecting the integrity of the skin. <b>Length of stay:</b> Mandated to enter data for all admissions under burn specialist services. Services can enter data from outpatient or outreach visits if it will help with demand and capacity calculations.	No formal exclusion criteria.

Japanese	Japan Society for	2011	Japan	120	Diagnosis: Any patient with a burn injury. Length of stay:	Patients treated on an outpatient
National	Burn Injuries				Admission of any duration. <b>Consent:</b> Patient consents to	basis only. Patients who do not
Burn					participate.	consent to participate.
Registry						
Norwegian	Haukeland	2022	Norway	1*	<b>Diagnosis:</b> Any patient with a burn injury. <b>Length of stay:</b>	Acute dermatological conditions.
Burn	University				Admission for over 24 hours, or death within 24 hours.	Patients treated on an outpatient
Registry	Hospital, Norway					basis only.
South Asia	Pilot register	2014	Pakistan;	2	Diagnosis: Any patient with a burn injury. Length of stay:	Acute dermatological conditions.
Burn	collaboration*		Bangladesh		Presentation to a participating hospital's emergency	Patients already admitted at the
Registry					department. Consent: Patient consents to participate.	start of the study. Patients who do
						not consent to participate.

\*Table notes. **Burn Care Quality Platform – Register:** An earlier version of the register was known as the National Burn Repository; **Countries included:** Earlier versions of the register also included Sweden and Switzerland. **Burn Model System - Number of sites:** Over the lifetime of the project there have been seven different institutions contributing data. **Global burn registry - Countries included/Number of sites:** Any healthcare facility providing inpatient burn care can contribute. 36 healthcare facilities from 20 countries (Argentina, Chile, China, Estonia, Ethiopia, India, Iran, Kenya, Laos, Mexico, Nepal, Nigeria, Pakistan, Peru, Philippines, Russian Federation, Saudi Arabia, South Africa, Sri Lanka, Tanzania) have submitted data [data downloaded 17<sup>th</sup> May 2023]. **Norway - Number of sites:** National register currently being piloted at the Norwegian National Burn Center, Haukeland University Hospital, Norway. **South Asia Burn Registry - Register custodian:** Pilot register (6 months data) collaboration between John Hopkins Bloomberg School of Public Health, USA; Centre for Injury Prevention and Research, Bangladesh; the National Institute of Burn and Plastic Surgery, Bangladesh; Aga Khan University, Pakistan; and Civil Hospital Karachi, Pakistan.

# 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 8). 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.

**Table 8.** 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.

Register	Required variables	Total number of
	(Percentage of total variables)	variables
Burn Care Quality Platform	61 (64.9%)	94
Burn Centres Outcomes Registry the Netherlands	7 (11.1%)	63
Burn Model System	204 (22.9%)	890
Burns Registry of Australia and New Zealand	60 (31.9%)	188
Burn Unit Database Sweden	29 (45.3%)	64
Care of Burns in Scotland	14 (18.9%)	74
Dutch Burn Repository R3	18 (4.8%)	372
German Burn Registry	6 (9.2%)	65
Global Burn Registry	45 (65.2%)	69
International Burn Injury Database of England	118 (24.0%)	492
and Wales		
Japanese National Burn Registry	22 (78.6%)	28
Norwegian Burn Registry	45 (19.1%)	235
South Asia Burn Registry	125 (100%)	125

Almost a quarter (median 24.0%, IQR 18.9-64.9%) of all variables were required to be collected (Table 8). 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 [136]. 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 7). 'Inpatient' care was the most common theme, accounting for 40.4% of all variables (Table 9). 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 [137].

**Table 9.** 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.

Theme and subtheme	Required	Total	Example variables
	variables	variables	
	(% of total)		
Patient information	186 (48.6%)	383	
House	31 (47.7%)	65	Patient address, number of people in household
Demography	46 (68.7%)	67	Age, gender, ethnicity, hospital identification number
Economic	11 (23.9%)	46	Education level, occupation, income
Pre-existing mental health	27 (34.6%)	78	Mental health diagnoses, alcohol or drug dependence
Pre-existing physical health	71 (64.5%)	110	Physical health diagnoses
Pre-existing social health	0 (0%)	17	Engagement with social activities, quality of life
Admission details	76 (56.7%)	134	
Admission timing	19 (82.6%)	23	Date of admission, time of admission
Reason	14 (37.8%)	37	Type of admission, reason for admission
Hospital	30 (81.1%)	37	Treating hospital type, hospital name, hospital address
Referral	13 (35.1%)	37	Referral timing, referral source, transportation
Injury	169 (35.7%)	474	
Timing of injury	16 (64.0%)	25	Date of injury, time of injury
Intent	13 (44.8%)	29	Recorded intent, suicide or violence in circumstances of injury, external cause code
Mechanism	26 (41.3%)	63	Injury cause (e.g. flame, chemical), accelerant, fuel
Place	20 (57.1%)	35	Address location where injury occurred, location type
Activity	5 (15.6%)	32	Activity being completed at time of injury
Contributing factors	7 (25.9%)	27	Alcohol, drugs, mental state
Size and distribution	50 (31.1%)	161	Total body surface area of burn, location of burn on body, depth of burn
Inhalation	18 (26.9%)	67	Presence of inhalation injury, inhalation signs and symptoms
Other injuries	6 (37.5%)	16	Additional injuries (e.g. brain injury, fracture)
Prehospital care	8 (42.1%)	19	First aid applied, prehospital fluids
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Inpatient	246 (22.0%)	1116	
Non-surgical management	50 (20.9%)	239	Intensive care treatment, medication, fluids, dressings
Surgical management	30 (14.0%)	214	Burn excision, grafts, procedure timing, product type, body location of procedure
Clinical monitoring	28 (42.4%)	66	Observations, blood tests, urine volume
Physical functioning (IP)	10 (9.4%)	106	Basic care needs, physiotherapy assessment, rehabilitation screening
Nutrition	14 (27.5%)	51	Height, weight, nutrition assessment, feeding target, feeding type
Pain/itch (IP)	16 (33.3%)	48	Pain assessment, itch assessment, pain medication,
Mental health (IP)	2 (11.1%)	18	Psychosocial assessment, timing of assessment
Complications	52 (20.6%)	253	Complication type (e.g. amputation, sepsis), measurement (e.g. cultures),
			treatment
Death	16 (26.2%)	61	Cause of death, timing of death
Disposition	28 (46.7%)	60	Discharge timing, discharge destination, length of stay
Outpatient/ Long term follow up	51 (8.7%)	588	
Timing/location	5 (41.7%)	12	Timing of follow up, location of follow up, date of discharge from service
Scar/wound	23 (25.6%)	90	Scar and wound evaluation, management (e.g. dressings, surgery) since discharge
Physical functioning (OP)	10 (5.6%)	178	Physical problems, activity performance, physiotherapy received
Pain/itch (OP)	12 (18.2%)	66	Pain and itch assessment, medications
Mental health (OP)	0 (0%)	139	Mental health assessment (e.g. PTSD, alcohol dependence)
Social health (OP)	0 (0%)	75	Social health assessment (e.g., interactions, sexuality)
Work	1 (3.6%)	28	Time to return to work/education, barriers to return to work, occupation change
Other	25 (39.1%)	64	
Register specific	16 (34.8%)	46	Record identification, data collection timing, form completion
Consent	2 (50.0%)	4	Patient consent completion, consent timing
Respondent	2 (33.3%)	6	Respondent relationship to patient



**Figure 7.** Bar plot showing the number of variables in each theme and subtheme. Abbreviations: Pre, preexisting; IP, inpatient; OP, outpatient.

The proportion of variables in each theme varies between registers (Figure 8). '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. 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.

We found a change in the proportion of variables in each theme when analysing required variables only (Figure 9). 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 '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%).



Figure 8. The proportion of all variables in each register classified by theme.\*

Figure 9. The proportion of required variables in each register classified by theme.\*



\*Figure notes. 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.

# 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. 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 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. 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. 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). "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 discusses that differentiation is challenging, and terms such as "suspected" are used to avoid legal problems with proof. Many registers recommend 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). 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 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). 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). 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). 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.

#### 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 interregister compatibility of concepts. We found some commonalities between registers and some differences. Commonalities will 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 [138]. 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 [139]. 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 [140]. 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 [85].

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 [103]. 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 [141]. 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 [83]. Sampling exercises are a good way to ensure thorough case ascertainment but are difficult in jurisdictions without nationalised healthcare data collection. Interregister 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. This involves careful consideration to avoid problems with selection bias.

Missing data is another significant challenge for observational health research that can introduce bias into analyses [142]. 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%. We found 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 [143]. 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 limitations that could lead to misclassification bias and unmeasured confounding were data to be 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 [144]. 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). 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 [145]. Self-reported age is prone to responder bias and less reliable than date of birth, particularly in communities where birth registration is not mandated [146]. 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) [147]. 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 [49]. 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 10 and Appendix B). We found 53 unique response options that appear sufficiently similar based on the information provided in the data dictionaries to be mapped to 6 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 [44, 148]. It is prone to responder (e.g. patient) and observer (e.g. clinician, data entrant) differential misclassification bias [41, 149]. 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.

**Figure 10.** 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.



Inhalational injury variables could be harmonised using two new variables and mapping current response options to the new options (Appendix B). 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 [150]. 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 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 [151]. Diagnosis and management of infection is complicated by deranged physiological parameters, immunosuppression, invasive monitoring, procedures, and prolonged hospital stays [152]. 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 [153]. 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 [154]. Development of burn specific common data elements would vastly improve the reliability of analyses if burn register data sharing were to occur. Additionally, measurement bias could be reduced by inclusion of non-circular definitions and agreed method of measurement/assessment for both the clinician and person completing data entry. These could be used as part of a global minimum data set for burn registers.

Some limitations are present for this study. We did not identify any active countrywide burn registers in many parts of the world. The majority of burn registers 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. We did not explore operational differences, such as method of data collection, that could affect the national representativeness of registers. These factors can 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 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 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.

Chapter three - Terminology and methods used to differentiate injury intent of hospital burn patients in South Asia: A systematic scoping review

## Preface to chapter three

South Asia is believed to have the highest number of intentional burn injuries from self-harm and interpersonal violence globally. Chapter two showed that there is no active national level burn register in South Asia. The South Asia Burn Registry has not been implemented following the pilot in Pakistan and Bangladesh. The only burn register that healthcare facilities can submit data to is the World Health Organization Global Burn Registry. Submission of data to the WHO register is voluntary. Results showed that there is inconsistency in the terminology, definitions, and method of assessment used to differentiate burns that are: unintentional; due to self-harm; or due to interpersonal violence. This increases the risk of misclassification within and between register data sets. Overall chapter two showed there is inequity in data capture globally that is biased towards high-income countries. There are differences in the variables that are recorded. This reduces the reliability of international data on injury intent.

Results from primary research studies can be used for surveillance providing the data are of sufficient quality. This could be an option to improve surveillance of burn injuries in South Asia. Chapter three uses a systematic scoping review methodology to extract the same detailed variable information as chapter two (terminology, definitions, method of assessment, measurement information) for variables related to injury intent from published primary research studies from South Asia. If data are representative of the source population and collected in a sufficiently similar way, then they could be aggregated to provide population level estimates of the burden of burn injury according to intent category. Comparison of the way in which intent data is collected provides further evidence to determine if there is a need to standardise data collection internationally through development of a common data element.

## Paper 3: Protocol

A published version of this paper is available: Bebbington E, Ramesh P, Kakola M, McPhillips R, Bibi
 F, Hanif A, Morris N, Khan M, Poole R, Robinson C. Terminology and methods used to differentiate
 injury intent of hospital burn patients in South Asia: A systematic scoping review protocol.
 Systematic Reviews. 2023;12:153. doi: 10.1186/s13643-023-02317-y

## Abstract

#### Introduction

The greatest proportion of burn injuries globally occur in South Asia, where there is the highest reported number of intentional burns. Burn injury prevention efforts are hampered by poor surveillance data on injury intent. There is a plethora of local routinely collected data in the research literature from South Asia that could be used for epidemiological purposes, but it is not known whether the definitions and methods of differentiation of injury intent are sufficiently homogenous to allow valid study comparisons.

#### Methods

We will conduct a systematic scoping review to understand terminology and methods used to differentiate injury intent of hospital burn patients in South Asia. The objectives of the study are to determine the breadth of terminology and most common terms used for burn injury intent; to determine if definitions are comparable across studies where the same term is used; and to appraise the rigour of methods used to differentiate burn injury intent and suitability for comparison across studies. The databases Embase, MEDLINE, CINAHL, PsycInfo, and PakMediNet will be searched. Screening and data extraction will be completed independently by two reviewers. To be included the article must be: peer-reviewed, primary research, study cutaneous burns, based on hospital patients from a country in South Asia, and use intent terminology or discuss a method of differentiation of injury intent. Results will be restricted to English language studies. No date restrictions will be applied. A plain language summary and terminology section is included for non-specialist readers. This review has been registered with the Open Science Framework (https://doi.org/10.17605/OSF.IO/DCYNQ).

# Dissemination

Results will be used to inform stakeholder work to develop standardised terminology and methods for burn injury intent in South Asia. They will be published open access in peer reviewed journals wherever possible.

## Introduction

Burn injuries are a major source of morbidity globally. Estimation of the number of burn injuries is complicated by the numerous mechanisms by which a burn can be sustained (e.g. hot objects, chemicals, friction). The Global Burden of Disease study estimates that in 2019 there were 16.3 million people burn injuries from all causes [35]. 3.7 million are thought to have occurred in South Asia, the vast majority of these in India, but this may be an underestimate [35, 37]. Similar under-reporting may affect other countries where there is no national injury surveillance system. Burn morbidity surveillance statistics are compiled from hospital-based data [29]. A cornerstone of burn injuries in a standardised manner across institutions. There are no national registers in South Asia, though one has been proposed for India and there has been a successful pilot in Pakistan and Bangladesh [155, 156]. The World Health Organization Global Burn Register allows any hospital that admits burn patients to submit data, but these data are submitted voluntarily by individual hospitals rather than national sources meaning data are unlikely to be representative of the entire population of a country [102].

Intent is the first level of classification of an injury, deemed to be the most useful for identifying intervention opportunities and thus should be part of any minimum dataset [10, 11]. The International Classification of Diseases (ICD) External Causes chapter defines this concept as 'whether or not they [injuries] were deliberately inflicted and by whom' (e.g. unintentional, intentional self-harm, assault, undetermined intent, maltreatment) [10]. Information about burn injury intent that is used for surveillance purposes globally is typically collected from hospital records [41]. This information is documented by the healthcare professional caring for the patient. Collection of this information is influenced by personal, social, religious, and legal sensitivities, creating a bias for burn injuries to be misclassified in routinely collected data [66]. Patients may be reluctant to disclose the true cause of an injury in cases of assault [46, 149, 157]. Factors that contribute to misreporting include domestic coercive control, criminal investigation, personal safety, 'honour', and financial dependency [44-46, 149, 157]. Self-inflicted injuries may not be reported due to stigma or fear of criminal investigation, particularly in countries where suicide has not been decriminalised [45, 74, 158, 159]. There are variable requirements internationally for hospitals to report injuries due to self-harm or assault to the police [160]. These factors also affect the accuracy of clinicians' documentation [161].

Local studies suggest South Asia has the highest proportion of intentional burns in the world [162]. Prevention of burn injuries in South Asia is hampered by unreliable population-level estimates due to poor surveillance systems, lack of data disaggregation by injury intent, unreliable classification of intent where data are collected, and incomplete sharing of data [68, 163]. There is a wealth of routinely collected data and primary research data on injury intent in the peer-reviewed literature from South Asia that could potentially be utilised for surveillance purposes. However, little work has been done to understand how these data have been collected and if the methods are comparable across studies. Differences in definitions or method of differentiation of intent may act as sources of bias if attempting to compare data across studies. We will conduct a systematic scoping review to understand terminology and methods used to differentiate injury intent of hospital burn patients in South Asia.

#### **Study objectives**

1) Determine the breadth of terminology and most commonly used terms for burn injury intent, including the stem term and classifiers.

2) Determine if definitions are comparable across studies where the same term is used.

3) Appraise the rigour of methods used to differentiate burn injury intent and suitability for comparison across studies.

A preliminary search of MEDLINE and PROSPERO was conducted and no systematic reviews or scoping reviews on the topic were identified.

#### Methods

#### Protocol and registration

This protocol has been written using preferred reporting items for systematic review and metaanalysis protocols (PRISMA-P) and preferred reporting items for systematic review and metaanalyses extension for scoping reviews (PRISMA-ScR) [164, 165]. PRISMA does not have a protocol guideline for scoping reviews. This review has been registered with the Open Science Framework (https://doi.org/10.17605/OSF.IO/DCYNQ).

## **Eligibility criteria**

# Population

Articles that present data on patients with a cutaneous burn injury will be included. A burn is defined as "an injury to the tissues caused by a pathological flux of energy which causes cellular destruction and irreversible denaturation of proteins and is primarily caused by thermal or other acute trauma [e.g. chemical, electricity, friction]" [67]. Studies that focus exclusively on ocular burns (e.g. chemical burn to the eye) or internal burns (e.g. oesophageal burn from ingestion of corrosive substances) will be excluded because such burns are unlikely to be looked after in burn specialist services. Burns sustained during combat (e.g. blast injury, military casualties) will be excluded because the concept of intent during armed conflict is distinct from intent during peacetime. Articles not related to burn injuries (e.g. professional burnout, heartburn) will be excluded.

## Concept

Studies will be included that use a term referring to intent (e.g. intent, motive), or its classification (e.g. unintentional, intentional, accidental, homicidal, suicidal, undetermined). These will be referred to as 'stem' and 'classifier' terms, where stem is overarching term for the concept, and classifier is a type of response option (Figure 11). Articles using an ambiguous term (e.g. aetiology, cause, circumstances of the injury) will be included at the title and abstract screening phase and undergo full text review. Reviewers are not restricted to these terms and can infer meaning from the rest of the abstract or article. Studies that do not include information on burn injury intent will be excluded.

**Figure 11.** Example of how terms used in the International Classification of Diseases 11th Revision External Causes of Morbidity and Mortality chapter could be split into stem and classifier terms [61].



# Context (i) Hospital

Studies will be included that have taken place in hospital. This will be decided at the title and abstract screening stage, where the article should include the term 'hospital' or equivalent (e.g. secondary care, tertiary care). If the study does not explicitly state data was collected from a hospital but it is inferred, then it will be included at the title and abstract screening phase for full text review. Articles will be excluded where data has not been collected from hospital patients (e.g. autopsy studies, coroner's studies, medicolegal death studies).

# Context (ii) South Asia

Studies will be included that have taken place in South Asia. We will use the World Bank definition for South Asia, which includes the countries of Afghanistan, Bangladesh, Bhutan, India, Sri Lanka, Maldives, Nepal, Pakistan [166, 167].

## Study design

Only peer reviewed publications based on primary research data will be included (e.g. quantitative studies, qualitative studies, case series, and case reports). Articles that do not present original data (e.g. review articles, opinion pieces, and personal practice) and grey literature (e.g. unpublished works, published conference abstracts) will be excluded due to the large volume of relevant peer reviewed publications with original data identified in the preliminary search.

## Report characteristics

There will be no restriction on the year of publication. Results will be restricted to human studies. Research conducted by South Asian researchers is almost always published in English [168]. Therefore, search results will be restricted to English language papers.

## Information sources

Searches will be conducted using the major medical and social science databases Embase, MEDLINE, CINAHL, and PsycInfo. PakMediNet will be used to search peer-reviewed Pakistani medical journals that may not be indexed in the aforementioned databases. No date restrictions will be applied.

## Search strategy

An initial search strategy was developed for key concepts from the review question (burns, hospital, South Asia) in MEDLINE. MESH headings and keywords were identified for each concept. Each term was looked up in an online dictionary to identify similarly spelt words. This dictated which terms were truncated and excluded. An initial limited search of MEDLINE was undertaken using the search strategy. The results were cross-referenced against previously identified articles of interest. Search terms were modified to include index terms of articles that had not been identified in the preliminary search. The preliminary search was repeated using the key concepts 'burns' and 'South Asia', but excluding 'hospital'. Results were screened for any articles of interest that were missed by inclusion of the concept 'hospital'. The text words contained in the titles and abstracts of relevant articles, and the index terms used to describe the articles, were used to further refine the full search strategy for MEDLINE (Appendix C). The search strategy, including all identified keywords and index terms, will be adapted for each included database.

# Study records

Searches of Embase, MEDLINE, and PsycInfo will be completed using the Ovid platform. Searches of CINAHL will be completed using the EBSCO platform. Searches of PakMediNet will be completed

using the database website. All searches will be saved in a user account. A separate record of the search results will be kept in a spreadsheet file including date of search, search terms, and number of retrieved articles. Search results will be exported into reference management software Endnote X9. Duplicate articles will be removed using the method by Bramer et al. [169]. Remaining references will be uploaded into systematic review software Covidence (Covidence systematic review software, Veritas Health Innovation, Melbourne, Australia. Available at www.covidence.org). Title and abstract screening, and full text review will be completed by two researchers using Covidence (EB, PR). Any disputes will be resolved by a third researcher (RM). Authors undertaking study screening will undergo training to ensure the study objectives are understood and a standardised process is followed (Appendix D). The reason for full text article exclusion will be recorded in Covidence based upon a hierarchy of predefined criteria:

- Duplicate
- Not in English
- Non-human study
- Not a peer reviewed publication
- No original data presented (e.g. not a primary research study)
- Cutaneous burns not studied (e.g. focus of article are ocular/oesophageal burns)
- Study not from a country in South Asia
- Study not based on hospital patients (e.g. autopsy study)
- Burns sustained during combat
- Intent terminology or method of differentiation not discussed

Results from each of these steps will be downloaded as a spreadsheet file from Covidence. Full text copies of all included articles will be uploaded into Covidence for data extraction. Extracted data will be entered into a template on specially designed template in Covidence. Two reviewers (EB, PR) will extract data from the full text articles individually. The results will then be compared, and discrepancies resolved by discussion. Reviewers will meet regularly to discuss any issues that may have arisen. Any deviation from the review protocol will be recorded and reported in the review manuscript.

## Data items

Data items will include: study name, journal name, date of publication, first author name, institution(s) where the study took place, dates of study, study aim, number of participants, age range of participants, stem term(s) used for burn injury intent (e.g. intent, aetiology, motive, cause),

definition of stem term(s) used for burn injury intent, classifier term(s) used for burn injury intent (e.g. unintentional, intentional, accidental, homicidal, suicidal, undetermined), definition of classifier term(s) used for burn injury intent, method used to differentiate burn injury intent, role of person completing assessment (e.g. healthcare professional, researcher), timing/location of burn injury intent assessment in the patient's hospital journey (e.g. emergency department triage, arrival at burns ward, upon discharge from burns ward). Where data items are missing or not applicable to a study the research will assign a code (e.g. NA - not applicable, INIS - information not in study). This is to ensure missing data is not attributed to the data entrant. A spreadsheet file with all extracted data will be downloaded from Covidence for data analysis and synthesis.

## Risk of bias in individual studies

The risk of bias overall in individual studies will not be assessed beyond assessing rigour of the method used differentiate injury intent.

## Data synthesis based on study objectives

1) Determine the breadth of terminology and most commonly used terms for burn injury intent, including the stem term and classifiers.

A list of stem terms with the number of papers using each term will be compiled using spreadsheet software. A full list of terms will be presented as supplementary data. The top five terms will be presented in tabular format in the results manuscript. The same process and presentation of results will be completed for classifier terms.

# 2) Determine if stem term and classifier term definitions are comparable across studies where the same term is used.

Definitions for each stem term will be tabulated with the corresponding study. The number of times a term is not defined will be presented. Full results will be presented as supplementary data. Examples of comparable and incomparable definitions for terms will be presented in the results manuscript. The same process and presentation of results will be completed for classifier terms.

3) Appraise the rigour of methods used to differentiate burn injury intent and suitability for comparison across studies.

The method of differentiation of burn injury intent by each study will be compiled in tabular format. Studies using the same methods will be presented together. A list will be compiled of studies that do not include details about the method of differentiation of intent. A table with summary data will be included in the results manuscript. Full results will be presented as supplementary data.

The rigour of the method used to determine burn injury intent will be appraised by a modification of the method described by Maguire et al. [170]. This method was developed for ranking quality of evidence for identification of paediatric burns caused by abuse. Consequently, there is no ranking system for burns due to self-harm. For cases of assault the method of differentiation will be ascribed a ranking between 1 and 5 (1 – assault confirmed at court proceeding, or admitted by perpetrator; 2 – assault confirmed by stated criteria including multidisciplinary assessment; 3 – diagnosis of assault defined by stated criteria; 4 – assault stated as occurring but no supporting detail given as to how it was determined; 5 – abuse stated as "suspected" with not details given on whether it was confirmed or not). For accidental burns the method of differentiation will be ascribed a ranking A-C (A – scene of incident recreated, or forensic police investigation of scene, or criminal investigation ruled out assault as a cause; B – efforts specifically made to exclude assault as a cause for burn through multidisciplinary investigation; C – no discussion about how burn was deemed to be accidental). Summary statistics for each category will be presented in tabular format. There is no plan to complete assessment of meta-biases or the strength of the body of evidence.

#### Patient and public involvement

This protocol has been reviewed by two people who were not researchers but do have volunteering and practice experience in the fields of child protection, adult safeguarding, criminal justice, and substance misuse. Both will be involved in the analysis and write up of the results manuscript to ensure the paper is accessible and service user focussed. We have included a summary and terminology section for non-specialist readers to increase the accessibility and usability of this article.

#### Plain language summary (Words in italics are included in the terminology table)

This article describes how we plan to review some research. We wish to look at articles that include patients from South Asia with a *burn injury*. We are interested in the words that are used to describe the *intent* of the injury. How those words are defined. As well as how the injury intent was determined. Injury intent often includes if the injury was caused on purpose and who did it. For example, the injury could be classed as an accident, self-harm, or assault. We will review existing literature using a method known as a *systematic scoping review*. This is a standardised way to review lots of research articles. We have described how we will do the review so that it can be understood by others and repeated. It is important to do this review because it is believed that most burns due

to self-harm and assault happen in South Asia. There is not much data collected about this at a national level (*surveillance*). This data is needed to develop ways to prevent burns occurring in the first place. Lots of hospitals in South Asia publish their own data on burn injuries. If the data is collected in similar ways it might be able to be used for surveillance. This is why we want to understand how the words for intent are used, defined, and measured in the articles.

## Discussion

There are a number of strengths in the methods of this planned systematic scoping review. PRISMA protocol and scoping review guidelines have been followed for the preparation of this protocol. An information specialist is part of the author team and has helped to devise a robust search strategy. Two members of the public have co-produced this research to ensure it is suitably service user focussed, as well as helping to create a glossary and summary for non-specialist readers to ensure the article is accessible. We plan to appraise the rigour of method to determine burn injury intent. There is no accepted method to do so in adults, so a method devised for paediatric populations has been adapted for this review. A database with good coverage of social science papers (e.g. SCOPUS) has not been used. This is a potential limitation of the review.

This review process is expected to generate peer-reviewed publications on terminology and operational criteria for classifying burn injury intent. This includes recommendations for standard terminology, methods of determination of burn injury intent, recommendations on minimising misclassification, and an assessment of whether the literature is sufficiently methodologically consistent to allow valid inter-study comparisons. Publications will be open access wherever possible to ensure results are accessible to clinicians and stakeholders in South Asia, as well as the public. Results will provide the basis for stakeholder engagement in international consensus work on standardised terminology and methods for burn injury intent in South Asia.

#### Terminology

Key terms used in this protocol have been defined for readers who are not specialists in the field (Table 10).

Term	Description
Burn injury	Burns are a type of injury to the skin (cutaneous burn) or other type of body tissue
	(e.g. eye – ocular burn). They may be caused by heat (thermal burn), chemicals,
	radiation, electricity, or friction [171].
Surveillance	Surveillance is a key aspect of public health. It is the practice of collection, analysis,
	and reporting of data on injuries and diseases. These data provide timely data used to
	set government priorities and inform methods to stop injuries and diseases [172].
Injury intent	This review aims to understand the breadth of definitions of the concept of injury
	intent in South Asia. The International Classification of Diseases (ICD) defines this
	concept as 'whether or not they [injuries] were deliberately inflicted and by whom'
	(e.g. unintentional, intentional self-narm, assault, undetermined intent, intent
	pending) [10]. ICD is a standardised method of coding diseases. These codes are used
	to bring together surveillance data. South Asia is recognised to have incomplete
Burn register	A hurn register is a collection of pro-specified and systematically recorded details
Durirregister	about hurn patients [84]. Burn registers typically collect data about hurn patients
	requiring admission to bosnital for their injury. Register data about built patients
	surveillance
Systematic	A systematic scoping review is a method of comprehensively drawing together
scoping review	literature on a research question. The research question tends to be broad [173]. It
	involves a number of stages (in brackets is name of the stage corresponding to the
	subheading in this article): developing the research question, defining which papers
	will be included (eligibility criteria), deciding which databases will be used to identify
	literature (information sources), developing the terms that will be used to search
	databases for literature (search strategy), screening of the search results to identify
	studies meeting the inclusion criteria (study records), extraction of data from included
	studies (data items), and drawing together the results in a meaningful way (data
	synthesis).
Systematic	Systematic reviews use similar methods to systematic scoping reviews. Systematic
review and	reviews tend to answer research questions that are more narrow than systematic
meta-analysis	scoping reviews [173]. They were originally developed to summarise information on
	medical interventions (e.g. medications) to understand if there is a benefit for
	patients. The process of drawing together numerical data from multiple studies is
Ductorned	Known as meta-analysis.
reporting itoms	developed to promote transparent reporting of systematic reviews to ensure that they
for systematic	are as understandable as possible for readers. PRISMA now issues guidance for other
review and	types and aspects of reviews including protocols and systematic scoping reviews [165
meta-analysis	174].
Medical and	Medical and social science databases are online warehouses of published literature.
social science	They are searched during a systematic scoping review to find articles meeting the
databases	study inclusion criteria. MEDLINE is a well-known example of a database in the field of
	medicine.
Search strategy	A list of words based upon the research question used to search the database for
	articles that may meet the study inclusion criteria. The search strategy is developed in
	a series of steps and must be adapted for each database. Some databases use 'index
	terms' to classify their articles. Index terms may be combined with free text words to
	develop the search strategy. They can be refined with Boolean operators (e.g. AND,
	OR, NOT) and filters (e.g. restrictions by date or language). Systematic scoping reviews
	answering a medical research question tend to include their search strategy as it
	would be inputted into MEDLINE. This allows readers to repeat the search if they wish.

## Paper 4: Results

A published version of this paper is available: Bebbington E, Ramesh P, McPhillips R, Bibi F, Khan M, Kakola M, Poole R, Robinson C. Terminology and methods used to differentiate injury intent of hospital burn patients in South Asia: Results from a systematic scoping review. Burns. 2023. doi: 10.1016/j.burns.2023.10.008.

## Abstract

#### Introduction

A key component in the classification of all injury types is to differentiate whether the injury was deliberately inflicted and by whom, commonly known as "intent" in the surveillance literature. These data guide patient care and inform surveillance strategies. South Asia is believed to have the greatest number of intentional burn injuries, but national surveillance data is not disaggregated by injury intent. Scientific literature can be used for injury surveillance where national data collection does not exist. In order to synthesise research findings, it is essential to assess the potential impact of misclassification bias. We therefore conducted a systematic scoping review to understand terminology and methods used to differentiate injury intent of hospital burn patients in South Asia.

#### Methods

We followed the methods in our registered protocol (https://doi.org/10.17605/OSF.IO/DCYNQ). Studies met defined population, concept, context, and study design criteria. The databases Embase, MEDLINE, CINAHL, PsycInfo, and PakMediNet were searched. Two reviewers independently screened results. Data were extracted in a standardised manner and verified. The rigour of the method used to differentiate injury intent was appraised.

#### Results

1435 articles were screened. Of these, 89 met our inclusion criteria. Most articles were from India and Pakistan, and used an observational study design. There were 14 stem terms used in the articles. The most common was "cause". There were 40 classifier terms. The most common were "accident", "suicide", and "homicide". Few articles defined these terms. The method used to differentiate injury intent was only described explicitly in 17% of articles and the rigour of the methods used were low. Where methods of differentiation were described, they appear to be based on patient or family report rather than multidisciplinary assessment.

# Conclusion

The heterogeneity in terms, lack of definitions, and limited investigation of injury intent means this variable is likely to be prone to misclassification bias. We strongly recommend that the global burn community unites to develop a common data element, including definitions and methods of assessment, for the concept of burn injury intent to enable more reliable data collection practices and interstudy comparisons.

#### Introduction

A key component in the classification of all injury types is to differentiate whether the injury was deliberately inflicted and, if so, by whom [10]. This concept is frequently referred to as injury "intent" in the surveillance literature, and is important to guide patient care and to inform prevention strategies [66]. The utility of these data is such that major global surveillance studies disaggregate morbidity data by injury intent. For example, the Global Burden of Disease study disaggregates injury data into 5 main groups: unintentional; self-harm; interpersonal violence; conflict and terrorism; and, execution and police conflict [35]. Standardisation of definitions and methods of assessment used to generate these data is essential to ensure meaningful international comparisons can be made.

The global standard for diagnostic health information is the World Health Organization's (WHO) International Classification of Diseases (ICD) [67]. ICD codes are used for intra- and inter-country disease comparisons. It includes a chapter on external causes of morbidity and mortality, which recommends that the first level of classification of an injury is according to intent [10]. Although ICD provides a definition for the concept of intent ("whether or not they were deliberately inflicted and by whom"), definitions for classifier terms (e.g. unintentional, self-harm, interpersonal) are not provided. There is no recommended method for differentiation of intent, despite recognition from international classification groups that determination of injury intent is difficult [66]. Accuracy of intent surveillance data tends to focus on the coders precision compared to clinical documentation [49]. However, responsibility for clinical documentation lies with the health care practitioner looking after the patient [42]. Health care practitioners and patients are likely to be influenced by personal, cultural, social, and legal sensitivities that can lead to misclassified intent data. This makes injury intent an important, but potentially unreliable, variable in surveillance data.

Standardised definitions and methods of assessment for variables of interest are a stalwart of good research practice to reduce misclassification bias. Items related to this are included in epidemiological study reporting guidelines and quality assessment tools [142, 175]. Observational research studies can be used to inform injury surveillance where national data collection does not exist, and to provide fine grain detail about antecedents, causal factors, treatments, and patient outcomes [176-178]. However, lack of standardisation of variables between studies can limit interstudy comparisons and data pooling.

The Global Burden of Disease study estimates that there were 16.3 million burn injuries in 2019, of which 79% are believed to occur in low- and middle-income countries [35]. Approximately 3.7

million burn injuries are thought to have occurred in South Asia, but this is likely to be an underestimate because of incomplete national level surveillance data in the region [37, 68]. Local studies suggest South Asia has the highest number of intentional burns globally, but national level surveillance data is not disaggregated by intent, which limits analyses [80, 162]. Hospital level burns data in India has been found to have poorly categorised external causes of injury when using ICD codes [163]. However, the research literature from South Asia has a wealth of non-standardised hospital level burn injury data that includes intent information. It may be possible to utilise these data for surveillance purposes, such as using research synthesis methodologies to estimate incidence and prevalence. This is an underexplored area, as existing systematic reviews from the region have excluded intentional injuries [179, 180]. Before such work can be undertaken, it is essential to understand how prone the intent variable is to misclassification bias. We conducted a systematic scoping review to understand terminology and methods used to differentiate injury intent of hospital burn patients in South Asia. The objectives of the study were to:

1) Determine the breadth of terminology and most commonly used terms for burn injury intent, including the stem term and classifiers.

2) Determine if definitions are comparable across studies where the same term is used.

3) Appraise the rigour of methods used to differentiate burn injury intent and suitability for comparison across studies.

## Methods

## **Protocol and registration**

The full protocol for this systematic scoping review has been published [3]. It was registered with the Open Science Framework (https://doi.org/10.17605/OSF.IO/DCYNQ). A summary of the methods and any changes to the protocol are included below. This manuscript has been prepared in accordance with Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) [165, 181].

#### **Eligibility criteria**

Eligibility criteria were defined using a population, concept, context approach (Table 11). Detailed rationale for the eligibility criteria has been published in the protocol.

Table 11. Study inclusion and exclusion criteria.

Criteria	Inclusion	Exclusion
Population	Patients with a cutaneous burn injury	Studies including non-cutaneous burns only
		(e.g. ocular burns, internal burns), or multiple
		injury types where burns comprise under 50%
		of cases. Studies that use the word burn in a
		different context (e.g. professional burnout,
		heartburn).
Concept	Use of a stem term related to intent	Studies that do not include stem or classifier
	(e.g. intent, motive) or its classification	term related to intent.
	(e.g. accident, suicide, homicide).	
Context	Studies that have taken place in a	Studies that do not focus on hospital patients
	hospital in South Asia. South Asia is	(e.g. autopsy studies). Burn injury sustained
	defined as the countries of Afghanistan,	during combat. Study not conducted in a
	Bangladesh, Bhutan, India, Sri Lanka,	South Asian country.
	Maldives, Nepal, and Pakistan [166].	
Study design	Peer reviewed primary research	Review articles, opinion pieces, personal
	studies.	practice, conference abstracts. Not published
		in a peer reviewed journal.
Report	Results were restricted to human	Animal studies. Article not written in English.
characteristics	studies and English language articles.	

## Information sources and search strategy

Searches were conducted using the Ovid platform for the databases Embase, MEDLINE, and PsychInfo. CINAHL was searched using the EBSCO platform. PakMediNet was searched using the database website. The most recent search for all databases was conducted on 15<sup>th</sup> July 2022. The search strategy used for each database is provided as supplementary material (Appendix C).

# Selection of sources of evidence

Search results were exported into Endnote X9 [182]. Duplicates were removed using the method by Bramer et al [169]. References were then uploaded into systematic review software Covidence [183]. Further duplicates identified by Covidence were reviewed manually before removal. Title and abstract screening, and full text screening was completed by two researchers (EB, PR). Conflicts were resolved by a third researcher (RM). A screening document was used to train the researchers and as a reference during screening (Appendix D). Utility of the screening document was appraised by calculating inter-rater reliability using percentage agreement and Cohen's kappa. A good level of agreement was defined as percentage agreement of greater than or equal to 80% and kappa of greater than or equal to 0.60 [184]. No automated tools were used to exclude articles.

## Data charting process

A large number of articles met the study inclusion criteria, which necessitated a modification of the published protocol. A single researcher extracted data into a customised template in Covidence. Missing data were identified using spreadsheet filters on a download of the data. This method was used because validation parameters cannot be applied to extraction templates in the Covidence software. A random sample of 25% of articles (22 articles) were then verified by a second researcher using proofreading. Articles were chosen for verification using a random number generator [185]. It was decided by the review team prior to data extraction that no further verification would be completed providing error rates were below 5%.

## Data items

Data was extracted for 29 variables from full text studies (Table 12). A full list of variables, prompts, and response options are included as supplementary data (Appendix E).

Variables related to study	Variables related to terminology and methods used to
characteristics	differentiate injury intent
Title	Stem terms
Year of publication	Any definitions given for stem terms?
Journal	Definitions of stem terms
Lead author	Unintentional classifier terms
Dates of study	Intentional classifier terms
Country or countries of study	Other classifier terms
Type of study	Any definitions given for classifier terms?
Study aim	Definition or examples of classifier terms
Number of participants	Is a term used that is typically associated with intent used in a
Age of population under study	different context?
Details about age included	Details about the term used in a different context
	Is a method of differentiation of intent included in the
	methods section of the manuscript?
	Method of differentiation of intent
	Is a method for determining any other variable given in the
	methods section of the manuscript?
	Details about the other variables and method of assessment
	Rigour of the method to determine assault
	Rigour of the method to determine accident
	Any other notes/observations

Table 12. List of variables for which data were sought from the studies.

# Synthesis of results

We summarised the data and produced descriptive statistics according to the study objectives. All analyses were completed using Microsoft Excel and RStudio [133, 134]. For articles where the

method of differentiation of injury intent was described explicitly, the rigour of the method was appraised using a modification of the ranking system by Maguire et al. [170] (Table 13). The method was developed for determining burns due to abuse and accidents in a paediatric population. This means we did not appraise the rigour of the method used to determine injuries due to self-harm.

**Table 13.** Ranking of the rigour of the assessment method for accidental burns and burns due to assault.Method modified from Maguire et al. [29]

Ranking	Method of differentiation
Assault	
1	Assault confirmed at case conference, court proceeding, or admitted by perpetrator.
2	Assault confirmed by stated criteria including multidisciplinary assessment.
3	Diagnosis of assault defined by stated criteria.
4	Assault stated as occurring but no supporting detail given as to how it was determined.
5	Assault stated as "suspected" with not details given on whether it was confirmed or
	not.
Accident	
А	Scene of incident recreated, or forensic police investigation of scene, or criminal
	investigation ruled out assault as a cause.
В	Efforts specifically made to exclude assault as a cause for burn through multidisciplinary
	investigation, or social services investigation of home circumstances.
С	No mention about how burn was deemed to be accidental, how assault was excluded,
	or no mention that assault was considered as possible aetiology.

## Results

## Study selection and data extraction

A total of 2054 records were identified from the database searches (Figure 12). Of these, 619 were duplicate records. Title and abstract screening was completed on 1435 records, and full text screening on 130 records. There was a good level of agreement between reviewers during title and abstract screening (percentage agreement 96.1%, Cohen's kappa 0.74) and full text screening (percentage agreement 82.3%, Cohen's kappa 0.60). Inclusion criteria were met by 89 studies. Manual validation checks identified 18 empty cells (0.49% of all fields) following data extraction. These were cross checked against the original paper and filled in. This was primarily due to absence of non-response codes (e.g. Not applicable). Minor errors were identified in seven cells during verification and amended accordingly. The estimated error rate from verification was 0.78% (i.e. one error in every 129 fields).

#### Figure 12. PRISMA flow diagram of selection of sources of evidence [19].



#### **Study characteristics**

Most studies were conducted in India (n = 51) and Pakistan (n = 27) (Appendix F). Only four articles were identified from Nepal, three from Sri Lanka, and two each from Afghanistan and Bangladesh. No articles were identified from Bhutan or the Maldives. The majority (n = 73) used an observational study design collecting data either prospectively through patient and family interview, or retrospectively from patient notes or admission registers. Qualitative interviews were used in five articles. 11 articles did not state how data were collected. The study population was most often patients admitted at a tertiary government teaching hospital burn department. Year of data collection ranged from 1962 to 2020. Median duration of data collection was 12 months (IQR 6-36 months), but ranged from 10 days to 17 years. The total number of participants across all articles was 81122. The median number of participants per study was 198 (IQR 89-678). The age of the study

population included paediatrics and adults for 55 articles, only adults for 18 articles, and only paediatrics for 11 articles. No participant age range was stated for five articles. Some articles specified age cut-offs. For articles including only adults, age cut-offs were: 15 years and over (n = 5), and 18 years and over (n = 4). Paediatric only articles used a wider variety of age cut-offs from 18 years and under, to 10 years and under.

# Objective 1: Determine the breadth of terminology and most commonly used terms for burn injury intent, including the stem term and classifiers.

A total of 14 stem terms were used by 41 articles (median 1, range 1-3 per article) (Table 14; Full data for this objective can be found in Appendix G). The most commonly used term was "cause", which was used in 12 articles, followed by "mode" and "intent".

 Table 14. Number of stem terms used in the articles.

Stem term	Number of articles using term
Cause	12
Mode	7
Intent	6
Circumstances	5
Nature	5
Manner	3
Туре	3
Aetiology	2
Classification	2
Acquisition	1
Clinical forensic study	1
Demographic feature	1
Human behaviour	1
Reason	1
Total	50

At least one classifier term was used in all articles. They were subdivided into five groups – accident, intentional, suicide, homicide, and other based on the most common terms used by the authors (Table 15). "Accident" was the most commonly used classifier term found in 73 articles. Out of the 11 articles that included only paediatric participants, eight used the classifier term "accident" and did not discuss the possibility of non-accidental injury. Activity at the time of injury (e.g. occupational, industrial, recreational, work related) was used in some articles as a proxy for accidental intent. The terms "unintentional" and "non intentional" were used interchangeably with the term "accident", and have become more common in the past 15 years. Conversely, "intentional"

and "non accidental" were primarily used as a higher level of classification than terms such as "suicide" and "homicide". The term "suicide" was used in 45 articles. "Self-immolation" was only used in four articles despite the focus of all articles being on burn injuries. In one article it was used interchangeably with the term "suicide", in another article it was specified that self-immolation referred to the patient not having suicidal intent. The term "homicide" was used in 35 articles. There were only two instances where the term "homicide" and "assault" were used in the same article as different classifications of intent. "Accident", "suicide", and "homicide" remained as the dominant classifier terms when exploring the use of terms across all years of publication, country of study, and age groups of study participants.

Classifier term	Number of articles using term
Accident group	
accident	73
unintentional	10
non intentional	7
victim	4
disaster	2
mishap	2
occupational	2
carelessness	1
incident	1
industrial	1
recreational	1
self-incurred	1
work related	1
Total	106
Intentional group	
intentional	15
non accidental	5
unnatural death	1
Total	21
Suicide group (incorporates all self-inflicted injury)	
suicide	45
self inflicted	7
self immolation	4
self harm	5
self burns	1
self injury	1
self mutilation	1
Total	64
Homicide group (incorporates all interpersonal violence)	
homicide	35

**Table 15.** Classifier terms used in the included articles.

assault	13
dowry	3
victim	3
attack	2
attempted murder	1
torture	1
violence	1
Total	59
Other group	
doubtful	2
incidental	2
branding	1
burn were suffered by someone who tried to intervene	1
miscellaneous	1
miscellaneous/ not known	1
not ascertained	1
unclassifiable	1
unstated	1
Total	11

# Objective 2: Determine if definitions are comparable across studies where the same term is used.

A stem term definition was only found in one article (full data for this objective can be found in Appendix G). This was for the term "classification" and included a flow chart with the official procedure for women who have died from a burn injury in hospital [74]. The same article defined classifier terms of "accident", "suicide", "homicide", and "dowry death" according to victim allegations and relevant legal sanctions. Classifier term definitions were provided in one other article, which differentiated "suicide" as "those with suicidal intent", from "self immolators" as "those who mutilate themselves" [186]. The lack of definitions for stem and classifier terms means they cannot be compared across studies.

One article provided examples of response options for the stem term "cause" as part of a wider definition of burn injury. This included "intentional (homicidal or suicidal) or unintentional (accidental)" [187]. Some articles (n=22) provided example injury mechanisms for classifier terms rather than definitions. Examples were provided for the term "accident" in 15 articles, of which five were studies that included only paediatric patients. The similarity of examples suggest concordance in how clinicians classify descriptions of how the injury occurred (Table 16). Classification of injury intent is not straightforward despite many articles presenting data disaggregated by intent. For example, "branding" was used as a classifier term in one article (Table 15) [188]. It was inferred in
the article that branding is a full thickness burn used as a form of traditional medical treatment to relieve chronic pain. Such practices fall outside of the aforementioned groups of 'accident', 'suicide', and 'homicide' given that the patient has consented to the burn injury. Daruwalla et al. [189] note that complex antecedents such as poverty, drug and alcohol use, and domestic violence lead to a "blurred distinction between homicide and suicide", further complicating differentiation.

 Table 16. Mechanism examples given in articles for various classifier terms.

Classifier term	Examples
Accident	Aslam 2017: "Most common patterns in our study were falling of child into hot water
	pan meant for washing cloth, falling into hot food utensil and spillage of hot food. In
	all these scenarios, the common factor was an unsupervised child left with hot liquid.
	These accidents reflect the lapses in child supervision and need behavioural changes
	on the part of caregivers."[190]
	Gupta 1992: ""Thirty-three children either crawled to or reached up to vessels containing hot liquids which had been placed either on the floor or on a slightly raised platform. These children managed to tip the contents of the container over themselves."[191]
Suicide	Gupta 1993: ""In our series all the suicidal burns were married females and they
	burned themselves by pouring kerosene oil on their clothes and setting themselves
	afire. Their ages varied between 20 and 80 years. The single case of suicide in an 80-
	year-old woman was the result of a feeling of being unwanted and lonely."[192]
	Mukerji 2001: ""A 9-year-old female committed suicide by pouring kerosene over
	herself and setting herself on fire after a quarrel with her brother. She was most
	probably influenced by a similar recent incident in her neighbourhood."[193]
Homicide	Daruwalla 2014: "In two cases a husband told his wife to set herself on fire and, when
	she refused, lit the match himself (a drunken suitor did a similar thing and accidentally
	set himself alight). The reality of setting a woman on fire and the rapidity of spread
	usually unnerved the aggressor, who then helped to put it out."[189]
	Subrahmanyam 1996: "One case of branding by the husband on his wife was a
	homicidal attempt triggered by suspected infidelity."[194]
Branding	Raza 2009: "A 35-year-old Pakistani male with a history of chronic malaria, progressive
	splenomegaly and a complaint of severe left sided abdominal pain was treated by
	branding with a hot metal rod 7 days prior to admission."[188]

# Objective 3: Appraise the rigour of methods used to differentiate burn injury intent and suitability for comparison across studies.

The method used to differentiate burn injury intent was described explicitly in 15 articles (Table 17; Full data for this objective is available in Appendix H). For 58 articles the method of how the authors attributed injury intent could only be inferred based upon general data collection information (e.g. data collected from retrospective review of patient records). No information was available from 16 articles about how intent was determined. Conversely, 28 articles provided specific details about the assessment of 39 other variables. The most common was total body surface area (TBSA) of the burn using either the Lund and Browder chart or Rule of Nines (n = 18), followed by fluid resuscitation using the Parkland formula (n = 5), and socioeconomic status using the Kuppuswamy scale (n = 4).

Routine hospital admission processes that were used to differentiate burn injury intent were described in some of the articles (Table 17). These reveal that clinicians act upon and document what the patient or their relatives report the intent of the injury to be. This may trigger a police investigation to determine culpability. There is little opportunity for the clinician to investigate injury intent further when a patient reports the injury to be accidental, even if they suspect self-harm or assault. Only Laloe [195, 196] describes a method to capture if the clinician judges that there may be misclassification of injury intent. Most articles do not report injury intent outcomes following multidisciplinary assessment, or state the criteria used to differentiate intent. Consequently, the rigour of the method used to confirm assault or accidental injury was generally low (level 4/5, and C).

Reference	Quotes about the method of differentiation of intent used in the study		
		rigour*	
Ahmed 2009	9 Patients less than ten years of age were excluded from the study because medico-legal aspect is least likely in these patients.		
[197]	Patients and their relatives/attendants were carefully interviewed by medical officer and in charge nurse repeatedly regarding the		
	circumstances and nature of accident, complete profile of the patient and their family etc was recorded carefully. All these		
	informations were gathered in complete secrecy and by repeated informal interviews and discussions."		
Belur 2014	Semi-structure interviews were conducted with women admitted with a burn injury or their relatives, healthcare providers, and		
[74]	police as part of qualitative study: "Clinicians at the frontline in emergency or burns wards take an initial history from the patient or		
	her relatives, register a medico-legal case and inform the police stationed in the casualty ward.""His involvement was restricted to		
	taking down the history or cause of burns as narrated by the patient or relatives; he did not usually delve into the details of the		
	incident."" Even when doctors find that the narrative they have been given and the burn patterns do not accord with one another,		
	they seldom have the time or inclination to follow it up in order to try to ascertain the sequence of events that led up to the burns."		
Chakraborty	"The medico legal aspects were obtained by interviewing the patients or their relatives with the help of the schedule and also by		
2010 [198]	reviewing the relevant records like admission register and bed tickets."		
Daruwalla	Semi-structured and key informant interviews were conducted with women admitted with flame burns or their relatives, healthcare		
2014 [189]	providers, and police. They describe that clinicians document intent based on what the patient or relatives said e.g. "My job is	Accident: C	
	merely to document what I have got from the patient in the patient's own words".		
Das 2013	"Included in the study were both outpatients and inpatients who made specific complaints about the intentional nature of the	Assault: 2	
[199]	injury to police and who requested injury certificates for litigation purposes." "Although the health-care team was suspicious of	Accident: C	
	intent in some cases, the absence of investigation by the local authorities left no option but to categorise those as accidental."		
Hafeez 2019	"Data was retrieved manually from the hospital records of individual files of every victim using purposive sampling""Demographic	Assault: 5	
[200]	questionnaire was developed in the light of literature and it includedassaulted body parts, assaulted by, and the reason of	Accident: NA	
	assault."		
Laloe 2002	"Deliberate self-harm, acknowledged by patient or relatives during the course of hospitalisation, was classified as such. Suspected	Assault: 5	
[195]	but unconfirmed cases, either because of the distribution of the burns or the behaviour of the patient or the relatives, were	Accident: C	
	classified as doubtful." No details included about determination of cases due to assault or accident.		
Laloe 2002	"We have classified as self-inflicted those cases acknowledged by patient or relatives during the course of hospitalisation. Doubtful	Assault: 5	
[196]	cases were those where the distribution of the burns or the behaviour of the patient or her relatives suggested that they were not	Accident: C	
	accidental""doubtful origin [burns are those that are] allegedly accidental but thought [by the clinician] to be self-inflicted or due		
	to violence." No details included about determination of cases due to assault or accident.		

 Table 17. Method of differentiation of burn injury intent from articles where this information is described explicitly.\*

Marsh 1996	"Patient interview" about circumstances of injury		
[201]		Accident: C	
Newberry	"Data included demographics, medical history, physical exam, care rendered by the EMT [emergency medical technician] and		
2019 [202]	whether the injury was accidental or non-accidental (per patient or caller report)."		
Rao 1989	Data collected on proformas by staff. Psychological autopsy was performed on fatal cases. "Each case was discussed by the		
[203]	research team and the decision on the nature of the burns was arrived at (accidental, suicidal or homicidal)."		
Segu 2016	"Information regarding the circumstances surrounding the incident, burn severity, cause of suicide and any associated illnesses was		
[204]	also collected. During history taking particular emphasis was given to know the intent of suicide by talking to		
	patients/relatives/friends."		
Wagle 1999	9 "All the patients and their relatives were seen one to three times in the first week post-burns. When possible, friends and		
[205]	neighbours were interviewed. All of the initial interviews were carried out by a female psychiatrist (SW) The main purpose was to		
	gather information about the socio-demographic details and also to find out whether or not the injuries resulted because of a		
	suicide attempt. The patients were divided into two groups depending on the presence or absence of a suicidal intent. The		
	information about the suicidal intent was obtained by speaking to patients, their blood relatives and by referring to case notes."		
Yerpude	"The medico legal aspects were obtained by interviewing the patients or their relatives with the help of the schedule and also by		
2011 [206]	reviewing the relevant records like admission register and bed tickets."		
Zopate 2017	"The detailed history was obtained from the patients close relatives or friends available and the person who was present at the time		
[207]	of incidence or the one accompanying the victim. Information was also collected from the relatives, maternal as well as in laws,		
	neighbours and police investigation reports. In doubtful cases, the dying declaration given by the patient in presence of the		
	magistrate was compared with the statement given by the patient at the time of admission."		

**Table notes:** \*Ranking of the rigour of assessment of reported cases of assault and accidents uses a ranking system of 1-5 for assault and A-C for accident. NA (not applicable) means there were no reported cases. For cases of assault the method of differentiation was ascribed a ranking between 1 and 5 (1 – assault confirmed at case conference, court proceeding, or admitted by perpetrator; 2 – assault confirmed by stated criteria including multidisciplinary assessment; 3 – diagnosis of assault defined by stated criteria; 4 – assault stated as occurring but no supporting detail given as to how it was determined; 5 – abuse stated as "suspected" with not details given on whether it was confirmed or not). For accidental burns the method of differentiation was ascribed a ranking A-C (A – scene of incident recreated, or forensic police investigation of scene, or criminal investigation ruled out assault as a cause; B – efforts specifically made to exclude assault as a cause for burn through multidisciplinary investigation, or social services investigation of home circumstances; C – no mention about how burn was deemed to be accidental, how assault was excluded, or no mention that assault was considered as possible aetiology). The method was developed for use in a paediatric population and does not include a system for appraisal of burns due to self-harm.

### Discussion

This is the first study to systematically investigate the terminology and methods used to differentiate burn injury intent of hospital patients in South Asia. We found there was a wide variety of stem and classifier terms for the concept of intent used across the 89 included articles. These terms were poorly defined. The method used to assess injury intent was only described explicitly in 17% of articles and the rigour of the methods were low. These are important findings because the variability and incompleteness of burn injury intent information found in the articles would increase the risk of misclassification bias if data were compared across studies.

We found that over half of the articles did not use a stem term for the concept of intent. The term 'intent' itself was only used in six articles. The most commonly used stem term was "cause". This is a broad term in the field of injury surveillance. For example, ICD-11 uses multiple data elements for injury causation since the incorporation of the International Classification of External Causes of Injury [10, 26, 66]. Amongst others, these include intent (e.g. unintentional, self-harm, interpersonal), mechanism (e.g. exposure to a controlled fire), activity when injured (e.g. paid work), object or substances producing injury (e.g. hot drink), place of occurrence (e.g. home), and alcohol and psychoactive drug use in injury. We found that other elements of causation were sometimes incorporated with intent. Terms indicating activity when injured (e.g. occupational, industrial) were used as a proxy for accidental intent and it was not clear whether intentional injury had been considered. The workplace is recognised as a place where self-inflicted injuries occur, so unintentionality should not be assumed [208, 209].

All articles used at least one classifier term. "Intentional" was used as a higher level of classification, whereas "unintentional" or "non intentional" were used interchangeably with "accident" (Figure 13). We found the terms "unintentional" and "non-intentional" have become more common in the past 15 years. This is consistent with the international injury prevention community, which now favours the term unintentional over accident to emphasise the preventable nature of all injuries [34]. Common terms and their hierarchical structure in the articles were consistent with categories used in the WHO injury surveillance guidelines, although we found no terms referencing injuries caused by legal intervention or war [11]. Self-immolation is a commonly used term in the research literature about burn injuries [70, 210]. We found this term was only used in 4 articles possibly reflecting that it is not a term widely used in clinical practice given that most articles included in this review report data from burn departments. The terms "accident", "suicide", and "homicide" were the most common classifier terms. Few articles differentiated between self-harm and suicide, or

homicide and assault. The dominance of the terms suicide and homicide suggests that they are used as broad classifier terms reflecting who was responsible for the injury, rather than reflecting the desire of the patient or assailant to cause death. The use of broad classifier terms is a pragmatic approach for hospital-based surveillance systems as it can be difficult to determine underlying motives in the acute setting [43].

**Figure 13.** Common stem and classifier terms used in included articles including the most common hierarchy structure of classifier terms across all articles.



Defining variables reduces the risk of misclassification bias in a study and is a key attribute in surveillance systems to improve reliability of data [11]. We found very few articles defined their stem or classifier terms. This may lead to different collection and interpretation of the data. A survey sent to the members of the International Association for Suicide Prevention found considerable variation in the definitions associated with English-language terms for suicidal behaviours, including variation between members from low- and middle-income countries compared to high-income countries [211].

Standardised methods of assessment are recommended as a means to reduce misclassification bias [142]. This is particularly important for variables that are likely to result in inter-rater differences. We found that 18 articles described a method to assess TBSA. TBSA of the burn injury is a key predictor of patient outcome. Efforts to standardise assessment of TBSA have been ongoing since the 1920s, but the Lund and Browder chart and Rule of Nines are the most commonly accepted

methods [212]. Almost twice as many articles provided specific methods of assessment for variables other than intent. This suggests that authors were not averse to using and documenting standardised methods of assessment where they exist. The development of a method to differentiate burn injury intent has been identified by numerous studies from South Asia as an area of research and service need [80, 213, 214]. A list of features suggestive of intentional burns in children was developed by Maguire et al [170] using systematic review methodology, but no similar tool exists for adults. Features suggestive of intentional burns were collated from 26 studies that rigorously confirmed intentional injury (rank 1-3) and excluded accidental injury (rank A or B). The majority of studies were identified from the United States (17 studies). Only two studies were from LMICs, but not from countries in South Asia. In our review, only two articles used a method of differentiation of intent that would meet the rigour criteria used by Maguire et al. This suggests that the same systematic review methodology could not be used to identify features consistent with intentional injuries using current literature from South Asia.

Of the articles included in our review that did describe a method for assessment of intent, there was clear evidence that misclassification could occur due to the healthcare professional or researcher documenting the history provided by the patient or family, rather than their own assessment of the presenting burn and circumstances. Only Laloe [195, 196] described documenting cases as 'doubtful' based on the pattern of the burn and behaviour of the patient and relatives. The WHO Global Burn Registry includes a question that allows the clinician to record the intent of the burn, and their degree of clinical suspicion that a burn of 'undetermined intent' was caused intentionally [102]. Based on our findings it is likely this variable would reflect who, if anyone, the patient or family reports to be responsible for the injury. The WHO Global Burn Registry pilot evaluation included burn experts from Afghanistan, Bangladesh, India, Sri Lanka, Nepal, and Pakistan. Over 20% of respondents believed that intent variables were likely to be inaccurate, which suggests that the approach to collection of intent data could be refined. Inclusion of a data item in registers that allows clinicians to document their degree of clinical certainty in the patients' reported injury intent could allow estimation of responder bias. However, further exploration is required with clinicians in South Asia to understand the acceptability of this approach given the requirement in some countries to report intentional injuries to the police [148].

There are a number of strengths to this systematic scoping review. There were minimal deviations from the registered and published protocol. Reporting guidelines for systematic scoping reviews were followed throughout [165]. A global study is underway to assess comparability of injury intent variables used in burn registers globally, but there are no active national burn registers in South Asia

[1]. Our review helps to address this gap by assessing the comparability of injury intent variables from the research literature, which is a possible alternative source of surveillance data. We have identified a number of future research needs including qualitative exploration of the method of assessment of injury intent in hospitals by healthcare professionals. There are some limitations to this review. We did not include grey literature due to the volume of articles that met our inclusion criteria in preliminary searches. This may mean some relevant articles were missed. Resource limitations meant that data could only be extracted by a single researcher. We tried to minimise errors in the data by checking for missing data and through verification. We were unable to fully complete objective 2 (determine if definitions are comparable across studies where the same term is used) due to lack of data in the included articles. However, this is an important finding for the study. Our results may not reflect practices across the whole of South Asia because the majority of articles were from India and Pakistan.

Overall, our findings hint at the potentially spurious use of the term "intent" in surveillance literature. From a philosophical and legal perspective, intent encompasses both who completed the act and why [215]. In an acute clinical setting determination of why an act was carried out may not be feasible, but it is feasible to try to differentiate who, if anyone, was likely to have inflicted the injury. We recommend that the global burn community works together to develop a common data element for burn injury intent, including definitions and method of assessment. It should be considered whether the term 'intent' itself is the correct term for the data being captured in surveillance systems. In the meantime, we recommend that all authors and journal editors define intent related variables and explicitly describe their method of assessment to bring more studies in line with international guidance for observational research. We recommend that researchers conducting systematic reviews on a single classification of injury intent (e.g. unintentional injuries) scrutinise the method used to differentiate injuries to ensure data are comparable. The list of terms used to denote injury intent can be used to construct search strategies for systematic reviews that focus intentional or unintentional injuries. This may increase ascertainment of articles of interest.

#### Conclusions

We have shown that there is a wide breadth in terminology used for injury intent, but that the most common classifier terms are accident, suicide, and homicide. Few definitions and detailed description of the method of assessment of intent are provided in research articles, which limits interstudy comparisons. Where methods of assessment were described, they appear to be based on patient or family report rather than clinician or multidisciplinary assessment. The heterogeneity in terms, lack of definitions, and limited investigation of injury intent means this variable is likely to be prone to misclassification bias. We strongly recommend that the global burn community unites to develop a common data element, including definitions and method of assessment, for the concept of burn injury intent to enable more reliable data collection practices and interstudy comparisons.

# Chapter four - Establishing self-harm registers: The role of process mapping to improve quality of surveillance data globally

## Preface to chapter four

Chapters two and three showed that international burn registers and published research studies from South Asia tend to include data from patients with burn injuries that are admitted to hospital. This is likely to miss patients that present to, and are discharged from, emergency departments (or their equivalent). This reduces the representativeness of the database population compared to the source population. Conversely, self-harm registers usually collect data in emergency departments to try to maximise case ascertainment and minimise selection bias. Emergency departments are not ubiquitous internationally. A thorough case ascertainment strategy must consider all pathways that enable patients to gain emergency care.

Self-harm registers could be an important source of data on burn injury intent providing all cases are captured, and there is accurate assessment of whether a burn is due to self-harm, unintentional, or due to interpersonal violence. The risk of misclassification may be so high for some injury mechanisms (e.g. burns), that it is preferable to include all injuries in a register regardless of reported intent. Self-harm registers are concentrated in high-income countries, but the greatest burden of disease is in low- and middle-income countries, particularly South Asia. Chapter four describes a project that established a new self-harm register in two hospitals with differing emergency care systems in south India. The inclusion criteria included all burn injuries regardless of reported injury intent. Deciding upon the point at which cases should be identified required understanding the pathways by which patients can present to hospital and where their details are recorded. This information was gained using process mapping. It enabled data collection points to be determined as well as providing insight into the points where patients may be missed. The technique is adaptable to improve case capture of new and existing registers.

## Paper 5

A published version of this paper is available: Bebbington E, Poole R, Kumar SP, Krayer A, Krishna M, Taylor P, Hawton K, Raman R, Kakola M, Srinivasarangan M, Robinson C. Establishing Self-Harm Registers: The Role of Process Mapping to Improve Quality of Surveillance Data Globally. International Journal of Environmental Research and Public Health. 2023;20:2647. doi:

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## Abstract

Self-harm registers (SHRs) are an essential means of monitoring rates of self-harm and evaluating preventative interventions, but few SHRs exist in countries with the highest burden of suicides and self-harm. Current international guidance on establishing SHRs recommends data collection from emergency departments, but this does not adequately consider differences in the provision of emergency care globally. We aim to demonstrate that process mapping can be used prior to the implementation of a SHR to understand differing hospital systems. This information can be used to determine the method by which patients meeting the SHR inclusion criteria can be most reliably identified, and how to mitigate hospital processes that may introduce selection bias into these data. We illustrate this by sharing in detail the experiences from a government hospital and non-profit hospital in south India. We followed a five-phase process mapping approach developed for healthcare settings during 2019–2020. Emergency care provided in the government hospital was accessed through casualty department triage. The non-profit hospital had an emergency department. Both hospitals had open access outpatient departments. SHR inclusion criteria overlapped with conditions requiring Indian medicolegal registration. Medicolegal registers are the most likely single point to record patients meeting the SHR inclusion criteria from multiple emergency care areas in India (e.g., emergency department/casualty, outpatients, other hospital areas), but should be cross-checked against registers of presentations to the emergency department/casualty to capture less-sick patients and misclassified cases. Process mapping is an easily reproducible method that can be used prior to the implementation of a SHR to understand differing hospital systems. This information is pivotal to choosing which hospital record systems should be used for identifying patients and to proactively reduce bias in SHR data. The method is equally applicable in low-, middle-, and high-income countries.

## Introduction

The surveillance of suicide attempts is an essential element of suicide prevention strategies [43, 216]. The two primary methods to obtain these data are surveys of self-reported suicidal behaviour, and registers of those treated for self-harm at healthcare institutions, usually hospitals [216]. Hospital-based registers include suicide attempts and self-harm without suicidal intent (known as self-harm registers or SHRs) [216]. Self-harm is the act of self-poisoning or injury irrespective of motive [217]. The neutral term 'self-harm' is used because the determination of the intention to die can be difficult in the acute setting where the patient may be uncertain of their underlying motives [43]. Data from SHRs can be used by researchers, clinicians, and policy makers. These data are particularly powerful when collected systematically and continuously [218]. They can provide information on emerging trends in behaviour and contributory factors, which can be used to develop preventative interventions and policy initiatives [43, 216]. The SHR can then be used to monitor the effectiveness of the intervention, as has been demonstrated in the UK with the restriction of pack sizes of paracetamol and salicylates, and in Sri Lanka with household lockable pesticide storage [219, 220]. SHR data can inform clinical services through providing information on peak presentation times that may merit an adjustment in staffing, as well as local patient populations that might have additional needs (e.g., occupational, age, ethnicity) [43, 218].

The Global Burden of Disease study estimates that in 2019 there were 5 million injuries due to selfharm with over 750,000 deaths [35]. Over a quarter of these injuries and deaths occurred in India despite its accounting for 18% of the global population [35, 221]. Only 11% of low- and middleincome countries (LMICs) have suicide surveillance data of sufficient quality and availability for country comparisons, compared to 71% of high-income countries (HICs) [39]. The unavailability of these data limits global efforts to reduce suicide and self-harm, such as Sustainable Development Goal 3.4.2 to reduce premature mortality from suicide by a third by 2030 [222]. Previous attempted suicide or self-harm is the strongest predictor of future risk of suicide in HICs [223-225]. There is evidence that methods, sex distribution, and patterns of repetition of self-harm differ between HICs and LMICs, particularly in South Asia [225, 226]. There is a physical, economic, and psychosocial burden associated with self-harm [227-229]. These factors support the establishment and maintenance of SHRs. SHRs are unevenly distributed across the world, being strongly concentrated in HICs, but most global suicides occur in LMICs [39, 230]. Even in HICs, there are only a small number of SHRs [230]. In establishing SHRs, it is essential that they are of high quality. Greater focus is needed on developing SHRs in settings that currently lack robust surveillance systems to ensure that relevant data are available to inform local interventions and evaluate policy initiatives.

The WHO Practice Manual for SHRs encourages countries to establish registers of hospital presentations of self-harm at all levels (national, subnational, regional or local), capturing and recording as many cases as possible [43]. It states that "Most hospital presentations will occur through the emergency department, but systems should be put into place to check records of all presentations to the hospital" (p. 19). This raises two issues that may lead to cases being missed by the SHR. Firstly, whilst emergency departments are ubiquitous in HICs, many LMICs have fragmented emergency care provision with few emergency departments [231, 232]. Second, the manual gives little guidance on how to ensure that all cases of self-harm presenting to a hospital are captured in the SHR.

Other authoritative sources on SHRs refer to data collection taking place in an emergency department, but it can be unclear what is meant by this and whether this data collection method is implementable globally [218, 224, 230, 233, 234]. In North America, Australasia, and much of Europe, emergency departments are the physical space associated with the practice of emergency medicine [235]. Almost all patients presenting to hospitals in HICs following self-harm will be assessed, investigated, and treated in an emergency department before hospital admission, where necessary. This represents a single-entry point for patients requiring hospital emergency care and as such is a common point for data collection on self-harm presentations. Routinely collected hospital statistics may underestimate presentations of self-harm by up to 60% compared to an established SHR with a well-developed case-ascertainment strategy [236]. Emergency medicine training varies globally, with incomplete specialist provision in LMICs [231, 232]. Emergency care in some LMICs is provided by doctors without specialist training, or by non-medical staff. These facilities are essentially triage systems. Patients are directed to relevant specialists earlier than in emergency departments. This is known as 'Casualty' in India [237]. Where emergency departments have been established recently, patients may not seek emergency care at a single hospital entry point. The routes by which patients gain care may not correspond to hospital policies, and we cannot assume that those who work in the system understand all processes completely [94]. Consequently, a SHR collecting data from a single pre-determined entry point that is not based on local processes could miss cases. Missed cases will lead to lower estimated rates of self-harm. They may have different demographic or clinical characteristics. It is not possible to know whether cases that bypass casualty or emergency departments are different without capturing data on them. This could mean that collected data is systematically biased due to the selection of cases and is, therefore, less reliable.

Self-harm is prone to misclassification and certain types of self-harm injuries, such as selfimmolation and major trauma, are particularly prone to this type of bias [44, 162, 216]. There is a risk that patients presenting with such injuries will not be included if there is a reliance on clinician judgement about whether the act was intentionally self-inflicted. SHRs require a case-ascertainment strategy tailored to the hospital system to ensure as many cases as possible are captured, and potential missing groups are recognised and accounted for in the reporting of the results [218].

Process mapping has been embraced as an essential technique in healthcare quality improvement to understand how a whole patient pathway works [238-241]. The technique is widely attributed to mechanical engineer Frank Gilbreth, who, in 1921, presented a method of depicting processes for any work environment in a standardised way [242, 243]. Gilbreth argued that visualising every aspect of a process is essential to understand the potential impact of a change [243]. Gilbreth's method has evolved into business process mapping, a widely used technique that aims to improve systems by understanding current processes that comprise a system, and then working to achieve improvements in bottlenecks or inefficiencies that are critically limiting the desired outcome of the system [244]. A product of the technique is a pictorial representation of the process being studied, known as a process map, which is analysed to identify where improvements could be made. Process mapping has been used in a wide variety of specialities and healthcare settings [245-249]. It has been employed in the field of suicide prevention to understand the barriers and facilitators to quality mental healthcare, inpatient suicide risk, and the development of care pathways for selfharm in prison [250-252]. Process mapping is advocated as a method to improve surveillance data, particularly civil registration and vital statistics (births and deaths) in LMICs [248, 253]. There has been no previous description of its use to establish an SHR, but this systematic approach could be utilised to resolve the major problem of how to capture the wide variety of possible self-harm presentations across diverse emergency care systems. It is equally applicable in low-, middle-, and high-income countries.

We aim to demonstrate that process mapping can be used prior to the implementation of a SHR to understand differing hospital systems, and that this information can be used to determine the method by which patients meeting the SHR inclusion criteria can be most reliably identified as well as mitigating hospital processes that may introduce selection bias into these data. We illustrate this by sharing in detail the experiences from two hospitals in south India.

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# Methods

## Setting

The South Asia Self-Harm Initiative (SASHI) is a multinational research collaboration on self-harm, one part of which is to implement SHRs. Process mapping was conducted at two hospitals in Mysore, India that are prospective study sites in the SASHI SHR project. Krishna Rajendra (KR) Hospital is a tertiary, government-funded hospital. JSS Hospital is a non-profit hospital. KR and JSS hospitals both have approximately 1800 beds, include all major specialities, and are attached to medical colleges. Approximately 42% of the population of India receive inpatient medical care in government hospitals, 3% in non-profit hospitals, and 55% in private hospitals [254]. The hospitals are funded differently and, therefore, were predicted to have differing patient processes that might affect SHR data collection.

## **SHR Inclusion Criteria**

Eligible patients will be identified from routine records. The SASHI SHR inclusion criteria (Table 18) are purposefully broad to avoid assumptions on patient intention by data collectors, which we are aware is a sensitive issue in South Asia.

Table 18. SASHI self-harm register inclusion criteria

SASHI self-harm register inclusion criteria				
Poisoning (medication and non-medication)				
Burn injury				
Hanging				
Drowning				
Fall from height				
Fall in front of train				
Self-laceration				
Firearm injury				
Unspecified self-harm				

## Approach

We followed a five-phase process mapping approach developed for healthcare settings, supplemented by specific surveillance information [238, 239, 244]. A process mapping team was assembled from the SASHI research group, and this included clinicians and researchers from India and the UK. Clinicians included psychiatrists, a public health doctor, a psychologist, and an emergency medicine doctor. The process mapping steps followed by the team are outlined in Figure 14.

**Figure 14.** Process mapping steps completed at each hospital to determine where SHR data collection should take place and which hospital processes may affect reliability of these data.



#### **Pilot Work**

At initial meetings, it appeared that hospital processes were well understood. However, when a diagram of these processes was drawn (process map), it was unclear which hospital record systems should be used to identify patients meeting the SHR inclusion criteria. Two senior members of the group then visited the non-profit hospital to observe and discuss hospital processes with clinical staff. This showed more detailed process mapping would be feasible. It highlighted that the clinicians only understood processes that they directly interacted with, and that uniform processes were not followed in all relevant departments. We determined a structured approach across multiple areas of the hospital was necessary to understand these processes in order to determine where patients meeting SHR inclusion criteria could be most reliably identified.

#### **Data Collection**

A clinician researcher gathered information during ten site visits between July 2019 and February 2020. The researcher had no prior experience of healthcare provision at either hospital, but is an experienced emergency medicine doctor in the UK so understands the principles of hospital patient flow.

Senior clinicians introduced the researcher to the hospital departments, and reassured clinical teams that permissions were in place. Initially, a tour was completed to orientate the researcher to each of the hospitals. The researcher was introduced to staff who were likely to care for patients meeting the SHR inclusion criteria, including casualty medical officers, emergency medicine doctors,

intensive care doctors, plastic surgeons, general surgeons, physicians, psychiatrists, psychologists, and rotational trainees. The researcher then completed a morning or an afternoon of observation in areas that were likely to receive patients meeting SHR inclusion criteria. This included casualty (government hospital), emergency department (non-profit hospital), medicolegal register office, burns unit, and psychiatry department. Doctors and nurses were interviewed opportunistically during periods of observation. Experienced staff members who were patient-facing in emergency care areas were identified and asked to participate in a longer interview at a convenient time and location. These interviews often took place in the workplace, which allowed the researcher to observe them 'in action', thus prompting further questions.

Written field notes, photos, and diagrams of the layout of key areas (e.g., hospital entrance, emergency care areas) were taken throughout. Particular attention was given to points where patients could make choices, to triage processes, to administrative procedures (e.g., registration, payment), to options for patient disposition or discharge, and documentation. These details were investigated for each patient group meeting the SHR inclusion criteria.

#### Data Analysis

Interviews were reviewed for commonalities. The notes, photos and diagrams were compiled into a working document that we termed a narrative process map. This was analysed by the researcher who conducted the interviews for inconsistencies and to identify processes that had not been fully understood. Repeat visits and interviews were conducted in both hospitals until all outstanding questions were answered. This required three cycles. Where possible, staff of different grades and specialities were approached in each cycle. Summaries were fed back to interviewees to check accuracy. Narrative process maps were then reviewed by the entire process mapping team to identify questions and gaps that required follow-up. Interviews were conducted with experienced staff members from both hospitals by other researchers in the process mapping team to gain a different perspective. Handwritten notes were taken during interviews. Additional information was added to the narrative process maps.

The narrative process maps were translated into pictorial process maps using Business Process Model And Notation 2.0 in Lucidchart software (Lucid Software Inc., South Jordan , UT, USA): the standard form for process diagrams, irrespective of environment [255, 256]. The process maps were then reviewed by the process mapping team to identify the method by which patients meeting the SHR inclusion criteria could be most reliably identified. Processes that may affect data reliability were identified, and solutions to mitigate these processes were discussed.

# Results

Processes for patients meeting the SHR inclusion criteria were different across the hospital sites. Tours and interviews conducted during data collection were iterative but were found to explore similar information at both institutions despite their differing processes (Table 19).

**Table 19.** Topics and questions explored during data collection at both hospitals organised according to the typical patient journey. Full narrative process mapping documents are not presented because they include sensitive, hospital-specific information and are not presented because they include sensitive, hospital-specific information and are not presented because they include sensitive, hospital-specific information and are not presented because they include sensitive, hospital-specific information and are not presented because they include sensitive, hospital-specific information and are not presented because they include sensitive, hospital-specific information and are unlikely to be of interest to a general readership.

Торіс	Specific details addressed in tours and interviews			
Overview	Type of hospital, funding, size, and specialities.			
	Other types of healthcare provision available locally.			
Patient arrival	Referral options (e.g. from other hospitals, primary care).			
	Means of arrival (e.g. walk, ambulance), method of ascertaining that			
	means (e.g. national telephone number), and associated costs.			
Point of arrival	Departments providing emergency care at the hospital (e.g. casualty,			
	emergency department, outpatient department).			
	Method by which patients are directed to the appropriate department.			
Main emergency care area	Consensus on the department responsible for providing immediate			
	emergency care to newly presenting patients (e.g. casualty, emergency			
	department).			
	Triage processes for new patients.			
	Patient registration and payment procedures.			
	Inclusion criteria for any routinely collected registers.			
	Areas of the department where patients may be treated.			
Management in the main	Clinician responsibilities and training.			
emergency care area	Whether there are any medicolegal processes.			
Medicolegal processes (if applicable)	Clinician responsible for completing medicolegal processes (e.g. Casualty Medical Officer).			
	Patient groups requiring medicolegal processing.			
	Paperwork completed for each patient (e.g. medicolegal register).			
	Inclusion criteria for any routinely collected registers, and details entered into these registers.			
	Clinician discretion for medicolegal processing.			
	Police involvement in medicolegal processes in hospital.			
	Length of time records kept.			
	Payment processes.			
Disposition from main	Main area or specialities where patients who meet the self-harm register			
emergency care area	inclusion criteria go (if applicable).			
	Inpatient admission registration and payment.			
Alternative means by which	Method by which patients access these services.			
patients can access	Handling of medicolegal processes.			
emergency care (e.g.	Patient groups (e.g. priority, injury type) that could present to these areas			
outpatient department,	or the main emergency care area.			
nearby hospitals, private ward).	Methods by which patients can be admitted to these areas directly and bypass normal administrative routes.			

Hospital entry points at the main emergency care areas differ significantly between the two hospitals, influencing where patients meeting the SHR inclusion criteria should be identified. The major difference is that the main emergency care area in the government hospital is casualty (Figure 15), whereas in the non-profit hospital, it is an emergency department (Figure 16).

The government hospital casualty triages patients to the appropriate speciality and completes the medicolegal processes. This includes a medicolegal register for cases that may require police investigation or legal proceedings to ascertain responsibility for injury or illness (see medicolegal processes box, Figure 15 and Figure 16). Although the Indian Mental Healthcare Act 2017 decriminalised attempted suicide, medicolegal documentation is still completed following self-harm [148, 257]. The non-profit hospital records around 10 times fewer medicolegal cases than the government hospital despite having a similar number of patients presenting to the hospital (Table 20). The casualty is run by a casualty medical officer with no specialist training in emergency medicine (see casualty medical officer lane, Figure 15). At the entrance to the government hospital casualty, a security guard provides advice on where to attend (see security lane, Figure 15). Cases requiring medicolegal registration are directed to casualty.

**Table 20.** Number of patients presenting to each hospital and the proportion who are recorded as a medicolegal case. The breakdown of the number of patients presenting to casualty and the outpatient department of the government hospital was not available.

	Number of patients		
	2019	2020	2021
Government Hospital (KR hospital)			
Outpatients			
(includes casualty and outpatient department)	476012	297682	329978
Medicolegal cases	24404	17969	24029
Non-profit hospital (JSS hospital)			
Outpatients			
(includes casualty and outpatient department)	664650	376870	415034
Emergency department	29330	23204	19153
Outpatient department	635320	353666	395881
Medicolegal cases	3969	2917	3021



Figure 15. Pictorial process map of casualty in the government hospital.\*



\*Figure notes: Grey data objects represent data source for SASHI SHR data collection. The process map has been drawn using business process model and Notation 2.0 (see key). The process map should be read from left to right. Each row (known as a lane) represents a participant in the process. Symbols (circle, triangle, square) depict events, decision points and tasks in the process. Arrows between participant lanes show the direction of flow of information for tasks occurring simultaneously. OPD = outpatient department, CMO = casualty medical officer, MLR = medicolegal register.



Figure 16. Pictorial process map of the emergency department in non-profit hospital. The same notation is used as in Figure 15.

In contrast, the non-profit hospital emergency department is run by doctors with specialist training in emergency medicine (see emergency medicine doctor lane, Figure 16). Medicolegal processes at the non-profit hospital are completed by a dedicated casualty medical officer who has no other clinical commitments and is situated across the corridor from the emergency department (see casualty medical officer lane, Figure 16). At the entrance to the non-profit hospital emergency department, patients are triaged by a senior nurse (see triage nurse lane, Figure 16). The triage algorithm at the non-profit hospital includes all SHR inclusion criteria, meaning such patients would be directed to the emergency department.

We found that SHR inclusion criteria coincide with the medicolegal register criteria that are set nationally and therefore applicable to all hospitals in India. All healthcare staff are aware of medicolegal register requirements. When a patient presents to a different part of the hospital (e.g., outpatient department, private ward) and meets medicolegal register criteria, the doctor in charge of their care is expected to report the case to the casualty medical officer for inclusion in the medicolegal register. Therefore, the medicolegal register should be the initial SHR data collection point in both hospitals.

Several processes were identified that may introduce bias into SHR data. Firstly, the patient, relative or ambulance crew chooses which hospital to attend. This is primarily a financial decision, but it may be influenced by the availability of services (e.g., ventilators), thus influencing the number of presentations to the hospitals. We have partially mitigated this through SHR data collection at multiple hospitals in the same city.

Once the patient has arrived at the hospital, they have a choice of where to seek emergency care (see patient lane arrival decision point, Figure 15 and Figure 16). At both hospitals, the patient can choose whether to attend the casualty/emergency department or the outpatient department. At the government hospital, obstetric, gynaecological and paediatric patients attend an adjoining women and children's hospital. At the non-profit hospital, patients with medical insurance can attend a private ward directly. Patients presenting with self-harm to the outpatient department, private ward, or women and children's hospital could be missed if the healthcare professional does not refer the case to the casualty medical officer for inclusion in the medicolegal register. We are aware of two self-harm patients who presented to the outpatient department at the non-profit hospital during the study and who were not recorded in the medicolegal register: a patient whose self-laceration wounds were sutured in the outpatient department prior to discharge, and a case of partial hanging where the patient was admitted under psychiatry. Indian outpatient department

clinics are extremely busy, and documentation is necessarily minimal. The outpatient department at the non-profit hospital sees 15–20 times the number of patients at the emergency department (Table 20). Because patients must be mobile and able to queue for long periods prior to being seen, only patients with minor physical injuries or self-poisonings are likely to present to the outpatient department. Patients sometimes abscond from the hospital when asked to complete medicolegal processes from the outpatient department. This is mitigated through the assistance of security staff or family escorts.

Finally, the casualty medical officer has some discretion about which cases to include in the medicolegal register, for example, self-laceration not requiring medical intervention is unlikely to be recorded. For patients who attend via casualty or the emergency department, such cases are recorded in a casualty or emergency department register of presentations but are not recorded in the medicolegal register.

Therefore, the medicolegal register should be the initial SHR data collection point in both hospitals to capture as many eligible cases as possible from the outpatient department. Case ascertainment should be optimised through cross-checking against casualty (government hospital) and emergency department (non-profit hospital) registers to capture potentially misclassified or less-severe injuries that present via casualty or the emergency department (see self-harm register data collection point symbol, Figure 15 and Figure 16).

### Discussion

There is a gap in guidance on thorough case ascertainment when establishing SHRs, due to an assumption that emergency care processes are uniform internationally. We have shown how process mapping can be used to identify where patients meeting SHR inclusion criteria may be reliably identified and how to mitigate hospital processes that may introduce selection bias into these data. This innovative work demonstrates that, although two hospitals differ significantly, the same systematic method can be used to understand the relevant processes. This informs decision-making on optimal case ascertainment. Without this, SHRs identify patients from a single point of convenience and may miss significant patient groups, creating selection bias in the data. Whilst the process maps themselves will not generalise per se, the method of producing them and the need to do so will be relevant for any healthcare system wishing to establish a SHR.

A simple and reproducible method to inform case-ascertainment processes is particularly important in countries with diverse healthcare infrastructures. We have shown that two hospitals in close vicinity offer different types of emergency care. The provision of emergency care globally is moving towards the model of emergency departments run by specialist emergency medicine doctors [231, 232, 258]. Training programmes are not universally available, particularly in LMICs, and the lived experience of patients attending such facilities is poorly explored [259]. Repeat reference to data collection in "emergency departments" in the WHO SHR Practice Manual is unhelpful [43]. We discovered multiple pathways through which patients access care at both hospitals, with no single clinical point at which all cases of interest could be captured. Data for the SHR therefore must be collected from multiple sources and cross-referenced. This finding is likely to be applicable to other hospitals in India, though the methods could be applied globally to any hospital wishing to establish a SHR.

The existence of routes to hospital care that by-pass the hospital's main emergency care area means that a comprehensive SHR cannot be solely based on records from those departments. We found such patients would be likely to be less severely unwell or injured and overlooking them would introduce selection bias to the data. It is conceivable that this type of bias contributes to ostensibly low rates of repetition of self-harm in South Asia [225, 226, 260]. Process mapping could be used in a similar way to understand the use of local primary healthcare infrastructure, and it would be an important step in assessing whether the surveillance of self-harm that occurs without hospital presentation is feasible.

The use of a systematic method to understand patient flow through healthcare facilities is particularly useful to protect surveillance when public health emergencies suddenly dictate changes to the healthcare infrastructure. For example, the COVID-19 pandemic led the Indian government to announce that all medical colleges were required to establish an emergency department staffed by emergency medicine doctors by 2022 [261]. Process mapping is well-suited to tracking changes that ensue, allowing SHR data collection to be modified and data quality maintained.

It is recognised that LMICs face greater challenges than HICs in establishing and maintaining national surveillance systems [244, 259]. The establishment of SHRs at individual hospitals may provide a partial solution. Good-quality data from a few locations are more powerful than poor-quality national data. This is exemplified by the longest running SHR, the Oxford Monitoring System for Self-Harm, which has been maintained at a single hospital emergency department in the UK since 1976 and has, for example, influenced UK national policy including the regulation of sales of over-the-counter analgesics [219, 262]. This supports the establishment of high-quality SHRs at individual hospitals that aim to enable local teams to evaluate interventions, outcomes, and policy initiatives.

It has not been possible to estimate the extent of missing data from outpatient departments, private wards, and the women and children's hospital due to the large number of presentations to these widely spread clinical areas. These areas are more likely to receive less severely unwell or injured patients who meet the SHR inclusion criteria. Process mapping revealed that patients who meet the SHR inclusion criteria of present to locations other than casualty or the emergency department should be referred to the casualty medical officer for inclusion in the medicolegal register. Using both casualty/ED registers and the medicolegal register should mitigate some of the bias introduced by patients presenting outside of the main emergency care area. Whilst the recommendation to use the medicolegal register to capture cases is likely to only apply to South Asia, the method by which we came to this conclusion is of more general applicability.

We recommend that process mapping is completed prior to the implementation of all SHRs globally. The technique allows the detection of potential problems in their real-world context, allowing bespoke solutions to be developed. This is particularly important given the difficulty and expense associated with maintaining a clinical register and may avoid an expensive register failing to meet its goals [263, 264]. Process mapping fulfils many of the same purposes as a feasibility study used prior to a randomised controlled trial, but it is more suited to the establishment of an SHR due to the innate difficulties of capturing this diverse patient group continuously and systematically [265].

The development of a 'narrative process map' prior to the pictorial process map is advised, particularly in international projects that include team members from different professional and national backgrounds. These allow a detailed description and explanation of each step of a process, which can be used to inform analyses. Groups wishing to establish a SHR could modify the topics detailed in Table 19 for use in semi-structured interviews completed during data collection. We recommend that the WHO SHR Practice Manual is updated to reflect differences in emergency care provision internationally and that it includes process mapping as the preferred method to optimise case ascertainment [43].

### Conclusions

Process mapping is an innovative solution to improve the data quality of newly established SHRs. It can be used to understand how patients presenting to a hospital following self-harm flow through a hospital system. This information is pivotal to choosing which hospital record systems should be used to identify patients for inclusion in a SHR, irrespective of the type of emergency care provision. It allows the identification of sources of selection bias, indicating how a SHR can be improved. The method is easily reproducible and can be used in the implementation of other registers globally.

Chapter five - Development of an electronic burns register: Digitisation of routinely collected hospital data for global burns surveillance

# Preface to chapter five

Chapter four focused on methods to establish a robust surveillance system that include data on burn injury intent, but development and upkeep of a register can be costly. Utilising existing routinely collected data can mitigate some of these costs. It can indicate which variables are feasible to collect and whether other variables need to be added to create a minimum data set. International injury surveillance guidance recommends utilising existing high quality data, but minimal guidance exists on how to appraise the quality of data and then digitise it.

Chapter five describes a method to appraise the quality and utility of existing routinely collected burn injury data for surveillance purposes, and then digitise and quantify the level of error during the digitisation process. This is done using a worked example of digitising a handwritten burn register at a tertiary government hospital in south India, which includes individual patient data about injury intent. The process of appraising data quality helps to address some of the issues with selection and misclassification bias identified in chapters two and three.

## Paper 6

A published version of this paper is available: Bebbington E, Kakola M, Nagaraj S, Guruswamy S, McPhillips R, Majgi SM, Rajendra R, Krishna M, Poole R, Robinson C. Development of an electronic burns register: Digitisation of routinely collected hospital data for global burns surveillance. Burns. 2023. doi: 10.1016/j.burns.2023.08.007.

## Abstract

#### Introduction

Burn registers provide important data that can track injury trends and evaluate services. Burn registers are concentrated in high-income countries, but most burn injuries occur in low- and middle-income countries where surveillance data are limited. Injury surveillance guidance recommends utilisation of existing routinely collected data where data quality is adequate, but there is a lack of guidance on how to achieve this. Our aim was to develop a rigorous and reproducible method to establish an electronic burn register from existing routinely collected data that can be implemented in low resource settings.

#### Methods

Data quality of handwritten routinely collected records (register books) from a tertiary government hospital burn unit in Mysore, India was assessed prior to digitisation. Process mapping was conducted for burn patient presentations. Register and casualty records were compared to assess the case ascertainment rate. Register books from February 2016 to February 2022 were scanned and anonymised. Scans were quality checked and stored securely. An online data entry form was developed. All data underwent double verification.

#### Results

Process mapping suggested data were reliable, and case ascertainment was 95%. 1930 presentations were recorded in the registers, representing 0.84% of hospital all-cause admissions. 388 pages were scanned with 4.4% requiring rescanning due to quality problems. Two-step verification estimated there to be errors remaining in 0.06% of fields following data entry.

#### Conclusion

We have described, using the example of a newly established electronic register in India, methods to assess the suitability and reliability of existing routinely collected data for surveillance purposes, to digitise handwritten data, and to quantify error during the digitisation process. The methods are likely to be of particular interest to burn units in countries with no active national burns register. We strongly recommend mobilisation of resources for digitisation of existing high quality routinely collected data as an important step towards developing burn surveillance systems in low resource settings.

## Introduction

Burn registers collect data about patients who present to hospital with a burn injury. They are an essential element of surveillance, providing data for purposes such as tracking of emerging injury trends, service improvement, care quality assessment, and evaluation of interventions [266]. This can reduce the likelihood of burn injuries occurring, as well as improving post-injury care and rehabilitation (i.e. primary, secondary, and tertiary prevention). Large scale country-wide and intercountry burn registers are primarily found in high-income countries (HICs) [87]. An exception is the World Health Organization Global Burn Registry (WHO GBR) – a burn register established in 2017 that collects variables tailored towards primary prevention and is free to participate [267]. Of the 37 healthcare facilities that submit data to the WHO GBR, 34 (92%) are from low- and middle-income countries (LMICs) [103]. There have been several pilot burn registers in countries including India, Pakistan, Bangladesh, and Kenya though these do not appear to have been scaled up to a continuous register [156, 268, 269]. The uptake of the WHO GBR, as well as the proliferation of pilot burn registers, suggests there is an increasing appetite in the global burns community for this type of data, but that long term sustainability may be an issue, particularly for LMICs. International guidance exists for establishing and maintaining other types of clinical registers, but there is none specific to burn injuries [43].

Arguably, burn registers are needed most in LMICs. The Global Burden of Disease study estimates that 16.3 million burn injuries were sustained globally in 2019 [35]. 12.9 million are thought to have occurred in LMICs, over a fifth of which were in India. However, the majority of LMICs have poor surveillance data meaning that injury rates may be underestimated and data are less reliable [29, 37, 68]. Countries without a national injury surveillance system are encouraged to establish their own (e.g. burn register) at whatever level is feasible (local, regional, or national) [11, 43].

Establishing and maintaining a clinical register is costly [263, 264]. It is essential that the variables collected by the register are useful, and that the resultant data is reliable, to prevent wasteful use of limited resources. Variables should provide data that is valuable at both local and national levels to ensure that it can be fed back into health systems to achieve improvements [11]. Published burn register studies tend to be from large country-wide or international registers, but a register is defined as any physical or electronic collection of pre-specified and systematically recorded details [84, 87]. They can be based in a single centre. Data that is rigorously collected from a single centre can still influence interventions and policy at a national level [219].

Injury Surveillance Guidelines were published by the WHO over 20 years ago and remain relevant, particularly for countries with no active injury surveillance system [11, 270]. The Guidelines recommend appraisal of existing data sources prior to establishing new data collection processes. Burn units may already collect data that could form a register, though the custodian of these data may not recognise this. An example is a handwritten admission book that collates simple variables such as patient name, hospital number, address, injury details, and discharge date. This type of routinely collected data is typically used for local administrative purposes, but may be of wider utility were it in a more readily analysable format [11]. Utilisation of existing handwritten data could be particularly useful for burn units wishing to establish a more detailed electronic register. It can provide information on which variables have been routinely collected using current resources, which of these should continue to be collected, and highlight areas that require new variables to be collected to provide additional detail. The existing data may provide important epidemiological insights that could justify scaling up of the register, as well as for surveillance. Digital data is easier to analyse and share than handwritten data, but the conversion process requires resources. Data quality should be assessed prior to committing to digitisation. High quality data is required to ensure that correct conclusions are drawn from it. It is well-recognised that register data is of highly variable quality, and this can have negative consequences for patients [271, 272]. Errors can occur in register data at multiple points, including failure to ascertain all cases of interest, incorrect documentation in case notes by the original clinician, and incomplete or incorrect information entered into the register database fields [109]. There is a gap in international guidance on how to appraise the quality of existing routinely collected burns data, how to employ modern digital methods to develop a reliable burn register from such data, and how to quantify the error in burn register data.

Our aim was to develop a rigorous and reproducible method to establish an electronic burn register from existing routinely collected data that can be implemented in low resource settings. We illustrate this by sharing the experience of digitising a handwritten register from a tertiary government hospital burn unit in south India.

## Methods

#### **Ethical review**

Ethical approval for the South Asia Self-Harm Initiative register workstreams has been granted by the University of Manchester University Research Ethics Committee (2019-6534-11297, 2021-10049-17533, 2022-10049-22753), JSS Academy of Higher Education and Research Institutional Ethical Committee (JSSMC/IEC/2903/09NCT/2018-19), and Mysore Medical College and Research

Institute Ethical Committee (MMC EC 18/19, MMC EC 86/21). This includes approval to utilise routinely collected hospital data for research purposes without additional patient consent. Stakeholder consultation completed during the process mapping exercise were conducted with informed consent.

### **Study objectives**

- Assess the suitability of a handwritten pre-specified and systematically recorded routinely collected data source (burn register) for digitisation
- 2. Establish a process for digitisation that enables all register data to be readily analysed
- 3. Quantify the level of error during the digitisation process

The processes followed to achieve the study objectives are shown in Figure 17. No reporting guideline for studies of this nature were found on the Enhancing the Quality and Transparency of Health Research Network website [273].

**Figure 17.** Steps followed to assess the suitability of a handwritten register for digitisation, the digitisation process, and quantification of the level of error during digitisation.



## Setting

Krishna Rajendra (KR) Hospital, Mysuru, India is a large government teaching hospital with approximately 1800 beds, all major specialities, and an attached medical college. One of the authors, MKa, established a register in 2001 of admissions to the burn unit of KR Hospital. Prespecified data fields are completed prospectively in handwritten A3 ledgers and as such can be

considered a register. Completed books are sent to the hospital records department for storage. The register was used for hospital audit purposes only until the present study. The data were known to be appropriate for burns surveillance but had not been used for this purpose due to the difficulty in analysing handwritten data.

#### Objective 1. Assess the suitability of a handwritten burn register for digitisation

Data quality was assessed firstly by reviewing a sample of register books, then reviewing data collection processes using process mapping, and finally by quantitatively assessing data capture (Figure 17). A clinician researcher visited KR hospital 10 times between July 2019 and February 2020. A sample of register books were requested from the medical records department to assess whether they could be retrieved, which fields were included in the register, if the fields were consistent within and between register books, and the amount of missing data. Process mapping was then used to understand how patients with a burn injury obtain medical care at the hospital. Particular reference was made to who has their data included in the burn register, and which patient groups are likely to be missed. This was completed as part of a wider process mapping exercise to understand potential sources of selection bias in register data. Detailed description of the method has been published previously [5]. In summary, observation sessions and interviews with staff members were completed in casualty, the burns unit, plastic surgery ward, outpatient clinics, and other departments applicable to burns care (e.g. theatre, intensive care) to establish how patients with a burn injury obtain medical care at the hospital. Data included written field notes, photos, and diagrams. These were reviewed for commonalities and summarised in a narrative document. Repeat visits and interviews were conducted until all processes were understood. A process map was drawn using standard notation (Business Process Model and Notation 2.0 in Lucidchart software) to show the administrative processes applicable to admission and discharge of a patient with a burn injury, including which patients are entered into the handwritten burn register [255, 256]. This was analysed to determine which patients are included and which are excluded from the register. Finally, the number of burn presentations recorded by casualty was compared to data recorded in the burn register to understand what proportion of cases are captured by the burn register.

# Objective 2. Establish a process for digitisation that enables all register data to be readily analysed

Standard operating procedures were written for quality checking of scans, file naming, version control, and assignment of unique identification numbers. The aim of which was to ensure that the corresponding scan could be easily identified from each entry in the database. Digitisation was

delayed until July 2021 due to hospital restrictions on research during the COVID-19 pandemic. Once research restrictions were lifted, register books were retrieved from the medical records department. Each page of the handwritten register books was scanned using an encrypted scanning application. Scanning was chosen rather than immediate transcription because it allowed the register books to be returned to the medical records department promptly and created a digital archive (e.g. for data verification). Scans were then collated into files corresponding to each month of the register book. Identifiable patient information was redacted using PDF editing software Wondershare PDFelement [274]. Redacted scans were transferred using an online encrypted large file transfer service WeTransfer and saved to a secure drive [275]. Each scan was reviewed to identify missing pages or unreadable data. Issues were logged in a spreadsheet and sent back to the scanning team for review and repeat scanning as required. Outcomes were logged and repeat scans saved to the secure drive. Optical character recognition software in Wondershare PDFelement was used on a sample of scans to trial automated data extraction, but no usable information was extracted due to the heterogenous nature of the handwriting in the register books.

A data entry form was developed using the secure, web-based software platform, REDCap (Appendix I) [276, 277]. Fields were created using the maximal analysable data identified during the register review process. Categorical response options were used for as many questions as possible to reduce the burden of data cleaning prior to analyses. Categorical options developed using census information were used to code address data to allow rapid analyses (Appendix J). This included state, district, and taluk (local administrative unit typically comprising of a number of villages or an area of a city) for areas closest to the hospital. The address was also entered as free text to ensure recording of data on villages and districts not included in the categorical coding, and to allow more detailed analysis in the future. Census information was used to cross reference free text address data and categorical options to ensure correct coding. Validation parameters were used where possible to reduce human error during data entry (e.g. age limited to 0 – 130 years). Questions that were left incomplete required the data entrant to choose a code to ensure that the cause of missing data were correctly attributed. These included unreadable, information not in the record, and not applicable. Dummy data were entered into the form to allow testing. Changes were made to the form to improve efficiency of data entry (e.g. use of radio buttons as opposed to drop down menus). Test analyses were completed on the dummy data using RStudio to ensure all fields were analysable [134]. Changes were made to the field names and response codes so that they were more intuitive for the analyst and therefore less likely to result in human error during analyses. Dummy data were deleted once testing was completed.

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One member of the research team carried out data entry. Data were entered into the REDCap form from the register books scans. Each admission in the register book was assigned a unique research identification number that allowed the record to be tracked back to the appropriate scan. A log was kept of conventions followed for each field during data entry.

## **Objective 3. Quantify the level of error during the digitisation process**

Verification was completed for all REDCap entries. First pass verification was completed once 12 months of data had been entered to ensure that issues were resolved, and solutions applied, before further data were entered. Data were downloaded and automatic checks were used for fields with consecutive numbering (e.g. year, month, and page of the register book). Remaining fields were manually cross-checked against the scan of the register book to look for inconsistencies. Proofreading was chosen as the method of verification because it was significantly faster than double data entry. All identified errors were corrected. A log of errors was kept. A further 15% of records were checked to determine the remaining error in the digitised data. A random number generator was used to randomly select 15% of the total records [278]. These were checked by a second researcher who had not been involved in data entry. An error rate for data entry was calculated for each field following the first and second rounds of verification.

## Results

## Objective 1. Assess the suitability of a handwritten burn register for digitisation

A sample of register books showed that each volume covered a period of approximately 3 years. There were often multiple data fields entered under a single column heading (Table 21). All fields, except patient name and identifiable address data, were relevant to burns surveillance. Data fields were collected consistently within and across books, and missing data were estimated to be less than 5% per field.
**Table 21.** Column headings used in the handwritten register book and the data that was recorded under these headings. Identifiable information such as patient name and detailed address information were not included in the subsequent electronic register.

Register column heading	Extractable information						
Patient admission number	Count of admissions to the burn unit that month						
	Count of admissions to the burn unit that year						
	Count of admissions to the hospital that year						
Name	Patient name						
	Patient address						
Age	Age						
Sex	Sex						
Income	Income						
Date of admission	Date of admission to hospital						
	Time of admission to hospital						
	Date of arrival at burn unit						
	Time of arrival at burn unit						
Nature of burn	Intent or mechanism of the burn						
	Lower limit of total body surface area of the burn						
	Upper limit of total body surface area of the burn						
Date of discharge	Date of discharge						
	Whether the discharge was against medical advice						
	Whether the patient was transferred						
Date of death	Date of death (if applicable)						
	Time of death (if applicable)						

Process mapping revealed that patients with a burn injury can self-present to the casualty or outpatient department of KR hospital (Figure 18), which see 368,000 patients annually (data for 2019-2021). Outpatient registration is required for attendance to casualty or the outpatient department. This costs 10 rupees, which is approximately US \$0.12. KR hospital has a casualty rather than emergency department, the primary function of which is to triage patients to the appropriate speciality and complete medicolegal processes. The Indian Government mandates that burn injuries must undergo medicolegal registration because they may require police investigation or legal proceedings to ascertain responsibility for the injury [148]. A Casualty Medical Officer completes medicolegal processes and then directs patients to the burn ward for specialist assessment. Patients who choose to attend the outpatient department rather than casualty are likely to be redirected by clinicians to casualty for medicolegal registration and specialist assessment.



Figure 18. Process map showing the admission and discharge process for a patient with a burn injury, including completion of the handwritten burn unit register.\*



\*Figure notes: Treatment processes (e.g. dressings, surgery, fluids) are not shown. The process map has been drawn using Business Process Model and Notation 2.0 (see key). The process map should be read from left to right. Each row (known as a lane) represents a participant in the process. Arrows show the direction of flow and connection between steps. Abbreviations: Casualty Medical Officer (CMO), Medicolegal register (MLR), Outpatient (OP), outpatient department (OPD).

All burn injuries are assessed on the burn ward. Minor burns that do not require admission are treated on the burn ward as outpatients and are not included in the burn register. Patients that require inpatient burn care are included in the burn register. The register is completed by nurses upon admission of the patient to the burn unit (see grey symbol *burn register data collection* point Figure 18). Admission criteria include all major burns (greater than 10% in adults, greater than 5% in children) and burns to sensitive areas (e.g. inhalational, hands, genitalia). Patients with inhalational burns are admitted to surgical intensive care initially but are transferred to the burn unit prior to discharge and thus are captured in the register. The admission process includes payment of a fee (200 rupees) for inpatient registration. This fee is higher than, and paid in addition to, the fee for outpatient registration. Staff recounted that occasionally patients do not return to the burn unit after being sent to complete inpatient registration and are thus not captured in the burn register.

Three volumes of register books were retrievable corresponding to admissions for February 2016 to February 2022. Older register books could not be located due to a shortage in medical record department staff during the ongoing COVID-19 pandemic. Complete data on the number of burn presentations was available from casualty for 42 months of 2018-2021 (Table 22). The number of burns cases recorded in the register was 95.4% of the number of burns presentations in casualty records.

These described and observed practices suggest that the population recorded in the burn register is consistent and that fields are completed in a uniform way. Overall, the initial review of the register suggested data were reliable and justified resource allocation for digitisation. **Table 22.** Number of burn injury presentations recorded in casualty and in the burn register. (\*Indicates

 years where there was incomplete Casualty data. Data missing for 5 months of 2019, and 1 month of 2020.)

		2018	2019	2020	2021
January	Casualty	40	37	21	21
	Burn register	41	36	20	24
February	Casualty	20	42	-	32
	Burn register	16	28	28	28
March	Casualty	37	31	27	23
	Burn register	31	30	23	29
April	Casualty	40	31	21	24
	Burn register	33	33	11	22
May	Casualty	27	38	20	17
	Burn register	23	28	17	15
June	Casualty	32	27	17	13
	Burn register	31	26	16	13
July	Casualty	21	24	8	22
	Burn register	18	27	13	22
August	Casualty	21	-	13	16
	Burn register	20	18	16	15
September	Casualty	42	-	11	34
	Burn register	32	23	15	23
October	Casualty	26	-	20	16
	Burn register	27	27	19	17
November	Casualty	41	-	21	28
	Burn register	34	29	20	27
December	Casualty	30	-	22	24
	Burn register	29	27	22	22
Total	Casualty	377	230*	201*	270
	Burn register	335	332	220	257

# Objective 2 and 3. Establish a process for digitisation and quantify the level of error during the digitisation process

All pages (458 pages) from register books were scanned. 20 pages were rescanned corresponding to an error rate of 4.4% during quality checking. This was due to 4 pages being missed, and 16 instances where some of the data were unreadable. Most issues were encountered early whilst processes were still being learnt and refined.

1930 patient admissions were recorded in the burn register and subsequently digitised covering the period of February 2016 to February 2022. This accounts for 0.84% of all admissions to the hospital. Each record took two to three minutes to enter onto the online data entry platform. During data

entry it was found that the intent of the burn was sometimes overwritten (e.g. accidental changed to suicidal). This was felt to be a potentially significant observation because clinicians in the department reported encountering patients who changed their account of the circumstances of their injury and thus the entry in the register would also be changed. It was found that for some entries patients were admitted to hospital at the same time and were from the same address, which may reflect a multi-casualty burn event. Additional fields were added to the data entry form to allow observations from the data entrant to be recorded.

Each patient record took between 30 seconds and one minute to proofread. The error rate during first pass verification was 0.33% per field (Table 23). The most common errors were in numerical fields such as date of discharge and time of admission. Incorrect numerical data in the online data entry form was often auto filled by the computer browser and then accidently inputted by the data entrant when moving between fields. Errors occurred with time data due to register entries being completed using a 12-hour clock, requiring the data entrant to manually convert it to a 24-hour clock as required for analyses. Second pass verification identified five fields with errors, corresponding to a remaining error rate of 0.06% per field (Table 23).

	First pass verification	Second pass verification
Number of records checked	1930	290
Number of fields checked	50180	7540
Number of errors per field	-	-
SASHI event ID	2	0
Register book year	2	0
Register book month	5	0
Register book page	0	1
Number of patients presenting to burn unit that month year	16	0
Number of patients presenting to burn unit that year	19	0
Inpatient number	13	1
Full patient address	3	0
Patient address: country	0	0
Patient address: state	0	0
Patient address: district	0	0
Patient address: taluk	2	0
Patient age	9	0
Patient sex	3	0
Hospital admission unit	4	0
Income	1	0
Date of admission	9	0
Time of admission	20	0
Date received to burn unit	0	0
Time received to burn unit	14	0
Intent or cause of the burn injury	2	1
Lower limit of total body surface area of burn	5	0
Upper limit of total body surface area of burn	6	0
Discharge status	5	0
Date of discharge or death	22	2
Time of discharge or death	5	0
Total errors	167	5
Error rate per field	0.33%	0.06%

**Table 23.** Errors identified during first and second pass verification with associated error rates.

# Discussion

We have presented three methodological processes that will be of interest to anyone wishing to establish a burn register, as well as custodians and users of existing registers. The first is a method to assess the suitability and reliability of existing routinely collected data for surveillance purposes; the second is a method to digitise handwritten data; and the third is quantification of error during the digitisation process. For health systems operating using purely electronic data, the second

method will not be applicable. We have exemplified these procedures by sharing our experience from a tertiary government burn unit in south India.

International guidance recommends that existing data is assessed prior to starting a new disease register as existing data may be sufficient to fulfil surveillance needs [11]. This should include an assessment of the quality and reliability of the data, but there is little information available on how to achieve this. In the first part of our paper, we address this issue by setting out a stepwise approach to assess data availability, data completeness, selection bias, and measurement bias in handwritten records. The method could be applied to electronic data. Given the resources associated with starting a new burn register, utilisation of existing data may be a more sustainable solution particularly in resource limited locations. There is no global minimum recommended data set specifically for burn registers to help determine which routinely collected data might be most valuable [128]. The WHO Injury Surveillance Guidelines recommend a minimum data set comprising of 8 variables (identification number, age, sex, place of injury, activity when injured, mechanism of injury, intent, and nature of injury) [11]. The Burn Unit at KR Hospital had collected 20 variables (including 5 of the WHO's minimum surveillance data set) for over 20 years using existing resources. This provided information about which variables are feasible to collect and is invaluable for planning how a more detailed electronic register could be sustainably integrated into current practice. We found that the variables collected in the register were highly relevant to surveillance purposes. Inclusion of an analyst early in the process meant we were able to extract more data than anticipated - multiple fields were collected under each column heading of the register, overwriting of data, and probable multi-casualty events. Although the variables were applicable to surveillance it was essential to understand the quality of that data and potential sources of bias before committing to digitisation.

Selection bias is one of the more pervasive problems with utilising existing routinely collected data. A well-publicised limitation of routinely collected health data is that not all cases of interest may be captured. For example, national UK Hospital Episode Statistic data has been shown to undercount presentations of burn injuries, as well as other injury types such as self-harm, compared to their counterpart disease register that has a specifically designed case ascertainment strategy [83, 236]. We found 95% of casualty cases were captured by the handwritten burn register. However, such numerical comparisons do not elucidate which patient populations may be missed. We used process mapping to understand possible sources of selection bias in more detail [5]. We found that patients with minor burns who are treated on an outpatient basis are not included in the handwritten burn register. This is in line with other burn registers internationally [83, 85, 102, 279]. Patients who

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abscond when asked to complete inpatient registration processes are likely to be missed. All burn patients are required to complete medicolegal processes upon presentation to casualty at the hospital. It has been shown that burn patients show a preference for private hospitals due to fear that government hospitals are more likely to report the injury to the police [44]. These factors are likely to skew the data towards more severe burns and those who are unable to afford private care. They may exclude the poorest in society who cannot afford inpatient registration costs.

Large health data sets are recognised to be prone to such biases, yet detailed information on the limitations of the data are rarely described [280]. To tackle this issue, an extension to the Strengthening the Reporting of Observational studies in Epidemiology (STROBE) guidelines has been created specifically for studies using disease register data and other types of routinely collected data [122]. The Reporting of studies Conducted using Observational Routinely-collected Data (RECORD) extension recommends that observational studies using register data include details about sources of selection bias, but lack detail about how the researcher can achieve this [122]. Although we present our experience from a single centre, the systematic method used to understand the quality and reliability of data is equally applicable to large multicentre data sets.

Published epidemiological burn studies utilising register data or other sources of routinely collected data often lack sufficient detail on data collection and digitisation processes to allow the reader to determine reliability and potential utility of that data [85, 159, 281]. This may result in the "big data paradox" where the reliability of large data sets is incorrectly thought to be greater than that of smaller data sets [93]. We have included as much detail as possible in the manuscript to assist other institutions that wish to appraise and digitise a data set, this provides information tailored to individual burn units that would allow reporting of data in line with RECORD and STROBE guidelines.

Many burn registers use a manual process to input data into the register database [279, 282]. Human error can occur when information is transferred from a record (e.g. patient notes, patient reported outcome measure form, survey) into a burn register database. Burn register database errors such as duplicate records, missing data, and internal inconsistencies have been found to affect a significant proportion of records, yet this information is rarely reported and may go unrecognised unless specific verification procedures are followed [98]. It is recommended that databases are designed to minimise human error during data entry, and records are checked for errors prior to completion of any analyses [98]. We explain in detail how we designed the database to minimise human error, as well as a process to explore and quantify the remaining error rate in the data. Our two-step verification process gave an estimated remaining error rate of 0.06% per

field (i.e. 6 errors in every 10,000 fields), which is considerably lower than other register studies that have shown human transcription errors ranging from 0.5% – 26.9% per field [271, 272, 283].

There are some limitations to this study. We had hoped to retrieve all register books, but we were only able to retrieve books for 2016-2022 due to changes in medical records staffing during the COVID-19 pandemic. This does not, however, affect the transferability of the methods to other centres. We calculated case ascertainment of the burn register compared to casualty based on the number of cases. We were unable to compare the name or hospital number of the patients to ensure the same cases were captured, however our process mapping exercise strongly supports the numerical results. We did not assess the accuracy of data entered into the handwritten register book beyond discussions with staff during process mapping. It is possible that there may be systematic errors such as misclassification of intent in the register, which we are aware is a sensitive issue in South Asia [44, 162]. There are likely to be simple non-systematic errors (e.g. incorrect date) [109]. This will be investigated and allowed for during analyses.

This project was funded by an international research grant. It is unlikely that government funded hospitals would have as much resource available to complete similar work. There were minimal consumables used in the project: existing computer hardware was used where possible; the encrypted file transfer service and data entry platform were free to use; but there was a one-off cost associated with using our chosen PDF editing software. The main cost associated with this work was staff salary. The bulk of the work (process mapping, operating procedure development, quality checks, data entry form development, data entry, first verification) was completed by a senior registrar with research experience, and a project manager (scanning, quality checks). The clinician researcher spent 2 days per week for 12 months on the project. The project manager spent 1 day per week on the project for 3 months. Input was gained from senior clinicians and researchers as required. A significant amount of this time was spent developing the methods used in the project. We have shared all relevant materials to streamline processes for those wishing to establish an electronic burn register from handwritten routinely collected data. Further materials and advice can be provided on request. Although we cannot demonstrate it on the basis of our data, we believe digitisation could be done on less than 50% of a junior clinician's time working under supervision.

We recommend that journals considering publication of observational burn studies based on digitised handwritten records ask for details on the how the quality of data were assessed, the digitisation process, and verification processes including estimated remaining error rates in the data. We recommend that process mapping is used as the technique to detail potential sources of

selection bias in routinely collected burns data and that this is used in addition to any numerical estimate of case capture. We feel it would be beneficial to the global burns community if an international organisation with specialist knowledge of burn injuries produced a manual for establishing and maintaining electronic burn registers. The methods in this paper would be useful to guide a section on utilising existing handwritten data sources.

# Conclusions

Routinely collected data is a potentially powerful source of data for a burn register but requires careful appraisal and conversion before it can be used. We have described, with real world examples from a newly established electronic register in India, methods to assess the suitability and reliability of existing routinely collected data for surveillance purposes, to digitise handwritten data, and to quantify error during the digitisation process. The resources and methods used in the article are likely to be of particular interest to burns units in countries with no active national burn register. There is a growing emphasis for register studies to report data set limitations. Custodians and users of multicenter electronic burn registers may, therefore, benefit from considering our pragmatic solutions to understand register population selection bias and human transcription errors.

# Chapter six - Exploring misclassification of injury intent: A burn register study

# Preface to chapter six

The methods described in chapters four and five help to address global inequity in the amount of robust data that is captured about patients with burn injuries that are: unintentional; due to self-harm; or due to interpersonal violence. Data that already exists about the intentionality of burn injuries is poorly explored to understand whether injuries may be misclassified.

Chapter six uses exploratory data analysis techniques to describe how injuries have been classified according to intent using data from the digitised burn register described in chapter five. Findings are contextualised by using information collected during process mapping. The results provide the basis for future data driven analysis techniques to identify groups at risk of misclassification, which may be useful to inform modelling of data by high level surveillance systems (e.g. Global Burden of Diseases). The study is described in accordance with the Reporting of Studies Conducted Using Observational Routinely-Collected Data guidelines. This highlights the utility of the methods described in chapters four and five in providing adequate detail to investigators about the strengths and limitations of their data set. Transparency is an important facet in strengthening international burn injury surveillance data.

# Paper 7

A published version of this paper is available: Bebbington E, Kakola M, Majgi SM, Krishna M, Poole R, Robinson C. Exploring misclassification of injury intent: A burn register study. Burns. 2024.

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# Abstract

#### Introduction

Burn registers are an important source of surveillance data on injury intent. These data are considered essential to inform prevention activities. In South Asia, intentional burn injuries are thought to disproportionately affect women. Assessment of injury intent is difficult because it is influenced by personal, family, social, and legal sensitivities. This can introduce misclassification into data, and bias analyses. We conducted a descriptive, hypothesis generating study to explore misclassification of injury intent using data from a newly digitised single centre burn register in south India.

#### Methods

Data from 1<sup>st</sup> February 2016 to 28<sup>th</sup> February 2022 were analysed. All patients in the data set were included in the study (n=1930). Demographic and clinical characteristics for patients are described for each classification of injury intent. All data cleaning and analyses were completed using RStudio.

#### Results

Injury intent data were missing for 12.6% of cases. It was the most commonly missing variable in the data set. "Accidental" injuries had a similar distribution over time, age, and total body surface area (TBSA) for males and females. "Homicidal" injuries were more common in females. Injuries reported as "Suicidal" affected men and women equally. A decrease in reporting of "Suicidal" injuries in females corresponded to an increase in high TBSA injuries classified as 'Other' or with missing data. Overwriting of injury intent was present in 1.5% of cases. The overwritten group had a greater proportion of females (62.1% vs. 48.5%) and higher median TBSA (77.5% vs. 27.5%) compared to the group where intent was not overwritten.

#### Conclusion

Our findings indicate that some subgroups, such as females with high TBSA burns, appear to be more likely to be misclassified and should be the focus of future research. They highlight that quality

of surveillance data could be improved by recording of clinical impression, change in patient reported intent, and use of a common data element for intent to standardise data collection. We recommend that injury intent is recorded as a unique variable and should not be mixed with other elements of injury causation (e.g. mechanism). Although this is a single centre study, the methods will be of interest to those who utilise routinely collected data and wish to reduce misclassification of this important variable.

#### Introduction

Surveillance of the cause of injuries is essential to inform planning, implementation, and evaluation of prevention activities [32]. The International Classification of Diseases external causes of morbidity or mortality chapter offers users multiple codes that can be used to record diagnostic health information about causation of an injury [10]. Codes include: intent (e.g. unintentional, self-harm, interpersonal violence), mechanism (e.g. exposure to excessive heat), activity when injured (e.g. unpaid work), object or substance producing the injury (e.g. cooking appliance), place of occurrence (e.g. home), and alcohol or psychoactive drug use. Intent is recommended as the first level of classification because it is especially useful for subgroup analyses and identifying intervention opportunities. Assessment of injury intent, however, is recognised to be difficult since it is influenced by personal, social, and legal sensitivities [66]. This can introduce misclassification into data, and bias analyses.

Burn injuries are a major source of morbidity and mortality. The Global Burden of Disease study estimates that 16 million burn injuries were of sufficient severity to require medical care worldwide in 2019 [29, 35]. Intentional burns due to self-harm or interpersonal violence are a global concern, and often result in poor patient outcomes due to burn severity [162, 284]. Successful prevention activities, particularly in high-income countries, have led burn units to experience a shift in case-mix towards smaller burns, but intentional injury remains a common cause of severe burns [285-288]. Almost 500,000 burn injuries due to self-harm and other forms of violence (e.g. assault, conflict and terrorism, executions and police conflict) are believed to have occurred in South Asia in 2019 [35]. This is the highest incidence of any region, but the reliability of these estimates are reduced by limited national injury surveillance data disaggregated by intent [37, 289, 290]. Burn injuries due to self-harm are thought to comprise 2% of all burn injuries, and interpersonal violence to comprise 6% of all burn injuries in South Asia [35]. Local hospital-based studies provide broader estimates for the proportion of burns that are intentional in the region. Available data from such sources suggest that 3-26% of burns reported as self-harm, and that 0.5-20% are reported as due to interpersonal violence [159, 195, 281, 291, 292].

It is likely that the proportion of intentional burns reported in routinely collected hospital data are an underestimate, particularly for women. One study from India showed 19% of accidental burn injuries in women were later reported to be self-inflicted, and 9% to be homicidal, when the patients were interviewed by a researcher [213]. Another showed that 62% of burns recorded as accidental or with missing data in medical records were later recorded as suicidal or homicidal in counsellors' records [161]. Females have the highest age-standardised incidence of burn injuries due to selfharm of any region in the world (5.9 per 100,000 population) [35]. South Asia is the only region where females have a higher incidence of unintentional burn injuries then men [35]. It is conceivable that this may be due to misclassification.

Misclassification in data can occur due to misreporting by either the responder (e.g. patient or attender) or the observer (e.g. healthcare professional recording the data). Patients may not feel able to disclose who, if anyone, inflicted the injury due to fear of criminal investigation, stigma, pressure from family members, or because of concerns about the future of their family [293]. Healthcare professionals may not wish to probe the patients' history due insufficient time or concerns about changes to their account affecting legal proceedings [44]. Distribution of the burns, or behaviour of the patient and their relatives, may lead healthcare professionals to suspect that the reported intent of the burn is inaccurate [196]. A study from Sri Lanka showed that age, sex, and total body surface area of the burn (TBSA) in cases suspected to be intentional closely matched that of burns reported as self-inflicted [196].

The need for improvement of surveillance data on burn injury intent is well recognised. Over a fifth of clinicians involved in the development of the World Health Organization Global Burn Registry believed that data on injury intent was unlikely to be accurate [102]. The development of a risk assessment tool to distinguish between burns that are unintentional, due to self-harm, or due to interpersonal violence has been identified as an area of research need [80, 213]. Current epidemiological studies tend to report injury intent as discrete categorical variables (e.g. unintentional, self-harm, interpersonal violence) with little exploration of the data to understand if there may be misclassification. This limits the utility of the data for development of a prediction tool. Current quantitative and qualitative studies from South Asia strongly suggest that females of childbearing age are at risk of self-harm and gender-based violence, and that intentional burns are more likely to result in larger TBSA burns. These are potentially useful variables to investigate when attempting to detect misclassification. The aim of this study was to explore possible misclassification of injury intent in burn register data.

The study objectives were to:

- 1. Explore patterns of recording of injury intent in burn register data.
- 2. Explore patient characteristics associated with different categories of recorded injury intent.

# Methods

We conducted a descriptive, hypothesis generating study to explore possible misclassification of injury intent using data from a newly digitised single centre burn register from a tertiary government burn unit in south India. We explored systematic variations in the recording of intent data and patient characteristics of different categories of intent. This manuscript has been prepared in accordance with the Reporting of studies Conducted using Observational Routinely-collected health Data (RECORD) Statement (Appendix K) [122].

#### **Ethical review**

Ethical approval for the South Asia Self-Harm Initiative register workstreams has been granted by the University of Manchester University Research Ethics Committee (2019-6534-11297, 2021-10049-17533, 2022-10049-22753), JSS Academy of Higher Education and Research Institutional Ethical Committee (JSSMC/IEC/2903/09NCT/2018-19), and Mysore Medical College and Research Institute Ethical Committee (MMC EC 18/19, MMC EC 86/21). This includes approval to utilise routinely collected hospital data for research purposes without additional patient consent.

#### Setting and participants

A handwritten register of admissions to the burn unit of Krishna Rajendra (KR) Hospital, Mysuru, India has been kept since 2001 for audit purposes. Data from 1<sup>st</sup> February 2016 to 28<sup>th</sup> February 2022 were digitised as part of an international research collaboration to improve surveillance data in the region. A detailed description of the digitisation process, including assessment of data quality, has been published [6]. In summary, KR Hospital is a tertiary government teaching hospital with approximately 1800 beds. It is one of four government funded burn units serving the population of Karnataka, which is estimated to be 70 million people [294]. A process mapping exercise completed during the digitisation project revealed that patients requiring inpatient care are recorded in the handwritten burn register, but patients with minor burns treated on a purely outpatient basis are not included. There are a variety of private and charitable hospitals in the same vicinity as KR hospital. Hospitals do not have a defined catchment area and patients can choose where to seek medical care. It is likely that the data set is skewed more towards severe burns and those who cannot afford private care. All participants in the data set were included in this study.

# Variables and method of assessment

All variables in the data set were available to investigators. The main variable of interest in this study was injury intent. Discussions with senior healthcare professionals in the burn unit were completed

to understand how injury intent is assessed. This information is recorded in the burn register based upon what the patient or family member reports during medicolegal registration in the casualty department. Options include "Accidental", "Suicidal", and "Homicidal" *sic*. These are overarching terms that relate to who, if anyone, was responsible for the injury as opposed to the desire of the patient or their assailant to inflict death. If there is doubt about the intent of the injury, then the entry is left blank in the burn register. If the patient changes their reported intent of the injury, then the medicolegal officer in the hospital is contacted and injury intent is changed in the register book. During the digitisation process, it was noted that occasionally injury intent was crossed out and overwritten (Figure 19). An additional variable was added during digitisation to allow this observation to be recorded as it may reflect the patient changing their reported injury intent.

Injury intent information was recorded in a column in the handwritten register book headed "Diagnosis". Free text entries in this column included injury causation information and total body surface area of the burn (TBSA). It was noted that other elements of injury causation were sometimes used instead of, or in addition to, injury intent (e.g. "Old burn", "Electrical", "Thermal", "Inhalational" injury). Discussion with staff revealed that "Electrical" injuries are usually occupational, so it is important not to attribute culpability because the patient may be eligible for compensation. "Old burn" injuries are those in which a patient is readmitted for further care, usually due to infection, so intent is not recorded again because medicolegal processes were followed during the original admission. Other free text causation information (e.g. "Thermal", "Inhalational" injury) was written particularly from 2020 onwards. We categorised this as 'Other'. A categorical variable for injury causation was created during digitisation. All information was transcribed during the digitisation process.

**Figure 19.** Example of overwriting of injury intent in the handwritten burn register. The scan shows that diagnosis of the burn has been changed from "Accidental" to "Suicidal", and that the burn size is 95-98% total body surface area.

HIO Acudental hubbr 95-981.

Other variables of interest include home address district, age, sex *sic*, income, date of admission, TBSA, multiple casualty injury, discharge status, and date of discharge. Additionally, a running total

of the number of admissions to the burn unit and to the hospital was available for each patient. Income was recorded in the register as a binary variable (no income or income over 5000 rupees per month). Income was determined using a government issued card shown during inpatient registration. Those with a Ayushman Bharat – Arogya Karnataka Scheme card were considered to be below the poverty line and entitled to free hospital treatment [295]. A multiple casualty event was defined as two or more patients presenting to the hospital from the same address at the same time with a burn injury. More detailed address data (beyond district level detail) will not be reported here because this will be the subject of a separate geographic mapping study.

#### Data access and cleaning

Investigators had access to the whole database for this study. The number of cases in the burn register during the study period determined the sample size. We created a single variable that included injury intent information. There were 107 instances where a patient had two elements of causation recorded (e.g. "Accidental" and 'Other'). Intent information was prioritised over other elements of causation (e.g. "Electrical", "Old burn", and 'Other'). Intent information was only considered to be missing if no causation information was included in the register. Even though "Electrical", "Old", and 'Other' injuries are not a classification of intent, we report these data because they are sometimes used in the register instead of injury intent. This gives a more accurate representation of the data that were recorded in the handwritten register. Validation parameters were used during digitisation so that no variable could be left unfilled. Non-response codes were used as necessary [6]. Variables with the code 'information not in record' or 'unreadable' were regarded as missing data. The code 'not applicable' meant that the variable had stopped being collected. We report the number of missing and not applicable values for each variable of interest. No data linkage was completed during this study.

#### Statistical methods

All data cleaning and analyses were completed using RStudio [134]. Packages included tidyverse, dplyr, ggplot2, readr, lubridate, stringr, and broom. This was an exploratory study designed to guide future areas of research. Consequently, no hypotheses were tested and therefore no statistical tests were applied. We used exploratory data analysis techniques to describe the data. For categorical variables, we report number and percentage for each category of injury causation. For continuous variables with skewed date, we report median and interquartile range. Histograms and density graphs were chosen to explore the underlying distribution of continuous and categorical variables that may influence misclassification of injury intent with particular reference to patient sex. Free y-

axis scales were used in panel density plots to allow easier comparison of the distribution patterns of causation groups of different sizes.

# Results

1930 patients were recorded in the burn register during the study period. We found three patterns in the recording of injury intent data: complete, missing, and overwritten. Injury intent data were missing for 12.6% of cases (Table 24). It was the most commonly missing variable in the data set followed by income (10.3%) and TBSA (8.9%). Complete data were available for 87.4% of cases (Table 24). The most common classification was "Accidental" injury accounting for 66.1% of cases. The number of burn admissions reduced over time (Figure 20), and as a proportion of all-cause hospital admissions (Figure 21).

**Table 24.** Demographic and injury characteristics according to intent and other categories of causation.Percentages are for columns. Data collection commenced 1st February 2016 and concluded 28th February2022, so data for 2016 and 2022 does not represent a full year.

	Accidental	Suicidal	Homicidal	Electrical	Old	Other	Missing
Total cases, n	1276	226	33	68	43	41	243
Admission							
year, n (%)							
2016	287 (22.5)	78 (34.5)	6 (18.2)	3 (4.4)	10 (23.3)	2 (4.9)	46 (18.9)
2017	203 (15.9)	24 (10.6)	5 (15.2)	12 (17.7)	9 (20.9)	1 (2.4)	53 (21.8)
2018	241 (18.9)	28 (12.4)	6 (18.2)	9 (13.2)	8 (18.6)	0	43 (17.7)
2019	221 (17.3)	45 (19.9)	7 (21.2)	25 (36.8)	10 (23.3)	0	24 (9.9)
2020	122 (9.6)	17 (7.5)	2 (6.1)	13 (19.1)	3 (7.0)	27 (65.9)	36 (14.8)
2021	168 (13.2)	30 (13.3)	7 (21.2)	6 (8.8)	3 (7.0)	10 (24.4)	33 (13.6)
2022	34 (2.7)	4 (1.8)	0	0	0	1 (2.4)	8 (3.3)
Sex, n (%):							
Female	614 (48.1)	121 (53.5)	20 (60.6)	10 (14.7)	29 (67.4)	24 (58.5)	121 (49.8)
Male	630 (49.4)	104 (46.0)	13 (39.4)	56 (82.4)	14 (32.6)	17 (41.5)	117 (48.2)
Missing	32 (2.5)	1 (0.4)	0	2 (2.9)	0	0	5 (2.1)
Age, median	28 (8-42)	32 (25-	28 (23-	29.5	34 (26.5-	30 (11-	26 (10-
(IQR)		40)	33)	(20.8-35)	45)	45)	40)
Missing, n	8 (0.6)	2 (0.9)	0	0	0	0	2 (0.8)
(%)							
Address							
district, n (%)	150 (12 5)	44 (10 F)	F (1F 2)	7 (10 2)	0 (10 C)	4 (0, 0)	
Chamaraja-	159 (12.5)	44 (19.5)	5 (15.2)	7 (10.3)	8 (18.6)	4 (9.8)	35 (14.4)
Kodagu	74 (5.8)	6 (2 7)	7 (21 2)	6 (8 8)	3 (7 0)	2 (4 9)	14 (5.8)
Mandva	232 (18.2)	41 (18 1)	8 (24.2)	17 (25 0)	6 (14.0)	11 (26.8)	59 (24 3)
Mysore	760 (59.6)	118 (52.2)	13 (39 4)	36 (52 9)	24 (55.8)	23 (56 1)	122 (50.2)
Missing	10 (0.8)	110 (32.2)	13 (33.4)	0	24 (33.0)	23 (30.1)	122 (30.2)
Income n (%)	10 (0.8)	4 (1.0)	0	0	0	0	0
No income	600 (51 8)	112 (/0 6)	15 (15 5)	16 (67 6)	32 (74 4)	12 (20 3)	126 (51 9)
	225 (17.6)	65 (28.8)	8 (24 2)	6 (8 8)	32 (74.4)	1 (2 /)	38 (15.6)
Not	223(17.0)	25 (15 5)	7 (24.2)	7 (10.2)	2 (7.0)	10 (46.2)	55 (13.0)
annlicable	218 (17.1)	55 (15.5)	/ (21.2)	7 (10.5)	5 (7.0)	19 (40.3)	55 (22.0)
Missing	134 (10.5)	14 (6.2)	3 (9,1)	9 (13.2)	5 (11.6)	9 (22.0)	24 (9,9)
Multi-	123 (9.6)	9 (4 0)	7 (21 2)	2 (2 9)	0	8 (19 5)	33 (13.6)
casualty, n (%)	120 (010)	5 (110)	, ()	2 (2.3)	Ŭ	0 (1010)	00 (10:0)
TBSA,	22.5	82.5	55	12.5	22.5	37.5	27.5
median (IQR)	(12.5-	(57.5-	(26.3-	(7.5-19.8)	(13.8-	(22.5-	(12.5-
	42.5)	92.5)	75.0)		28.6)	60.0)	57.5)
Missing,	87 (6.8)	9 (4.0)	1 (3.0)	14 (20.6)	33 (76.7)	2 (4.9)	25 (10.3)
n (%)							
Discharge							
status, n (%)		26 (44 5)		FO (72 F)	26 (02 7)	20 (40 0)	427 (56.4)
Discharged	845 (66.2)	26 (11.5)	17 (51.5)	50 (73.5)	36 (83.7)	20 (48.8)	137 (56.4)
Death	283 (22.2)	195 (86.3)	14 (42.4)	1 (1.5)	2 (4.7)	18 (43.9)	74 (30.5)
DAMA	107 (8.4)	5 (2.2)	2 (6.1)	9 (13.2)	0	1 (2.4)	26 (10.7)
Transfer	22 (1.7)	0	0	6 (8.8)	4 (9.3)	1 (2.4)	4 (1.7)
Missing	19 (1.5)	0	0	2 (2.9)	1 (2.3)	1 (2.4)	2 (0.8)

**Figure 20.** Number of admissions to the burn unit over time according to causation. Each bar represents one month.



**Figure 21.** Burn admissions as a percentage of all cause hospital admissions. Note the y-axis runs from 0-2% as opposed to 0-100% to show the trend more clearly.



There were approximately equal proportion of burns classified as "Accidental", "Suicidal", and with missing data for both sexes (Table 24). "Homicidal" injuries were more common in females, and "Electrical" injuries in males. "Accidental" injuries showed a uniform distribution by sex (Figure 22). There has been a relative increase in free text entries that relate to 'Other' aspects of injury causation (e.g. thermal injury, inhalational injury) since 2020, particularly for females. This coincides with a greater reduction in classification of "Suicidal" burns in females over the same period.

**Figure 22.** Panel of density plots for date of admission subclassified by injury causation and sex. The total area under the smoothed histograms sum to one. Note the y-axis varies between panels and is reflective of the relative size of each group.



Median age was similar across all classifications of causation (Table 24). "Accidental" injuries have a bimodal distribution affecting childhood and early adulthood, the peak for males was in childhood, whereas it was in early adulthood for females (Figure 23). For "Suicidal" injuries, the peak is seen at age 20-30 years for females, but age 30-40 years in males. Missing data for males shows a bimodal age distribution similar to "Accidental" injuries. There are more missing sex data for younger patients with "Accidental" injuries. Spikes in the number of cases are seen at five-year age bands from the age of 30 (Figure 24). Discussions with staff revealed that the patient or their attender estimates age to a round number if age is not known.



Figure 23. Panel of density plots for age subclassified by injury causation and sex.

Figure 24. Histogram of age subclassified by sex.



The districts of Mysore, Chamarajanagar, Kodagu, and Mandya accounted for 95.5% of injuries (Table 24). These districts are closest to KR hospital. There was a uniform distribution of injury classifications from these districts except for Kodagu, where a disproportionate number of "Homicidal" burns occurred in the year 2021.

The majority of patients had no income across all classifications of causation (Table 24). These data stopped being collected in October 2020, but there is an increase in recording of 'no income' from 2018 (Figure 25). This corresponds to when there was a change in the hospital billing system to allow those with no income to receive free care if the relevant government issued card is shown during inpatient registration. There was little difference in income across injury causation categories and sex.





"Suicidal" and "Homicidal" burns had the greatest median TBSA of all injury classifications (Table 24). They were particularly skewed towards larger burns in females (Figure 26). A secondary peak in high TBSA (80-100%) burns was also seen for women with burns classified as 'Other' or with missing data. The greatest proportion of deaths were seen in the "Suicidal" injury group, which was the outcome for 86.3% of patients in this group (Table 24). Spikes in the number of cases are seen at five percent TBSA increments (values ending in '0' or '5'), particularly for cases over 20% TBSA (Figure 27). This is likely to be due to rounding by the clinician.



Figure 26. Panel of density plots for TBSA subclassified by injury causation and sex.





Injury intent data was overwritten in 1.5% of cases (Table 25). The original word was legible for 21 cases (Table 26). These were from "Accidental" (n=12) and "Suicidal" (n=9) groups. The most common change was to "Suicidal", which had proportionally three times more cases than in the data that were not overwritten. Overwriting was more common for females, adults, and patients with larger burns (Table 25). A greater median TBSA was seen in the overwritten group for "Accidental", "Suicidal", and 'Other' burns. The "Accidental" group shows the greatest difference, where median TBSA was 82.5% (IQR 60.0-91.3) compared to 22.5% (IQR 12.5-42.5) for injuries that had not been overwritten. The higher TBSA in the overwritten group is likely to account for the greater proportion of deaths.

**Table 25.** Demographic and injury characteristics according to overwriting of intent information.

Percentages are for columns.

	Overwritten	Not overwritten	
Total cases, n	29	1901	
Injury intent/cause, n (%):			
Accidental	10 (34.5)	1266 (66.6)	
Suicidal	11 (37.9)	215 (11.3)	
Homicidal	4 (13.8)	29 (1.5)	
Electrical	3 (10.3)	65 (3.4)	
Old	0	43 (2.3)	
Other	1 (3.4)	40 (2.1)	
Missing	0	243 (12.8)	
Year of admission, n (%):			
2016	6 (20.7)	426 (22.4)	
2017	2 (6.9)	305 (16.0)	
2018	6 (20.7)	329 (17.3)	
2019	11 (37.9)	321 (16.9)	
2020	2 (6.9)	218 (11.5)	
2021	2 (6.9)	255 (13.4)	
2022	0	47 (2.5)	
Sex, n (%):			
Female	18 (62.1)	921 (48.5)	
Male	11 (37.9)	940 (49.5)	
Missing	0	40 (2.1)	
Age, median (IQR)	35.0 (28.0-45.0)	28.0 (13.0-40.0)	
Missing, n (%)	1 (3.5)	11 (0.6)	
Address district, n (%):			
Chamarajanagar	5 (17.2)	257 (13.5)	
Kodagu	4 (13.8)	108 (5.7)	
Mandya	6 (20.7)	368 (19.4)	
Mysore	12 (41.4)	1084 (57.0)	
Missing	0	14 (0.7)	
Income, n (%):			
No income	19 (65.5)	1023 (53.8)	
Income	7 (24.1)	339 (17.8)	
Not applicable	2 (6.9)	342 (18.0)	
Missing	1 (3.5)	197 (10.4)	
TBSA, median (IQR)	77.5 (56.3 - 92.5)	27.5 (15.4 - 57.5)	
Missing, n (%)	2 (6.9)	169 (8.9)	
Discharge status, n (%)			
Discharged	6 (20.7)	1125 (59.2)	
Death	19 (65.5)	568 (29.9)	
Discharged against medical advice	4 (13.8)	146 (7.7)	
Transfer	0	37 (1.9)	
Missing	0	25 (1.3)	

**Table 26.** Contingency table for the recording of intent.

		Final category						
		Accidental	Suicidal	Homicidal	Electrical	Old	Other	Missing
Original	Accidental	1266	8	1	3	0	0	0
category	Suicidal	5	215	3	0	0	1	0
	Homicidal	0	0	29	0	0	0	0
	Electrical	0	0	0	65	0	0	0
	Old	0	0	0	0	43	0	0
	Other	0	0	0	0	0	40	0
	Illegible	5	3	0	0	0	0	243

# Discussion

We have shown systematic variations in both the recording of injury intent data, and the characteristics associated with categories of injury intent in a newly digitised burn register from a tertiary government burn unit in south India. Findings highlight ways in which the quality of surveillance data on injury intent could be improved, as well as groups that may include misclassified data and should be the focus of future research. Although this is a single centre study, the methods will be of interest to those who utilise routinely collected data and wish to try to identify misclassification of this important variable.

Injury intent was found to be recorded differently to other variables in the register. It was more likely than any other variable in the data set to be missing, overwritten, or to have other data elements recorded. These findings suggest that it is problematic variable to complete. Discussion about missing data with staff responsible for completing the register suggested that the field is only left empty if there is doubt about injury intent. Data quality was otherwise good, suggesting that data entrants specifically had difficulty completing the intent variable rather than the entire record. Missing intent data in this register, therefore, could be considered equivalent to a classification of undetermined intent. Previous research has shown that individuals with no recorded injury intent may have burns due to self-harm or interpersonal violence [161]. We found a small secondary peak in high TBSA (80-100%) burns in females, which corresponds to the peak TBSA of "Suicidal" injuries. This may indicate that there is a subset of burns classified as missing that are actually self-inflicted injuries in women.

Staff reported that they may suspect an injury is intentional but cannot record it as such unless the patient wishes to change their statement with the medicolegal team. Intent recorded in this register, therefore, is a reflection of what the patient or attender reports, rather than clinical

judgement by a healthcare professional. The Global Burn Registry includes a field to allow the clinician to record their degree of clinical suspicion that an injury of undetermined intent was caused intentionally [102]. Such an approach allows capture of valuable clinical judgement about the intent of an injury in surveillance data, but further qualitative enquiry is required to understand differences in probabilistic judgements of different healthcare professions. If inconsistency was found between the patient reported intent and clinician judgement of intent, then it could indicate misclassification.

A small number of cases were found to have had injury intent overwritten. There was a greater proportion of cases classified as "Suicidal" or "Homicidal" in this group. There was also a larger proportion of females and a higher median TBSA. This is consistent with reports from clinicians and the literature of female patients with large fatal burns sometimes changing their account of the injury prior to death. Such injuries may initially be reported by the woman as accidental due to pressure from their husband or in-laws but are then changed to suicidal or homicidal once receiving support from their natal family [74]. Although there were a lower proportion of "Accidental" burns in the overwritten group, the TBSA of the "Accidental" burns was similar to "Suicidal" burns. Of the 10 "Accidental" overwritten cases, half were originally reported as "Suicidal" burns. The patient may be motivated to change their reported injury intent from "Suicidal" to "Accidental" in order to avoid police investigation [213]. These findings show that the change in intent data is multidirectional and thus is likely to introduce differential misclassification bias into analyses [296]. Given that a patient must engage with medicolegal processes to change their reported injury intent, and the major differences in characteristics of the overwritten group, it suggests that overwriting is a potentially important predictor variable for misclassification.

Injury intent was the main variable of interest, but it was found that other elements of causation were sometimes recorded instead of, or in combination with, intent. This has been identified in other studies from South Asia and in international burn registers [2, 4]. It reflects one of the challenges of accurate and consistent reporting of injury intent in surveillance data, and reduces the comparability of data between studies. A suggested solution to this is the use of common data elements (CDE), which are increasingly being used in multicentre studies to improve data consistency and sharing [153]. CDEs include a variable name, prompt, and set of permissible values. Prior work has shown that there is variation in the collection of burn registry data internationally and that CDEs for burn injuries would benefit from also including a variable definition, response option definitions, and recommended method of measurement [2, 4]. A CDE for injury intent was not found when searching the National Institutes of Health CDE repository [154]. Development of a set of CDEs for burn injuries is likely to be of value to the burns community beyond standardisation

of intent. It would facilitate a move towards FAIR principles (findability, accessibility, interoperability, and reusability) for all burns data [153]. The European Joint Programme on Rare Diseases recently developed a set of common data elements to be implemented across all rare disease registries in Europe [297, 298]. Development of a set of CDEs for a disease registry is typically done using an expert consensus process (e.g. Delphi) [297, 299, 300]. The process is time-consuming and CDE sets are usually relatively small to enable implementation across all registries [298]. This can be considered akin to a minimum data set. Implementation of a set of CDEs could be done in paper and electronic medical record systems. Paper based registers can then be digitised to a high standard, but it is likely to be easier to directly apply validation parameters (i.e. restricted response options for a CDE) in a fully electronic data collection system.

We found that the number of burn admissions for all classifications of intent reduced over time. They reduced as a proportion of all-cause admissions, which suggests that the number of burn admissions is reducing rather than there being a reduction in the number of patients being treated by the hospital. A downward trend in burn incidence is seen in international burn data [68, 288]. For India this may specifically relate to the removal of subsidies for household kerosene, and government targets for major cities to no longer use kerosene [301]. Kerosene is a commonly used substance for burns due to self-harm and interpersonal violence. This is because it is readily available in the home and remains liquid at room temperature meaning it can be poured or thrown [302, 303]. Households increasingly use bottled liquid petroleum gas or piped natural gas, which is likely to further reduce burn injuries [304].

The number of injuries categorised as "Suicidal" was similar for men and women. A greater number of self-inflicted burns might have been expected in women based on the literature and following discussion with clinicians in the burn unit [213, 305]. A relative reduction in "Suicidal" injuries in women is seen since 2020, but there is a corresponding increase in documentation of 'Other' aspects of injury causation (e.g. thermal injury, inhalational injury). The secondary peak in very high TBSA burns for women in the 'Other' classification group is suggestive of self-inflicted injury patterns. This may indicate that there is a subset of burns classified as 'Other' in women that are actually self-inflicted. Further gendered patterns were seen in the data. Injuries for women peaked at childbearing age for all classification groups. This is seen in national data and is thought to be due to cooking responsibilities and risk of gender-based violence when moving into the marital home [44, 80, 303, 306]. There are a number of strengths to this study. It was written in accordance with RECORD guidance for observational studies using routinely collected health data [122]. Although this guidance is aimed at studies using large multicentre databases, high quality single centre registers can still provide useful insights that can influence patient care and policy. It is important, therefore, for single centre burn register studies to consider and report the same criteria to allow readers to fully appraise the strengths and weaknesses of the data set. This study is the first burns study that we are aware of that utilise exploratory techniques to identify possible misclassified groups. These techniques are likely to be of interest to other users of routinely collected burns data. It provides a useful basis for future study and exploratory work to understand which variables cluster together as indicators of misclassification.

There are some limitations to this study. Firstly, we found that age and TBSA were often rounded to five-unit intervals. This is known as digit preference, where continuous data includes visible peaks usually at values that end in zero or five. It is a well-recognised phenomenon for self-reported age (also known as age-heaping), and has been found in Indian census data [307, 308]. We have not found any previous reports of digit preference in TBSA measurement, but it has been observed in other clinician-reported measurements that have a critical relationship with patient outcomes such as breast cancer diameter [309]. It is unlikely that digit preference affects individual patient outcomes. At a population level it distorts continuous data, which can lead to erroneous conclusions being made about the distribution of variables in a population [308]. It is likely to have introduced misclassification bias into our analyses that utilise age and TBSA data. It will limit the utility of these data as predictor variables in future studies. Digit preference can be identified relatively easily, but it also givens an indication of the pervasiveness of measurement bias in routinely collected data. The starting point of this study was recognising that misclassification bias is likely to exist in intent data, but that its identification is challenging. The methods demonstrated here are a starting point for improving identification of this, and we hope that this study will encourage others to explore methods to identify misclassification in problematic variables.

Secondly, we had intended to calculate length of stay using date of admission and date of discharge data. It was found that date of discharge could refer to the date of discharge from the hospital or from the burn unit. This meant length of stay could not be interpreted and so was not included in our analyses.

Thirdly, the determination of intent is inherently difficult. There is no gold standard for the determination of injury intent in a hospital setting. The term 'intent' can have different meanings to

different professional groups. In this setting, the terms "Accidental", "Suicidal", and "Homicidal" related to who, if anyone, was responsible for the injury as opposed to the desire of the patient or assailant to cause death. Assessment of who was responsible for an injury is more straightforward than the assessment of thought processes at the time of an injury. We have suggested techniques to potentially improve the reliability of data (e.g. implementation of a CDE) and methods that might indicate misclassification (e.g. overwriting, inconsistent distribution of variables, recording of clinician impression). In combination, this is likely to lead to a probabilistic categorisation, but it is unlikely that the 'true' intent of an injury can ever be known.

We recommend that users of routinely collected burns data consider critically exploring data recording practices for injury intent and explore groups that may be at risk of misclassification. We believe that quality of injury intent data could be improved by recording changes in patient reported injury intent, and the clinicians' impression about the intent of the injury. We recommend that injury intent is coded as a unique variable and should not be mixed with other elements of injury causation (e.g. mechanism). This can be achieved locally by development of a data dictionary that includes definitions for variables, response options, and how variables should be measured or assessed. These can be a used as a guide for staff and those utilising the data. However, to improve reliability and move towards FAIR principles (findability, accessibility, interoperability, and reusability) for all burns data internationally, we believe that is it necessary for the global burns community to unite to develop a set of CDEs that can be used as a minimum data set across all burn registers. We recommend that the data set includes a CDE for intent.

#### Conclusions

Burn registers are an important source of surveillance data on injury intent that informs prevention activities. Understanding likely sources of misclassification bias is essential to understand the limitations of these data, improve data collection techniques, and inform future areas of research. We found that intent data were more likely to be missing and overwritten than other variables. Some subgroups, such as females with high TBSA burns, appear to be more likely to be misclassified. This affects the reliability of a data item that is deemed essential for prevention activities. Although this is a single centre study, it is the first study that we are aware of to explore misclassification bias of burn injury intent. The next step in this work is to explore in more depth the grouping of responses to look for discrete classes that might indicate misclassification (e.g. latent class analysis). Data driven techniques to improve assessment of injury intent should not, however, overshadow the global need to improve data collection of injury intent information such as through recording

clinician impression, change in patient reported intent, and implementation of a common data element.

**Chapter seven – Discussion** 

# Key messages

# What is already know on this subject

- Disaggregation of data on injuries according to intent is essential to inform preventative interventions.
- Burn injuries are a major cause of morbidity and mortality internationally. The greatest burden of intentional injuries is believed to be in South Asia.
- Most national-level injury data for South Asia is modelled. There are concerns about misclassification of intentional injuries due to stigma and fear of criminal investigation. This is likely to bias surveillance data and lead to inappropriate allocation of resources for preventative interventions.
- Systematic investigation of how burn injury intent data is currently being collected internationally, and the likelihood of bias in those data, could be used to inform methods to strengthen surveillance data on burn injury intent.

# What this research adds

- This research brings together findings from 13 national-level burn registers, 89 published primary research studies from South Asia, and case studies from two hospitals in south India.
- The concept generally being assessed for an 'intent' variable was who, if anyone, inflicted the burn injury. Failure to distinguish this from legal and psychological concepts of intent, which are concerned with the degree to which the patient or another person wished to inflict death or harm, is likely to have led to confusion in the previous literature.
- Data collected about injury intent is not standardised internationally. This increases the likelihood of misclassification bias in existing data and limits the ability to compare results between data sets. In South Asia, recording of 'intent' is based entirely on what the patient or their family reports.
- Patients receiving emergency care in geographically close hospitals in south India did so through different mechanisms. This affected the routine data collected about them. Multiple data sources need to be cross-referenced to ensure thorough case ascertainment in a newly established self-harm register.

- High quality data about burn injuries that can be disaggregated by intent was available in a tertiary government hospital burn unit. Digitisation of these data provided useful epidemiological data.
- Exploratory analyses of burn injury data suggest intent is a problematic variable to complete.
   Data were missing for 12.6% of cases, and 1.5% of cases had overwriting of intent. Comparison of the distribution of variables suggests that certain groups may be misclassified.

# Key applications for research and practice

- Greater clarity should be provided in burn register documentation and training about what concept is being assessed by intent-related variables. It is likely that an explicit reduction of the concept to 'Who did the act that resulted in the burn injury?' would minimise confusion amongst professional groups, but still provide valuable public health data.
- Implementation of a common data element for injury intent as part of an international minimum data set for burns would help to standardise data collection and interoperability of data sets. Evaluation of the validity and reliability of an intent common data element would need to be completed.
- Process mapping is a rigorous method to understand how patients are processed in a hospital setting. This can be used to develop a robust case ascertainment strategy for a new register, or to explore selection bias in an existing register.
- High quality clinical data may not be in an accessible format in low resource environments.
   Handwritten registers can be assessed for their data quality and then digitised to enable use of these data. This is a valuable method to improve data equity.
- Data driven techniques offer an opportunity to strengthen surveillance data on burn injury intent. Further research is required to look at groupings of variable responses to explore latent classes and estimate the degree of misclassification in existing data.
- The methods presented in this thesis could be applied to other injury types, other clinical registers, or other complex variables.
# Summary of principal findings, and policy and practice implications arising from this work

The aim of this thesis was to answer the research question:

### How can international burn injury morbidity surveillance data be strengthened to better differentiate burns that are: unintentional; due to self-harm; or due to interpersonal violence?

At the start of the PhD, my intention had been to answer this question by developing a clinical prediction model using data from the SASHI self-harm register (the register described in chapter four) or the burns register from KR Hospital, Mysore (the register described in chapters five and six). There are two main types of clinical prediction models: diagnostic, and prognostic [310]. Diagnostic tools give a probabilistic result of a condition being present in a patient currently. Whereas prognostic tools indicate the likelihood of a condition being present at a specified point in the future. Development of a diagnostic prediction tool to help clinicians to identify patients in hospital with an intentional injury has been identified as an area of research need in India [80, 213].

A diagnostic prediction tool for injury intent could be a useful addition to a wider programme to prevent burn injuries. For example, it could help to estimate the degree of misclassification in existing data allowing better allocation of resources for preventative interventions in the future. It could also be used to help clinicians to identify those at greater risk of intentional burns, allowing support to be offered in hospital and at discharge. This approach has been used for paediatric burn injuries. The Burns Risk assessment for Neglect or abuse Tool (BuRN-Tool) was designed to help UK-based emergency department clinicians determine which children may have sustained a burn injury due to neglect or abuse [311]. This tool was found to be acceptable to clinicians and particularly helped to guide more junior clinicians about when to discuss a case with a senior clinician [312, 313].

Development of a diagnostic clinical prediction tool relies upon a gold standard for diagnosis (the outcome). Reliable and consistent collection of the outcome variable is needed in the data set used to develop the prediction model [314]. A major issue limiting prediction of injury intent is that there is no gold standard for the diagnosis of abuse, assault, or self-harm. It is recognised that this variable is prone to misclassification. The outcome measure used by the BuRN-Tool was clinician referral to social services [311]. This proxy measure is appropriate in the UK context but is likely to limit transferability of the tool to other settings. A similar approach has been taken for development of a prediction tool for other injury types such as paediatric head injury [315]. The outcome measure used in the Paediatric Brain Injury Research Network abusive head trauma tool was the treating

clinicians' final diagnostic impression. This was based upon factors such as admission or witnessed abusive act by the caregiver, inconsistent or implausible history, and inconsistent injury pattern. Data were collected independently at discharge to try to minimise misclassification bias.

The increase in availability of routinely collected data from electronic health records means that there is now a wealth of data available to researchers to develop clinical prediction models [314]. Over 4000 papers on clinical prediction models are published weekly on MEDLINE [316]. Few are thought to be implemented clinically [317]. There are concerns about high risk of bias and 'hacking' to inflate predictive performance, which is likely to result in misclassification of outcomes and could result in patient harm [316, 318]. A clinically useful and reliable prediction tool hinges upon the use of appropriate data to develop the model. The data set should accurately represent the population that the tool will be used on, be large enough that there are a sufficient number of participants with each outcome of interest, and predictor and outcome variables should be measured consistently using appropriate assessment methods [318].

Discussions with burn injury experts in India and the UK revealed that although there was a desire to create a tool to help clinicians better identify the intent of a burn injury, there were concerns about misclassification of intent in existing data. This is a critical issue because it would reduce the reliability of any model built using that data. There were concerns about the amount of data being collected internationally on injury intent, particularly from regions that are believed to have the highest incidence of intentional burns (e.g. South Asia). This would limit the ability to validate a model built using the SASHI or KR hospital burn unit data sets. If these issues were ignored and a prediction model was built, it would have been unlikely to be clinically useful and may have resulted in patient harm. A prediction model would only be a minor addition to the overall care and prevention of burn injuries. It is more pressing to address the wider issues that affect the reliability of surveillance data on injury intent. This is an essential prerequisite to enable meaningful development and appraisal of burn injury preventative interventions.

In order to answer the thesis research question, a broader approach was required that considered all factors affecting the reliability of observational data on burn injuries (Figure 28). By considering how to strengthen surveillance data on injury intent in general, it would still allow use of the data for development of a clinical prediction model, but it would enable a much wider application of the data for injury prevention. Most of the factors affecting the strength of surveillance data had not previously been systematically investigated with respect to intent of non-fatal burn injuries. The

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Figure 28. Epidemiological factors affecting the reliability of surveillance data on burn injury intent.



thesis objectives addressed this research gap and included exploratory work to answer the thesis question. The thesis objectives were to:

- Understand current surveillance data collected internationally on burn injury intent and the likelihood of selection and misclassification bias in those data (Chapter two).
- Understand comparability and standardisation of variables currently used to record burn injury intent (Chapters two and three).
- Develop a method to improve case ascertainment of new and existing hospital-based surveillance systems that include burn injury intent data (Chapter four).
- Develop a method to better utilise existing high quality hospital based surveillance data that includes burn injury intent data (Chapter five).
- Explore recording practices and patient groups that may be at risk of misclassification using existing injury intent data (Chapter six).

The studies in this thesis used a range of data sources and methods, both quantitative and qualitative. The findings and implications of this thesis can be summarised according to the factors that affect the strength of surveillance data on burn injury intent (Figure 28). The results can be further summarised according to the thesis objectives.

## Objective one: Understand current surveillance data collected internationally on burn injury intent and the likelihood of selection and misclassification bias in those data

The first objective was to understand what morbidity data is currently collected internationally on burn injury intent. The study in chapter two was used to answer this objective by comparing data dictionaries from national level burn registers. This study provided an overview of burn injury intent data internationally. It allowed other important concepts relevant to all the studies in the thesis, such as selection and misclassification bias, to be drawn out. These concepts run as a common thread throughout the discussion.

2759 unique variables about burn injuries are collected across 13 countrywide or intercountry burn registers. 43 variables across 12 registers included information on injury intent. Variables did show similarities that would facilitate international data comparisons. An example is included in the paper of how burn injury intent variables across burn registers could be harmonised to allow comparison of these data (Figure 10, and Appendix B: Table 4) using an extract-transform-load process.

Pooling and comparing data across the existing global network of burn registers could represent a powerful opportunity to strengthen international morbidity surveillance data on injury intent.

Presently there is no pooling of burn register data and these data are not used in large scale morbidity estimation studies such as the Global Burden of Disease study [319]. Pooled burn register data could be used to investigate risk factors associated with burns that are unintentional, due to self-harm, or due to interpersonal violence. They could be used to understand differences in exposures that may have a causal relationship with each outcome, allowing more tailored interventions to be developed. Pooling data can increase precision of results by increasing sample size, thus reducing random error, but there is a risk of amplifying systematic error [92]. Selection bias and misclassification bias are the main sources of systematic error. We found differences between registers that could introduce selection and misclassification bias. These issues would need to be addressed before data could be pooled.

Selection bias would be introduced into analyses if pooled burn register data does not accurately represent the global population of patients that require medical care for burn injuries. We found two main issues that could cause this; firstly, lack of data from low- and middle-income countries; secondly, different criteria used by burn registers to collect data from institutions and patients.

Only two of the 13 countrywide and intercountry burn registers collected data from low- and middle-income countries. These were the South Asia Burn Registry, and the World Health Organization Global Burn Registry. Data from these registers are unlikely to be representative of the countries that submit data. The South Asia Burn Registry has not been scaled up following their pilot in two hospitals in Pakistan and Bangladesh. The World Health Organization Global Burn Registry allows voluntary submission of data and currently includes data from 36 healthcare facilities in 20 countries. This means that pooled data from the existing network of countrywide and intercountry burn registers would not adequately represent low- and middle-income countries. Any results gained from analyses using these data would be biased towards high-income countries. This is an important finding because the greatest burden of burn injuries are in low- and middle-income countries [171].

The systematic scoping review conducted in chapter three added further useful evidence about international data inequity on burn injuries. It showed that the majority of published primary research studies from South Asia that include data about burn injury intent are from India (57%) and Pakistan (30%). There were no studies from Bhutan or the Maldives that met the systematic scoping review inclusion criteria. This suggests that existing published primary research cannot be used to address gaps in burn injury intent data for the region of South Asia. The combination of findings from the data dictionary study (chapter two) and systematic scoping review (chapter three)

suggests that in order to achieve data equity in low- and middle-income countries, new registers need to be established, or methods need to be developed to maximise the utility of existing data that might not currently be accessible (e.g. handwritten data).

Data from the existing network of countrywide and intercountry burn registers could still have an important role in strengthening surveillance data on injury intent internationally. It was important to investigate the possible sources of selection bias between these registers to understand the utility of pooling existing data (chapter two). We found different inclusion criteria are used by the burn registers. Differences were found in patient diagnosis, length of stay, and consent. These differences will affect how similar case capture is between registers and could introduce selection bias into analyses using pooled data. For example, a recent study comparing the Burn Model System and Burn Care Quality Platform (two American registers involved in the study in chapter two) showed that average burn severity was higher in the Burn Model System register [138]. This was thought to be due to the more restrictive inclusion criteria of the Burn Model System, which only invites patients to participate who require surgery and have a burn injury size over 10% or 20% (dependent upon age). Conversely, inclusion criteria for the Burn Care Quality Platform do not include a minimum burn injury size. Differences in inclusion criteria would limit the type of questions that could be answered using pooled burn register data, and may limit the generalisability of results.

Other factors that affect national representativeness of a countrywide burn register are the number and type of healthcare facilities that submit data. This was partially explored in the study in chapter two. We found the number of facilities that submitted data to the registers ranged from 1 to 120 sites. Criteria used to determine which facilities submit data varied between registers. For example, it is voluntary to submit data to the World Health Organization Global Burn Registry [141], but it is mandatory for all NHS commissioned burn care services in England and Wales to submit data to the International Burn Injury Database [83]. The four centres that submit data to the Burn Model System are funded on a five yearly cycle based on a competitive application process [320], whereas there is an annual participation fee for burn centres that submit data to the Burn Care Quality Platform [321]. These issues could affect the representativeness of the database population. For example, large burn centres are usually located in cities, this means that a register that only collects data from large burn centres may have fewer patients from rural areas. A register with a subscription-based model may be more likely to include hospitals that are profit making such as private hospitals. The register would then be unlikely to include patients who are unable to afford private healthcare. Selection bias of this nature could feasibly affect the reliability of data on burn injury intent given that lower socioeconomic status is recognised to be more common in patients with intentional, rather than unintentional, injuries [322-324].

It would be important to consider sources of selection bias in analyses that use pooled burn register data. It is unlikely that criteria used by burn registers to collect data from institutions and patients could be standardised internationally. Instead, analyses would need to allow for these differences. Model estimates would need to be investigated to understand if effects are biased by nonparticipation [325]. This would rely upon population representative data. Sampling exercises can be used to understand how closely the register population matches the entire population of burn injuries requiring medical care. This is more straightforward for countries with nationalised healthcare systems that collect centralised data on the number of hospital admissions for different diagnoses [236].

Misclassification bias is another important potential source of systematic error that could affect analyses using pooled burn register data. This is introduced by differences in the way that intent information is assessed and recorded. It is recommended that epidemiological studies use standardised methods of assessment and definitions for key outcome variables to reduce the risk of misclassification bias [142]. We found register data dictionaries included very little detail about how to assess injury intent (chapter two). Where guidance was given, it was aimed at the person completing data entry rather than the clinician who would be responsible for differentiating injury intent. Some data dictionaries included definitions for intent variables, but these definitions were often circular (i.e. used the same term as the variable name). For example, the Burn Registry of Australia and New Zealand has a variable "Intent when burn occurred". This is defined as "Clinician's assessment of the most likely human intent in the occurrence of the burn injury". Such definitions are unhelpful because the user must still use their own interpretation of the term to complete the variable. This is likely to lead to interrater differences between institutions that submit data to the same register, which can lead to misclassification bias within individual data sets. It means that the comparability of intent data between registers cannot be determined even where the same term is used.

The potential for differences in the assessment of injury intent within and between burn register data sets is important when considering how to achieve inter-register data comparisons. The example in the discussion section of chapter two uses a common data model approach to enable comparison of intent variables across registers (Figure 10, and Appendix B: Table 4). Common data models have been used to compare data across other disease registers, including cancer and diabetes [119, 120]. It has been agreed that NHS data will be transformed using the Observational Medical Outcomes Partnership (OMOP) common data model to enable comparison with other OMOP data sets globally [326]. To the best of my knowledge, no burn register has converted their data using a using a common data model [119, 120]. A major limitation when using a common data model is that assumptions must be made about whether the existing register variable is sufficiently similar to the variable in the common data model to allow it to be transformed. This decision may be made based on the similarity of variable name or set of response options. But without standardised definitions and method of assessment, it cannot be assumed that variable data will have been collected uniformly within and between registers. This is a particular risk for outcome variables that are prone to misclassification, such as injury intent.

An alternative method to enable inter-register data comparisons is to develop a common minimum data set that is collected across all registers. This should utilise standardised methods of assessment and definitions for variables where they currently exist. Standardisation of a variable is known as a common data element [153]. The National Institute of Health (NIH) defines a common data element as "a standardized, precisely defined question, paired with a set of allowable responses, used systematically across different sites, studies, or clinical trials to ensure consistent data collection" [154]. NIH-endorsed common data elements do include definitions, but these may be circular. For example, the common data element 'race' uses the definition "A textual description of a person's race" [327]. The risk of interrater differences is somewhat mitigated by detailed response option definitions. For example, Asian – "A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent, including for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam." Common data elements tend not to specify the method of assessment or measurement of a variable. This is a limitation because it increases the risk of inter-study and inter-rater differences, undermining the purpose of a common data element. It is not in line with international guidance for reporting of human studies [142, 328]. There is no NIH-endorsed common data element for injury intent in their repository. Burn register variables with a high likelihood of misclassification but without an existing common data element, such as intent, would benefit from development of a new common data element. This should include non-circular definitions, response options, and method of assessment.

Missing data is another pervasive issue that can arise when variables are inadequately defined, and methods of assessment are not specified. Data that is 'missing completely at random' (MCAR) can be handled in a straightforward manner by excluding cases from analyses [329]. Complete-case analysis is the most common method for handling missing data in epidemiological studies, but it can reduce the power of analyses [329]. Data that is systematically missing is more difficult to handle during analyses. If the variable is missing because of a reason that is measured by a variable in the data set (e.g. gender difference), it is known as 'missing at random' (MAR) [330]. Data that is missing because of reasons that are not measured in the data set is known as 'missing not at random' (MNAR). Missing at random and missing not at random data are commonly handled by estimation methods such as multiple imputation [330]. This can give less biased results than complete case analyses for data that is missing at random, but may result in worse bias for data that are missing not at random. This is a particularly important consideration for burn injury intent. Intent is recognised to be influenced by personal, social, cultural, and legal sensitivities. It has been shown this can result in intentional injuries having no intent data recorded in a patient record (i.e. for the intent variable to be missing) [161]. Missing data for injury intent, therefore, is more likely to be missing not at random. Arguably, the best method to deal with missing data is to try to prevent it occurring in the first place by ensuring the field is completed.

One strategy to reduce missing data is to make completion of a variable mandatory. Only 40% of variables in the national level burn registers (chapter two) that include intent information are mandatory to collect. Registers with mandatory collection of variables may still have incomplete records, so ensuring that variables are easily understood, and that data are easy to collect, is important to maximise variable completion [143, 331]. This could be addressed through the development of a common data element for intent that includes non-circular definitions, response options, and method of assessment.

### Objective two: Understand comparability and standardisation of variables currently used to record burn injury intent

The need for a common data element for injury intent was further demonstrated in chapter three. This study evaluated primary research literature from South Asia about patients presenting to hospital with a burn injury. Findings from chapter three and the data dictionary study in chapter two address the second thesis objective, which was to understand comparability and standardisation of variables currently used to record burn injury intent. Data were compared about the terminology used for the concept of intent (stem term), the terminology used for classification of intent (classifier term), definitions of stem and classifier terms, and methods of assessment of intent. This provided a broad overview of the collection of intent variable information in countries with a national level burn register (chapter two), as well as hospitals in South Asia that have published data about burn injuries (chapter three).

Less than half of the articles included in our systematic scoping review (chapter three) used a term for the concept of intent. In the articles that did use a term for the concept of intent, the most common was "cause". Conversely, "intent" was the most commonly used stem term in the burn register data dictionaries (chapter two).

40 different classifier terms for intent were used across the 89 included articles from South Asia in the systematic scoping review (chapter three). The most common were "accidental" (73 articles), "suicidal" (45 articles), and "homicidal" (35 articles). The way that these terms were used in the article text seemed to reflect who was responsible for the injury, rather than the desire of the patient or the attacker to cause death. Burn register data dictionaries (chapter two) included 24 different classifier terms across the 10 registers that had comparable intent information (Appendix B). The most common terms were "accidental" (6 registers) and "assault" (9 registers). There was less consensus for burn injuries due to self-harm. Terms included "suicide" (5 registers), "selfinflicted" (3 registers), and "self-harm" (3 registers). Two registers collected separate data about the desire of the patient to inflict a fatal or non-fatal injury. Results from chapters two and three show that, in general, broad classifications of intent are used in burns surveillance, rather than collection of detailed information about underlying motives. This pragmatic approach is used in self-harm registers [43]. Although similar terms are used between the registers in chapter two and the articles in chapter three, it cannot be assumed that terms were interpreted in the same way by those who collected the data. Defining a variable can help to ensure that it is interpreted in the same way by different users.

Definitions are recommended in surveillance guidelines to minimise systematic error due to misclassification [11]. Few definitions for stem and classifier terms were available in the data dictionaries in chapter two or the articles in chapter three. Failure to define key terms can increase the risk of inconsistent and inaccurate classification of intent because researchers and practitioners can interpret the same term differently. An international study on English language terms for suicidal behaviours conducted by De Leo et al. [211] showed differences in interpretation of terms between respondents, particularly for non-fatal injuries. Approximately 90% of respondents agreed that a "suicide attempt" is "when a person harms him- or herself, with the intention to die, and survives". A wide variety of terms were used for circumstances in which a patient did not intend to die or could not state their intention to die. The most common included "self-harm", "self-injury", and "suicide attempt". "Self-harm" was slightly preferred by the respondents, and the authors recognised it can be a useful overarching term for non-fatal suicidal behaviours. The authors argue though that "suicide attempt" should continue to be used where the patient expresses an intent to

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die. This appears to contradict the approach used by burn registers (chapter two) and articles included in the systematic scoping review (chapter three), where overarching terms are preferred and there is less emphasis on recording the desire of the patient to die. It is important to note that the survey by De Leo et al. [211] did not explore how such terms are distinguished clinically, nor if it is practicable or useful to do so during the acute phase of an injury. It has been shown in UK studies of self-harm that almost half of patients may not care whether they live or die at the time of the injury, and that the desire to die at the time of injury does not affect in-hospital mortality [332]. This supports the approach of using well defined overarching terms for burn injury intent by surveillance systems based in acute hospital settings (e.g. emergency department or burns unit).

Standardised methods of assessment are another important way of ensuring data is collected in a uniform way, thus reducing the risk of misclassification bias [142]. 50% of the burn registers in chapter two provide details in their data dictionary about how intent is assessed. These details are targeted at the person completing data entry. They suggest that the variable is completed based on clinician assessment or what is documented in the patient notes, but little information is given about how intent should be differentiated by clinicians. The Burn Care Quality Platform acknowledges that "It is often difficult to determine the intentionality of the injury. It is up to the user and treating physician to determine whether the injury should be reported as such [intentional]". Only 17% of the articles included in the systematic scoping review in chapter three provided detailed information about how injury intent was assessed. Where reported, this was primarily based upon what the patient, or their family, said. The studies explained that clinicians may not feel able to investigate injuries that are reported as accidental even if they suspect the injury to be due to self-harm or interpersonal violence. This was because of lack of time [74], a feeling that their duty as a clinician is to only document what the patient reports [44], or lack of investigation by local authorities [199]. Only the studies conducted by Laloe [195, 196] include data about clinician suspicion of intentionality of the injury. 7% of burn injuries reported as "accidental" were thought to be intentional due to inconsistencies in the pattern of injury or interaction between the patient and family. Laloe is a French general surgeon who was working for Médecins Sans Frontières in Batticaloa, Sri Lanka, at the time of the studies. Her foreign training background and employment by Médecins Sans Frontières may account for why she began collection of information about suspected intentional injury.

The description of methods used to assess injury intent described in the data dictionary study (chapter two) and systematic scoping review (chapter three) shows that differentiation of burn injury intent is currently at the discretion of the clinician or researcher. This is likely to mean that

there are interrater differences, which can introduce misclassification bias into analyses. As described in the introduction (chapter one), there are multiple points in the recording of injury intent data where misclassification can occur (Figure 29). This can include the patient or family not disclosing the true cause of the injury, the healthcare professional incorrectly recording or inadequately enquiring about the cause of the injury, or the coder inaccurately interpreting the patient record.

**Figure 29.** Points in the recording of routinely collected data where misclassification can occur in an individual patient record (duplicated from chapter one).



There have been numerous calls in the literature from South Asia to develop a prediction model or list of features suggestive of intentional injuries to help clinicians to better differentiate intent of burn injuries [80, 213, 214]. This suggests that researchers are most concerned about inaccuracies in recording that occur because the patient or family do not disclose the true cause of the injury.

Maguire et al. [170] used systematic review methodology to compile a list of burn injury features that are suggestive of abuse in children. We are unaware of a similar tool for burn injuries in adults that are caused by assault or self-harm. They assessed the rigour of the methods used to differentiate injury intent. Only those in which abuse had been confirmed (a ranking of 1 or 2 in their system) or actively excluded (a ranking of A or B in their system) were included in the review (chapter three: Table 13). Of the 258 studies reviewed by Maguire et al, 26 were of sufficient quality to be used to compile the list of features suggestive of abuse. We used the same system to rank the rigour of the method used to assess injury intent in the articles from South Asia included in our systematic scoping review (chapter three). Only two of the articles met the criteria used by Maguire et al. This suggests that existing literature from South Asia could not be used to compile a list of features.

Creation of a tool to aid identification of intentional burn injuries relies upon having reliable data on injury intent in the data set used to develop the tool. Maguire et al. [170] used multidisciplinary assessment or police investigation to determine whether a burn injury is due to abuse. A different approach was taken by Kemp et al. [311] when developing a clinical prediction tool to identify paediatric burns due to abuse or neglect. They used a proxy measure for determination of intent, which was referral to social services for investigation of suspected maltreatment. Features that might raise suspicion of abuse include implausible, inadequate, or inconsistent history; introverted or fearful behaviour of the patient; or suspicious pattern of burn injury [170]. Both approaches rely upon the clinician being empowered to raise concerns about possible intentional injury, which is likely to be influenced by social and cultural factors.

There is plentiful guidance and training aimed at healthcare professionals in the UK to improve recognition and reporting of suspected child maltreatment [333, 334]. Similar guidance exists in Australia, Canada, and European countries [335]. International uniformity in the approach to recognition and reporting of child maltreatment cannot be assumed. In our systematic scoping review (chapter three), 11 articles included only paediatric patients. Of these, seven studies were from India and four were from Pakistan. Non-accidental injury was only discussed as a possible cause of a burn injury in three of the 11 articles. These were published from Indian hospitals in 1979, 2001, and 2016 [193, 204, 336]. In 2012, the Protection of Children from Sexual Offences (POCSO) Act was introduced in India. Early analyses of published data suggest this has led to increased rates of reporting of all forms of abuse [337]. The four other articles from India that include only paediatric patients were published prior to 2012, which may account for why they do not discuss non-accidental injury.

Identifying and recording intentional injuries in older children and adults is less straightforward. Intentional injuries may be self-inflicted, caused by assault, or caused by domestic abuse. Assault or abuse may be reported by a patient as unintentional or due to self-harm. Although a clinician may suspect that an injury is intentional, they may not wish to record it as such in patient notes or a surveillance system. This may be due to fear of being required to give evidence in a criminal investigation, or due to a belief that investigation of intentionality is not in the patient's best interest [44]. Ethical principles of patient confidentiality and patient safety may, at times, be conflicting. This can make it difficult for clinicians to determine the best course of action. In the UK context, the need for patient consent to share information with other agencies can be overridden if information sharing is required for the safety of the individual or society [47]. Sharing information with law enforcement agencies may not always benefit patients. Reporting of domestic abuse is mandatory

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in the United States, but has been found to reduce help-seeking by survivors [338]. Fear of police involvement has been found to affect the reported intent of women with burn injuries in India [44, 74]. Healthcare professionals and police in India may adjust their documentation and investigation based upon what they believe is best for the patient [45]. Reporting of injuries suspected to be due to abuse is mandatory in Turkey, but clinicians are more likely to only report large or deep burn injuries that are suspected to be due to abuse [160]. These factors highlight the need to ensure that a surveillance system that collects data on intent does so in a way that is acceptable and useful to whoever collects the data (e.g. clinician), and in doing so does not put a patient at greater risk of harm.

These results further strengthen the argument to develop a common data element for injury intent to try to find a culturally acceptable method internationally to assess and record these data. Until this has been developed and widely adopted, it is important that researchers and journal editors ensure that methods used to assess injury intent are adequately described. This would bring research more in line with recommended guidance for observational studies [142]. It is important that all potential sources of bias are explored and described within existing routinely collected data sets to help users better determine the strengths and limitations of the data [122].

#### Objective three: Develop a method to improve case ascertainment of new and existing hospitalbased surveillance systems that include burn injury intent data

Review of national level burn registers in chapter two showed there are no burn registers in lowand middle-income countries that are likely to include nationally representative data. The systematic scoping review in chapter three showed that existing published primary literature from South Asia is too heterogenous and of poor methodological quality to be used to compare burn injury intent data. This suggests that there is a need to develop systems to provide high quality burn injury intent data in many parts of the world, either through collection of new data, or increasing the accessibility of existing data.

When establishing a new data collection system, it is important to ensure there is a process in place to ascertain all cases of interest. This ensures that selection bias is minimised in any analyses using the data [142]. Understanding which patients are included, and which may be systematically missing from a data set, is crucial to ensure accurate inferences are drawn from the data. Chapter four utilised process mapping as a method to improve case capture and understand which patients may be missed in a newly established self-harm register at two hospitals in south India. It addressed the third thesis objective, which was to develop a method to improve case ascertainment of new and existing hospital-based surveillance systems that include burn injury intent data.

Self-harm registers could be an important source of intent data for burn injury surveillance. The studies from chapters two and three showed that current burn injury intent data is primarily collected from patients admitted to hospital with a burn injury. This is likely to lead to underestimation of the true burden of burn injuries. It is thought that fewer than 10% of people presenting to emergency departments in the UK with a burn injury are admitted to hospital [339]. In the Netherlands, 95% of patients are treated in primary care, 3% in emergency departments, and only 1% are admitted to hospital [82]. It is understandable that burn registers usually collect data about patients admitted to hospital because they primarily exist to improve the care of severely injured patients. The function of a register determines where data is collected. For example, the International Burn Injury Database of England and Wales is designed to be used as a clinical tool to inform care of patients with injuries severe enough to require treatment by specialised services, so data are primarily collected from inpatients (chapter two) [83]. There is the option to collect data from outpatient services, but no data is collected from emergency departments. Capturing outpatient and emergency department care may become more important as the case-mix of burns shifts more towards lower severity injuries [288]. The greater case load of burn injuries in emergency departments and outpatient departments may make it untenable to collect the highly detailed data sets currently used by most burn registers.

Conversely, self-harm registers typically collate data from patients presenting to emergency departments because few are admitted to hospital [43, 230]. Capturing cases in an emergency department rather than inpatient ward increases ascertainment of hospital presenting cases of self-harm. But this can be challenging because patients may only remain in hospital for a short amount of time. The self-harm register described in chapter four included all patients with burn injuries due to the high likelihood of misclassification of injury intent in this patient group. Guidance for self-harm registers recommends collecting data on self-harm presentations from emergency departments [43]. Provision of emergency care is not ubiquitous internationally, so it cannot be assumed that all healthcare facilities will have a single point of entry for all patients presenting with self-harm [232]. This further complicates the development of a register case ascertainment strategy.

The process mapping study in chapter four showed that two geographically close hospitals in south India had differing emergency care systems with multiple points at which patients could gain care. The non-profit hospital has an emergency department, the government hospital has a casualty, and both offer open access outpatient departments. The study showed that there was no single point at which all cases of interest could be captured, meaning that patients meeting the register inclusion criteria needed to be identified from multiple sources and cross-referenced. Without doing so, register data would be prone to selection bias.

I am unaware of any other self-harm register studies that have described in this level of detail the routes to care and the impact that differing routes could have on case ascertainment. It is possible that the multiple routes by which patients can gain emergency care may not be explored in all studies of self-harm in South Asia. It has been consistently reported that South Asia has low rates of repeat self-harm, which is counterintuitive because it contradicts findings from many other areas of the world [225, 226, 260]. It is conceivable that selection bias could account for this finding.

There are intrinsic difficulties in capturing a diverse patient group continuously and systematically, especially as healthcare services evolve. Process mapping is well suited to register development because it allows detection of potential problems in their real-world context, allowing bespoke solutions to be developed. Anticipating problems and finding a solution are important to try to mitigate against an expensive register failing, or incorrect conclusions being drawn from data that could lead to patient harm [263].

### Objective four: Develop a method to better utilise existing high quality hospital based surveillance data that includes burn injury intent data

International injury surveillance guidance recommends that existing routinely collected data is appraised prior to establishing new data collection processes, as these may fulfil surveillance needs without the need to collect new data [11]. Little guidance exists on how to achieve this, or how to use modern digital methods to develop a reliable burn register from existing records. The study in chapter five was developed to address this research and service need. It included evaluating the quality of data, digitising handwritten notes, and quantification of error during the digitisation process.

Initially we appraised the quality of existing routinely collected data to ensure that resources were not wasted by digitising data that would not aid burn injury surveillance. Existing injury surveillance guidance does not include details about how users should decide whether data is of sufficient quality to justify digitising it (as opposed to moving straight to new data collection systems) [11]. We used a three-step process to assess quality of the data in the handwritten registers. Firstly, we reviewed the register books to check consistency in collection of data within and between books, and the relevance of the variables to injury surveillance. There was good consistency between books and minimal missing data. It became clear that the Burn Unit at KR hospital has consistently collected 20 variables, including five of the WHO minimum injury surveillance variables, for over 20 years without specific funding to do so [11]. This was an important finding because it suggests that it may be possible to systematically collect a small minimum burn injury dataset in low resource environments. All variables were found to be relevant to injury surveillance. Injury intent was one of the variables included in the data set.

Secondly, process mapping was used to understand the way data were collected and recorded, which gave some indication of the likelihood of selection bias and misclassification bias in the data. Discussions with burn unit staff suggested that data were recorded prospectively by the senior burn unit nurse at the time the patient arrived on the ward. Data were based on the inpatient record. Data were only recorded about inpatients on the burn unit, which is in line with other burn registers [85, 102]. In India, patients are able to choose which hospital they attend. This can affect the patient population that would be captured by the burn register. Studies have shown a patient preference for private hospitals due to a perception that government hospital staff are more likely to report burn injuries to the police [44]. This may skew the register population towards those who cannot afford private care.

Thirdly, we compared the number of presentations included in the casualty department register to the number of patients included in the burn register. 95.4% of patients were included the burn register. It was not possible track individual patients in each register (e.g. by hospital identification number). The similarity of the number of cases per month in each register suggested good case ascertainment by the burn register. This was further supported by detail gained from stakeholders during the process mapping exercise. Process mapping showed that most patients with a burn injury would present through the casualty department and be directed to the burn unit. Here patients are required to complete inpatient registration prior to admission on the burn unit. This incurs a fee of 200 rupees (approximately US\$2.50), which can result in some patients absconding prior to inpatient registration if they cannot afford the fee. Patients treated on a purely outpatient basis, and those who abscond prior to paying the inpatient fee, may account for the slightly lower number of cases included in the burn register. Numerical comparisons of register data with centrally compiled routine admission statistics are used by other registers such as the International Burn Injury Database of England and Wales, and the Multicentre Study of Self-harm in England. This is done as a sampling exercise to understand case ascertainment of the register compared to routine

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hospital admission data (e.g. Hospital Episode Statistic data) [236]. Such exercises have shown numerical differences in case ascertainment. Process mapping can provide additional detail to understand where differences arise. This is useful for describing sources of selection and misclassification bias. It could be used to provide detail on these factors in peer-reviewed publications as recommended by Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) and Reporting of Studies Conducted using Observational Routinely Collected Data (RECORD) guidance [122, 142].

Following this process of quality appraisal, the register books were digitised. This was done by scanning and saving of the digital files, manual entry of the data onto an online data entry platform, and then quantification of the level of error incurred during the digitisation process. Many national level burn registers manually input data into their database from patient notes [85, 279]. This is not dissimilar to the process we used, where data from scans of the handwritten burn register was manually entered into an online form for each patient. Manual data entry is time consuming, but the heterogenous nature of patient notes means that it is difficult to automate data extraction. We attempted to use optical character recognition software to convert the scanned handwritten register files into digital text that could then be transferred onto a spreadsheet. The variability in handwriting meant that this was unsuccessful. Natural language processing offers a promising method to retrospectively extract register variables from unstructured digital patient notes [340]. Natural language processing cannot be used on scans of handwritten notes, so it has limited applicability in systems that do not have electronic patient records.

Manual data entry can introduce error into a register database. Verification procedures can mitigate some of these errors [98]. It is important to minimise human error during data entry. We tried to achieve this by using validation parameters (e.g. limiting age that can be entered to 0-120 years), mandatory completion of all questions, as well as practical techniques such as keeping checks of which records had been completed. Once data has been entered it can then be verified. This can be done through double data entry or proofreading. Double data entry requires each patient record to be entered twice. It was not used in this study due to resource constraints and concerns that human errors could be made twice. Instead, proofreading was chosen as the method of verification. During first pass verification, register scans were compared to the online form for every patient. During second pass verification, a random sample of 15% of records were checked by a second researcher with no prior involvement in the digitisation process. Our process of scanning, quality checks, and double verification resulted in a very low estimated error rate of 6 errors in every 10,000 fields

(0.06% per field). Other register studies have shown rates of 0.5-26.9% per field, which could act as a signification source of bias in analyses [271, 272, 283].

This study addresses an important need, namely to develop a method to better utilise existing high quality hospital-based surveillance data that includes burn injury intent. Our results suggest that this process can achieve error rates lower than registries that input data directly into an electronic database. We estimated that appraisal of data quality and digitisation could be completed on less than 50% of the time of a full-time junior clinician. This could be a viable method to better utilise existing hospital-based data that includes information on injury intent for surveillance purposes.

The results are likely to be of interest those with existing burn registers. Epidemiological studies of burn injuries are frequently published in peer reviewed journals. These studies often do not describe digitisation of data in sufficient detail to enable the strengths and limitations of the data set to be fully appraised [159, 281]. The methods used in chapter five would enable data processes to be described in sufficient detail to comply with STROBE and RECORD guidance.

### Objective five: Explore recording practices and patient groups that may be at risk of misclassification using existing injury intent data

Chapters two to five focus on methods to improve data quality and quantity to strengthen international surveillance data on burn injury intent. These methods can be employed during routine data collection prior to collation and analysis. A well-rounded strategy to improve differentiation of burn injury intent should include methods used during data analyses as well. This was addressed in chapter six. We used burn register data collected by the methods described in chapter five to explore recording practices and patient groups that may be at risk of misclassification of injury intent.

There are many examples of burn injury studies that describe statistically significant features associated with different types of intent. The aim of this is to help clinicians identify the features most predictive of different classifications of intent. The potential effect of misclassification or missing intent data on these results is rarely explored. This is despite recognition that error can occur in the classification of burn injury intent from multiple sources including the patient, their relatives, the healthcare professional, or coder [45, 293]. For example, Mushin et al. [341] compared patients with self-inflicted and non-intentional burns at a regional burn centre in the United States. They found statistically significant differences in age, gender, previous psychiatric history, and mechanism of injury between groups. They conclude that "this demographic data can inform clinicians regarding risk factors for self-inflicted burns. There is an interplay of factors such as

gender, psychiatric illness, employment status, and marital status. These variables may increase the likelihood of self-harm by thermal energy." Yet in the article they fail to describe how intent was determined, or the risk of misclassification of intent. Similarly, Vetrichevvel et al. [342] compared patients with intentional and unintentional burns from a health administrative database of patients in Western Australia. They found statistically significant differences in gender, age, race, social deprivation, rurality, and mental health status between groups. Burns were classified as intentional if they had ICD-10 codes for self-harm or assault, otherwise they were assumed to be unintentional. This is a major limitation of their analysis for two reasons: external cause codes may be incomplete, which would results in overestimation of unintentional burns [343]; or external cause codes may be inaccurate, which could lead to over- or under-estimation of each group [344]. Siddiqui et al. [159] used data from the Pakistan National Emergency Department Surveillance program to compare characteristics between patients with intentional and unintentional burns. They compared demographic and burn injury characteristics, finding statistically significant differences between patient groups for body part injured and emergency department disposition. They found higher percentage of intentional burns in men, which the authors did not expect as many other studies have reported more women with intentional burns. They suggest that this may be due to women not being supported to seek care following an intentional burn. Misclassification of injury intent is not discussed as a possible cause for this discrepancy. Similarly, intent data was missing for 24% of patients. The reason for the missing data is not discussed and characteristics of the patients with missing data is not explored. There is enough data presented in the paper to calculate that intent data is missing for 30% of women, but only 19% of men. This may account for the described differences in intentional burns.

Misclassification and missing data can affect traditional inferential statistical techniques (e.g. t-tests, regression analyses) and may invalidate results. For example, a study that fails to find a statistically significant relationship between burn injury features (e.g. gender, TBSA) and a classification of intent (e.g. accident) may be because the group included cases that are from a different classification of intent (e.g. suicidal). Strengthening differentiation of burn injury intent using data analysis methods, therefore, requires a less confirmatory approach and acceptance that the intent variable may be unreliable in some cases.

There is an increasing emphasis on utilising exploratory techniques for large routinely collected data sets to classify or predict outcomes. Popularised by John W. Tukey's 1970 book of the same title, exploratory data analysis is a means to examine data without preformed hypotheses or inferential goals [345]. Tukey encourages use of simple summary statistics and graphical methods to explore

patterns in data to learn about the population from which the data was collected [346]. This has become easier with the advent of open access software like RStudio, which allows easy manipulation and summary of large data sets [134]. Increasingly easy access to large data sets and advancement in computational techniques has led to a great deal of hyperbole over the potential of 'big data' and the application of 'artificial intelligence' for exploratory data analyses. This is also known as 'unsupervised machine learning' or 'deep learning'. For example, the NHS has invested £123 million over four years to accelerate artificial intelligence technologies in health and social care in the belief that this will help to meet aims set out in the NHS Long Term Plan [347]. Projects include identification of skin cancers, MRI and CT scan interpretation, and mammography assessment [348]. The hyperbole often overshadows discussion of data limitations and the reliability of inferences drawn from flawed data. Indiscriminate use of biased data has the potential to worsen health inequalities [349]. Exploratory analyses can be powerful in understanding outcomes, providing that the strengths and limitations of the fundamental data are well understood [350, 351].

In chapter six we describe how we used an exploratory data analysis approach to understand burn register data, particularly with respect to intent information. We used basic summary statistics and transparent graphical methods to look at the distribution of data. We then looked for deviations from the normal distribution that may be indicative of misclassification. This approach has been used to identify measurement bias in continuous variables like self-reported age (known as ageheaping), and clinician reported results like breast cancer diameter [309, 352]. Inaccuracies in which have been attributed to the phenomenon of digit preference, where peaks in values are found at 'zero' and 'five' (with no physiological basis), suggesting rounding by the individual responsible for recording the value [308]. Identification of misclassification in categorical variables like intent is not as straightforward because there is no known distribution. Instead in this paper we examined the distribution of variables in relation to each other as the starting point for trying to identify misclassification. Discerning patterns in the data is unlikely to lead to the identification of misclassification of the features that may indicate misclassification in the population under study.

We found that intent information was the most commonly missing variable in the data set (12.6%), suggesting that it is a problematic variable. Other studies have shown that women with missing intent data may later go on to report their burns are due to self-harm or interpersonal violence [161]. Intent data was missing for approximately equal proportions for men and women. We found that there was a secondary peak of high total body surface area (TBSA) burns (i.e. over 80%) in women with missing intent data. This corresponded with the peak TBSA for burns classified as

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"suicidal" in women. It is possible that female patients with high TBSA burns and missing intent information had burns due to self-harm, and are currently misclassified in the data.

There were approximately the same proportion of "accidental" and "suicidal" burns in men and women, but a greater proportion of "homicidal" burns in women (60.6% vs. 39.4%). We found that there was a relative reduction in the number of "suicidal" burns in women since 2020, but a corresponding increase in those classified as 'other'. There was a secondary peak in high TBSA burn injuries in the 'other' group similar to that seen in "suicidal" injuries. International morbidity statistics and research studies have shown higher rates of burns due to self-harm in women than men [35]. Our study showed a roughly equal split between genders. It is possible that some burn injuries in women in our data set that are currently classified as 'other' are actually due to self-harm.

We found that other elements of causation were sometimes recorded instead of intent (e.g. thermal injury, electrical injury). This is consistent with findings from the data dictionary review study in chapter two and systematic scoping review in chapter three. In the review in chapter three, we found that intent and mechanism may be combined or, particularly for 'accidental' injuries, used interchangeably. Some studies included used terms indicating activity when injured (e.g. industrial) as a proxy for unintentional injuries, but it was not clear from the methods whether intentional injury had been considered. Injuries due to self-harm do occur in the workplace, so unintentionality should not be assumed [208, 209]. These findings further support the need for a common data element for intent, and the response options should not include other elements of causation. This may improve the reliability of data.

Intent variable information had been crossed out and overwritten for 1.5% of cases. These data showed a greater proportion of females, burns that were "suicidal" or "homicidal", and higher median TBSA compared to the group in which intent was not overwritten. Discussion with clinicians on the burn unit revealed that documented intent was based upon what the patient reported. This could only be changed if the patient requested it and agreed to engage with medicolegal processes. It is likely that overwriting of injury intent reflects instances in which the patient has changed their account of the injury. This is a potentially very useful finding to help estimate misclassification in a data set and features that might be consistent with misclassification. The reasons for a change in reported and documented burn injury intent has been explored in other research. Qualitative research has shown that women may admit a burn is intentional after receiving care and support from their natal family [45, 74]. A woman's natal family may not be present when she initially arrives at hospital because she is likely to live with, and thus be brought to hospital by, her affinal family.

This means that the first statement about injury intent taken on arrival (and recorded in the burn register) would need to be changed.

From the literature it may be expected that the direction of change would be from unintentional to intentional injury categories. Our analyses revealed that when intent was overwritten, the direction of change was not consistent. Some cases changed from unintentional to intentional, and others from intentional to unintentional categories. We found that 10 of the 21 overwritten cases changed their reported injury intent to "accidental". This group showed the greatest difference in median TBSA. It was 82.5% for the overwritten group, and 22.5% for the group that wasn't overwritten. This is more consistent with TBSA of "suicidal" injuries, and may indicate that these injuries are misclassified. It is clear that, in this context, intent is prone to differential misclassification bias - the effect of bias (either towards or away from the null) is not predictable for inferential analyses.

It is important to note that in the context of this register that 'intent' was documented based upon what the patient or family reported, not clinical suspicion of the cause of the injury. This is due to medicolegal requirements placed upon the clinician. Consequently, some may consider the term 'intent' to be a misnomer in this context. It is not mens rea – the degree to which an individual planned to inflict death either on oneself or another. Instead, it relates to who, if anyone, inflicted the injury. It is for that reason that the terms "suicidal" and "homicidal" are used rather than finer grade distinctions like non-suicidal self-injury, suicidal self-injury, assault, attempted homicide, etc. The data in this register refers to who completed the act as follows: "accidental" means no one was responsible, "suicidal" means the patient did it to themselves (with no judgment about their desire to die), and "homicidal" means someone else did it to the patient (with no judgement about the desire of the person to inflict death). For example, if a female patient reported the cause of her injury to be a "stove blast", then this would be recorded as "accidental". This is consistent with findings from the articles from South Asia described in the systematic scoping review in chapter three, where data rarely included clinician impression and do not include finer grade distinctions of intent. A better term than 'intent' in the context of surveillance might be 'agency', but intent is the most commonly used term in surveillance literature, meaning that the label cannot be changed. This research highlights what is really meant by 'intent' and the response options used in this burn register and others (as discussed in chapters two and three). Understanding 'intent' in the context of its intended pragmatic clinical application helps in understanding the utility of the data, and ways to improve its accuracy and reliability.

Assessment of *mens rea* is an inherently legal concept, and doctors in India are discouraged from making such judgements. Assessment of who was likely to be responsible for the injury is more straightforward than finer grade distinctions. This has an empirical clinical grounding. At an individual level, it is likely to be relatively safe to send a patient home who has a burn injury due to self-harm because in South Asia there is evidence of low rates of repeat self-harm and suicide after non-fatal self-harm [226]. However, if that injury has been caused by another person in the household, then the patient could be at risk of serious future harm by being sent home. The distinction between suicidal self-injury and non-suicidal self-harm, and assault and homicide, is not as important as the overall distinction between a self-inflicted injury and an injury caused by someone else. Misclassification at that level has the potential to negatively affect individual patients and the wider population.

At a population level, accurate data on the distribution of intentional and unintentional injuries is essential to develop and evaluate preventative interventions. The WHO World Report on Violence and Health [50] recommends use of hospital surveillance data for morbidity data to describe the scale and impact of self-harm and inter-personal violence, the factors leading to these injuries, and to evaluate preventative interventions. Population interventions can be implemented at different stages of the injury cycle (i.e. primary, secondary, and tertiary prevention), for different at risk groups (i.e. universal, selected, indicated), and be delivered at different levels (i.e. local, national, global) (Table 27) [50].

Aspects of preventative interventions	Definition
Preventative intervention type by	
injury stage	
Primary	An approach that aims to stop an injury before it occurs.
Secondary	An approach that aims to identify an injury early and stop the
	immediate sequalae (e.g. access to emergency care).
Tertiary	An approach that aims to stop the long term sequalae of an
	injury (e.g. rehabilitation).
Target population	
Universal	Approaches that aim to reach the general population (i.e. no
	assessment of individual risk).
Selected	Approaches that aim to reach those with some risk factors for
	an injury (e.g. women).
Indicated	Approaches that aim to reach those who have already
	sustained an injury (e.g. previous self-harm)
Level of intervention	
Local	Approaches initiated and implemented at a local level (e.g.
	community action).

**Table 27.** Definitions for aspects of preventative interventions by injury stage, target population, and level of intervention. Adapted from the WHO World Report on Violence and Health [50].

National	Approaches initiated and implemented at a countrywide level
	(e.g. laws).
Global	Approaches initiated and implemented at a multinational level
	(e.g. World Health Assembly Resolutions).

For example, data from a local hospital surveillance programme in India showed that 50% of burns were due to unintentional injuries from kerosene lamps in the home [353]. This led to a locally initiated primary prevention programme targeting households in rural areas that used kerosene lamps. These lamps were replaced with LED or solar-powered lamps, which would not cause ignition of clothing when falling onto the floor. However, a community survey completed to evaluate the programme suggested a much lower incidence of flame burns from kerosene lamps in preceding years than in the hospital data. The authors concluded that it was possible that patients provide a "false history" when hospitalised with a burn, which leads to misclassification in the hospital data. If this is the case, then a different intervention may have been more appropriate.

Data may also be used to implement and evaluate national level interventions. The National Suicide Prevention Strategy for India includes an indicated tertiary prevention strategy objective, which is to build capacity to provide psychosocial support for those who have attempted suicide [354]. The evaluation measure for this objective is the "number of people who attempted suicide/bereaved provided with regular contact" [354]. In order to appropriately plan psychiatric and psychological services, accurate data on the number of presentations will be required. However, the only nationallevel data on suicides is from the National Crimes Record Bureau, which is thought to under ascertain cases because of misclassification [355, 356]. Greater use of hospital-based surveillance is likely to be required to plan and evaluate these interventions. These examples highlight the need for accurate and reliable intent data from hospital-based injury surveillance systems. Without such data, scarce resources may be allocated inappropriately.

Little work has been done to try to identify misclassification of intent in existing burn injury data. Our results show that exploratory analyses can be used to as a first step to identify possible misclassification of injury intent, but it does not provide a full solution to the problem. We have identified groups that might be at risk of misclassification bias and should be the focus of future research (e.g. women with high TBSA burns). We have found that overwriting of intent may be a useful predictor variable for identification of high-risk groups. There is no gold standard for the assessment of injury intent, and it may not be possible to develop a single measure that accurately assesses intent in hospital-based surveillance systems. Instead, a more probabilistic approach may be required to identify inconsistency in recorded intent across multiple measures such as comparing patient reported intent to clinical certainty in the patients' reported injury intent. Evaluation of the validity of such measures is required. This study also supports earlier findings about the need for a standardised way to record intent in order to improve reliability of data. This could be through the creation of a common data element for intent that is accepted and implemented widely in the burns community.

#### **Strengths and limitations**

An overall strength of this work is that it considers a broad range of factors that can be addressed to improve morbidity surveillance data on burn injury intent internationally. These factors were considered at multiple levels of surveillance from high level data sources such as intercountry burn registers, down to individual hospital-based data collection. The results from this body of work are directly applicable to public health and healthcare. Findings have the potential to influence change that can lead to improved outcomes for patients and the public. They will inform future areas of research for patient and public benefit.

The studies in each chapter addressed a recognised, but neglected, research need that required an innovative approach. Methods used in chapters two (data dictionary comparison project), four (selfharm register process mapping), and five (burn register digitisation) were novel. They have been described in sufficient detail to allow them to be replicated or transferred to other settings. This increases the likelihood that this novel work can have a positive impact beyond academia. The analysis of burn register data described in chapter six was the first I am aware of to explore recording of injury intent and possible misclassification. This has identified patient groups that may be at risk of misclassification and should be the subject of future research. Results from each study synergises with studies from other chapters offering greater evidence on how surveillance data on injury intent can be strengthened. The systematic review in chapter three provided much needed information on injury intent terminology and methods in South Asia. This closely mirrored the detailed variable extraction from the data dictionaries in chapter two. When combined, these data enable a better appreciation of injury intent variable data availability and comparability internationally. Methodological rigour was paramount to all studies. Chapters two (data dictionary comparison project) and three (systematic scoping review) followed published protocols with minimal deviation in implementation. Any deviations were reported in the results manuscripts. Where possible, protocols or findings were reported according to recommended guidelines from the Enhancing the Quality and Transparency of Health Research (Equator) network [273].

There are some limitations that apply to individual chapters and others that apply the overall body of work. 88% of articles included in the systematic scoping review in chapter three are from India and Pakistan. Grey literature was not included in the searches due to the large number of research studies meeting the inclusion criteria in the preliminary searches. Searching grey literature may have provided more studies from locations other than India and Pakistan. The greatest age-standardised incidence of burn injuries across both sexes is in Afghanistan (531.52 per 100,000 population) (rank order: Afghanistan, Sri Lanka, India, Nepal, Bhutan, Maldives, Bangladesh, Pakistan) [35]. However, two thirds of these were sustained during conflict. Articles that included only burn injuries sustained during combat were excluded because the concept of intent during armed conflict is distinct from intent during peacetime. This means that some relevant data may have been inadvertently excluded, particularly from Afghanistan. Our findings may have less relevance there than in India and Pakistan.

In chapter four, process mapping was used as a key method to understand patients with self-harm injuries who present to hospital and flow through hospital systems. It was used to develop a self-harm register case ascertainment strategy that would minimise selection bias. The extent of cases that might be missed from areas such as the outpatient departments, private wards, and other hospital facilities were not evaluated numerically. If hospital processes were followed exactly, patients should be referred to the casualty medical officer for inclusion in the medicolegal register. These cases would then be captured in the self-harm register. But clinicians reported examples where patients did not follow these procedures. Interviews with clinicians suggest that those with more minor injuries are likely to present to outpatient departments, which is likely to skew the self-harm register data towards more severe presentations.

During the analyses of burn register data described in chapter six we found that age and TBSA were often rounded to five-unit intervals. This would introduce misclassification bias into analyses using these variables. Digit preference is recognised to occur in several clinical settings where individuals are relied upon to provide clinical data including self-reported age, smoking rates, emergency department waiting times, and birthweight [307, 352, 357-359]. It has been used to detect data fabrication in clinical trials [360]. This type of bias can be identified when there is a difference between the reported and expected distribution of values. Digit preference gives some insight into the pervasiveness of misclassification bias in routinely collected data. It is paramount though to consider and develop methods to tackle misclassification for all variables, not just those that are straightforward to identify. This was the starting point for the intent variable analyses in chapter six, which will be developed further in future work.

These analyses used six years of register data from the burns unit in KR hospital, Mysore. Preliminary work completed before the COVID-19 pandemic suggested that the register had been completed systematically and prospectively since 2001. This would have represented one of the largest routinely collected datasets of burn injuries in India. Unfortunately, changes to medical records staffing during the COVID-19 pandemic meant that it was only possible to retrieve six years of register books. Analyses in chapter six, particularly those investigating changes over time, would have been strengthened by having additional years of data.

The studies in chapters two, four, five, and six are primarily concerned with register data. Clinical registers are an important source of surveillance data. Other routinely collected data sources, such as admission and insurance claims data, can be used for surveillance. Registers have some advantages over admission and insurance claims data. They have been shown to achieve greater case ascertainment, and they are likely to include a wider range of variables that can be used in analyses [236, 361]. Clinical registers can allow the collation of tailored outcomes data required for primary, secondary, and tertiary prevention. Conversely, admission and insurance claims data are more likely to be tailored to billing or management requirements. This means that clinical registers are more useful for answering clinically important research questions, more able to minimise bias, and collect more data on possible confounders. Identification and measurement of confounders in observational data is important for causal analyses [362]. Lack of randomisation in observational data means that confounders are unlikely to be evenly distributed between groups, so can account for an apparent association if not adequately controlled for during analyses. Another limitation of focusing on clinical registers is that these data primarily include hospital presenting burn injuries. Patients seek care for burn injuries in community settings, or, in remote areas, where there may be no healthcare provision [82]. Strengthening surveillance data on burn injury intent in these settings has not been considered in this thesis.

Although clinical registers provide a useful source of systematically collected data, they may duplicate data that is being collected elsewhere (e.g. patient notes). Manually collated clinical registers will become obsolete if healthcare services achieve fully standardised digital health records allowing data extraction to be automated, effectively achieving a "real-time registry" [363]. Healthcare digitisation is progressing more rapidly in high-income countries. Targeted strategies are required to help integrate electronic health records into healthcare service provision in low- and middle-income countries in order to mitigate widening of data inequities [364]. The work in chapters three, four, and five are directly targeted at addressing these inequities.

Inequity in surveillance data on burn injury intent is an issue for many low- and middle-income countries globally. The majority of burn registers included in the data dictionary comparison project described in chapter two are from high-income countries. The World Health Organization Global Burn Register, and pilot registers from countries without an existing national register, were invited to participate in the study to try to capture variables that are pertinent to burn prevention and care in low- and middle-income countries. Operational differences for burn registers were not explored. This could provide insight into factors that limit the collection of national level register data in lowand middle-income countries. Chapters three to six focus on South Asia. This region is believed to have the highest number of burns due to self-harm and other forms of violence. It was chosen for pragmatic reasons because it is a region where our research team had pre-existing links, and there was a program of work in progress to improve surveillance data on self-harm. Other regions with a high proportion of low- and middle-income countries have a significant burden of burn injuries. Burns due to executions and police conflict disproportionately affect sub-Saharan Africa, and burns due to conflict and terrorism disproportionately affect the Middle East and North Africa [35]. Neither have been addressed in this work. Findings from this thesis are, however, likely to be of interest to practitioners, policy makers, and researchers wishing to establish their own surveillance systems. Much of the work presented in this thesis is already published and available open access [1, 3-6]. Papers that are currently submitted for publication are likely to be published open access as well. Although not presented as part of this thesis, the knowledge gained from this work has enabled personal contributions to a number of global burn injury workstreams including: updating the World Health Organization Global Burn Registry guidance document and website; providing advice to emerging burn related registers in Australia and Canada; and working collaboratively with burn professionals as part of the International Society for Burn Injuries Prevention Committee to reduce violence against women [365].

Finally, this work has been conducted using an explicitly epidemiological and medical perspective. The views of patients and the public have not been explored. The consequences of burn injuries and support options available to patients who have sustained intentional burn injuries have not been explored. This must be incorporated into future work. For example, the method of assessment recommended as part of the development of a common data element for injury intent must be acceptable to clinicians and not put patients at risk of further harm. The results of this, and future, work have the potential to inform care pathways for patients with intentional burn injuries. This is likely to include safeguarding options that consider the potentially deleterious effects of medicolegal requirements on patient safety, as well as care options that healthcare professionals can provide.

#### **Future work**

The body of work in this thesis lays the groundwork for future research to strengthen morbidity surveillance data to improve differentiation of burns that are: unintentional; due to self-harm; or due to interpersonal violence.

A recurrent issue highlighted in this thesis is the lack of standardisation used in existing systems that collect injury intent information. This is likely to lead to differences in the way intent is assessed between users, institutions, and registries, which can lead to biased data. Use of a common data element for burn injury intent could reduce the risk of misclassification bias by improving reliability and accuracy of data on intent. Common data elements (CDEs) typically include a standardised prompt, unit of measure, and set of permissible values [153]. Based on the findings in this thesis, we have also suggested that definitions and method of assessment are included in burn injury CDEs to further increase standardisation. Most studies focus on the benefits of CDEs for interoperability of databases, allowing comparison of large data sets [153]. Little work has been done to understand if CDEs improve reliability and accuracy of registry data, which is an area for future research.

The international collaboration established for the data dictionary comparison project in chapter two would be well placed to complete consensus work on standardising burn variable data collection through the creation of CDEs. I plan to propose to this group that we conduct a Delphi study to develop CDEs that can be used for an international minimum data set for burn injuries. The majority of custodians in the current collaboration are from registers in high-income countries. It will be important to include stakeholders from low- and middle-income countries to ensure that the variables serve all partners and do not contribute to widening health inequalities globally. Teams that collate international morbidity surveillance data such as GBD and WHO will be invited to participate in this work.

It is likely that intent will be included in a CDE minimum data set for burn injuries. If so, it will provide a platform to reach international consensus on definitions and methods of assessment for intent. A valid method to assess burn injury intent is essential to ensure accuracy of the data. Face and content validity of the method will be addressed through the Delphi study. There is no gold standard for the assessment of burn injury intent in hospital, so a traditional assessment of criterion validity will not be possible. Change in reported injury intent (e.g. overwriting of intent) may provide a useful measure of predictive criterion validity. Use of multiple measures of intent (e.g. patient report, change in patient report, clinician impression, exploratory analytical techniques) will provide an insight into convergent construct validity. Reliability of a CDE for intent would also need to be evaluated. Internal reliability of a CDE may not be possible in the context of a minimum data set where the aim is to minimise the number of variables as much as possible so that there is no duplication. Reliability could be evaluated by test-retest to assess the stability of the results from the CDE over time, and by calculation of inter-rater reliability (e.g. kappa statistic) across individual observers and institutions.

ICD external cause codes may provide a useful starting point for the development of a CDE for injury intent. They include specified units of measure and a set of permissible values. It is not clear why ICD codes are not used more widely in burn registers. This might be because training is required to accurately use the codes; it may be that registers were not set up with the aim of comparing data across databases; or it may be because those setting up the register were unaware of ICD external cause codes [49]. The utility of ICD codes could be enhanced through inclusion of definitions for response options (classifier terms), and a recommended method of assessment for the clinician and person completing data entry. Making ICD codes more user friendly may enable them to be incorporated into burn registers. Burn register data is not currently used in GBD estimates, but use of ICD codes would help to facilitate international data comparisons [personal correspondence with GBD injuries team].

The term intent has been used throughout the thesis because it is commonly accepted in the injury surveillance literature [41]. In this context, it tends to encompass both who inflicted the injury and the envisaged consequences of the act [10]. The term 'intent' has legal connotations. In British law, it is associated with *mens rea*, the conscious planning or negligence that leads to a crime [366]. A criminal offence usually requires both *actus rea*, a criminal act, and *mens rea*. In some countries, there are requirements for clinicians to report acts of self-harm or assault to the police. Such requirements can affect the accuracy of data provided by patients and recorded by clinicians. Additionally, accurate assessment of why the act was completed can be particularly challenging in the acute hospital environment where the patient may be unsure of underlying motives. This results in biased surveillance data and may limit support options that can be provided to patients. For these reasons, data collected in hospital by clinicians should not include determination of who is to blame for an act. This is the role of the law and/or any coronial system. Instead, hospital-based surveillance should focus more on the circumstance surrounding the injury and who is likely to have inflicted the injury. A more appropriate term for this might be 'agency'. It will be important in any future work

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to standardise collection of intent data, that the underlying concept being measured (i.e. who did the act that resulted in the burn injury, not their underlying motives) is made explicit such as through definitions and the method of assessment.

One might argue that healthcare professional should not be responsible for collection of data on injury intent. This risks further compartmentalisation of domain knowledge and may inhibit interdisciplinary collaboration to address the overlapping upstream causal factors in the injury event [41]. Different categories of injury intent already receive input from different professions. For example, a psychiatric team may be involved in the care of a patient with self-harm, but a patient who is the victim of assault is more likely to have the police involved during their hospital care. Separate academic disciplines have developed that research unintentional injuries, self-harm, and interpersonal violence. At an individual patient level, interaction with healthcare services can be a rare opportunity for violence to be recognised and addressed (e.g. human trafficking) [149, 367]. Surveillance data on injury intent collected by healthcare professionals can help to highlight the close relationship between intentional and unintentional injuries, and wider determinants of health. Strengthening intent data is an essential part of a public health approach to injury prevention.

Further qualitative inquiry is required with clinicians and patients to understand how data on assessment of intent could be improved, and what would be feasible to collect in different countries and cultures. Preliminary analyses of interviews I have conducted with different healthcare professions at two hospitals in south India suggest that emergency medicine doctors are restricted by medicolegal process to document only what the patient or family report. Psychiatrists, however, are more likely to enquire about the intended consequences of an act and to document their clinical impression. Full analysis of the data still needs to be completed. Full international standardisation the assessment of injury intent may not be possible due to legal reporting requirements. Other measures identified in this thesis that might indicate misclassification include clinician suspicion that the injury is intentional, or whether the clinician believes that the pattern of injury matches the reported injury mechanism. It may be possible to collect these data as proxy measures for responder bias.

Another important future area of research is the development of a model to investigate misclassification of burn injury intent in existing data sets. One approach would be to remove intent variable data from analyses, and then use exploratory analysis methods to investigate groupings based upon other shared characteristics. This type of analysis is known as cluster analysis. It has become a popular method to reveal potentially meaningful clinical groups in large data sets [368].

One suitable option for investigating misclassification of intent would be latent class analysis, which uses groupings of variable responses to classify individuals into mutually exclusive groups. The clinical meaningfulness of the model could be further enhanced through development of a directed acyclic graph to identify all variables that are likely to be causally linked to a certain classification of intent. This might include age, sex, education, access to means, time of admission, burn size, family conflict, etc. A directed acyclic graph can help to identify confounders, missing data in the model, and likely sources of selection bias [362]. This allows model refinement in the future as new methods to measure variables are found. Using a causal approach in the development of a prediction model is advantageous because predictor variables have a quantifiable link to the predicted outcome [369]. Comparison of recorded injury intent with latent classes may then provide further insight about misclassification (Figure 30). There is interest from the GBD study to refine their estimation models in regions with low availability of injury intent data [personal discussion with GBD injuries modelling] team]. This approach will initially be tested using the register data from KR hospital, Mysore (data set used in chapter six). A greater number of variables have been measured as part of the SASHI self-harm register that was described in chapter four. These data may include more of the predictor variables and confounders. This data set may be useful for testing or refining the model.

**Figure 30.** Example of variables that might be used to construct a latent class model on burn injuries. The probabilistic result at the end shows how the intent variable might be distributed between groups if it was overlayed after the model had been developed.



There is considerable international expertise in establishing and maintaining burn registers. Guidance exists for establishing self-harm registers and general injury surveillance systems, but there is no guidance specific to burn injuries. Development of a manual that shares best practice experiences would benefit the burns community, particularly countries that do not have national level burn morbidity surveillance systems. The work from this thesis would be of use for sections about standardisation of variables, development of a case ascertainment strategy, utilising existing routinely collected data, and data analyses.

Finally, many of the methods presented here could be applied to other injury types, other clinical registers, or other complex variables. There are multiple areas of future research that these methods could inform:

- National clinical registries in other disciplines that wish to embark on international data comparisons may wish to use the methods described in chapter two to compare data dictionaries. This will provide an overview of the population covered by existing registers internationally and risk of bias if data were compared in their current format. This is useful to inform the approach for future data comparisons.
- Published research data may provide an alternative source of surveillance data for injury causes, treatment, and outcomes. Before completing aggregated analysis of these data (e.g. through a systematic review), it is important to understand how comparable the data are. The methods described in chapter three provide a useful roadmap for comparing terminology, definitions, and methods of assessment for a clinically important variable in published research studies.
- Ascertainment of all cases of interest is essential for a clinical register. Processes should not be assumed to be ubiquitous between countries and institutions. The process mapping methods described in chapter four can be used when establishing a case ascertainment strategy for a new register, or to explore sources of selection bias in an existing register.
- Data inequity between high-income countries, and low- and middle-income countries exists across all domains of medicine, not just burn injuries. Handwritten routinely collected hospital data may provide useful local data prior to establishing a fully digitised system. The methods described in chapter five enable the quality of existing data to be assessed, as well as a method for digitisation such that the data can be analysed for epidemiological purposes.
- Clinical registry research is still dominated by interferential analyses. Exploratory data analyses are an important prerequisite of model development. The methods described in chapter six may be useful for other registry studies that wish to explore a specific variable believed to be at risk of misclassification bias prior to any inferential analyses.

#### Conclusions

This work has shown that international burn injury morbidity surveillance data has numerous areas that can be strengthened to enable better differentiation of burns that are unintentional, due to self-harm, or due to interpersonal violence. Factors that contribute to the utility of surveillance data were considered at multiple levels, from high level data sources such as intercountry burn registers, down to individual hospital-based data collection. Sharing of existing sources of burn injury intent data such as countrywide and intercountry burn registers could be improved. These primarily exist in high-income countries, so it is important to establish or make available data in low- and middleincome countries to reduce data inequities. Quality of existing data sources should be appraised, with particular focus on the risk of selection and misclassification bias. Process mapping was shown to be a promising method to understand and detail potential sources of selection bias for new registers. It can be used as part of a method to appraise the quality of existing data prior to resource allocation for digitisation. Misclassification bias is a pervasive problem in routinely collected data on injury intent. Multiple studies in this thesis showed that collection of these data requires standardisation. Development of a common data element for intent, including standardised definitions and method of assessment, may help to address this. There needs to be better description of methods of assessment of intent, and the definitions of stem and classifier terms, in published literature to allow appraisal of the likelihood of misclassification of this variable. This may enable interstudy comparisons. Exploration of existing data showed groups that might be at risk of misclassification. This will be the subject of future work, including development of models that might enable prediction of misclassification. The results of this body of work have the potential to directly influence patient care and public health. It is important to continue this work to take further steps to address the preventable causes of burn injuries globally.

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Appendices

Flow chart: Registers were partly identified from a systematic scoping review by Gus et al. [87].



# Table: Register responses to invitation to participate in the study. Registers listed alphabetically.

Burn Care Quality PlatformAmerican Burn AssociationAgreed to participateBurn Centres OutcomesDutch Burns Foundation and Association of DutchAgreed to participateBurn Model SystemBurn CentresBurn Model System National Data and Statistical CenterAgreed to participateBurns Registry of Australia and New ZealandAustralian and New Zealand Burn Association, and Monash UniversityAgreed to participateBurn Unit DatabaseDepartment of Hand Surgery, Plastic Surgery andAgreed to
Burn Centres OutcomesDutch Burns Foundation and Association of DutchAgreed toRegistry the NetherlandsBurn CentresparticipateBurn Model SystemBurn Model System National Data and Statistical CenterAgreed toBurns Registry of Australia and New ZealandAustralian and New Zealand Burn Association, and Monash UniversityAgreed toBurn Unit DatabaseDepartment of Hand Surgery. Plastic Surgery andAgreed to
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Burn Unit Database Department of Hand Surgery, Plastic Surgery and Agreed to
Burns, Linköping University, Linköping, Sweden participate
Care of Burns in ScotlandNational Managed Clinical Network, NHS NationalAgreed to
Services Scotland participate
Dutch Burn Repository R3Association of Dutch Burn CentresAgreed to
participate
German and AustrianNow part of the German Burn RegistryNot applicable
Pediatric Burn Registry
German Burn Registry/German Society for Burn Treatment (DGV)Agreed to
Deutsches participate
Verbrennungsregister der
DGV
Global Burn RegistryWorld Health OrganizationAgreed to
participate
International Burn Injury United Kingdom National Health Service Agreed to
Database         participate
Iran national burn registry         Burn Research Center, Iran University of Medical         No response
Sciences, Tehran, Iran. Custodian identified from a
recent publication.[370]
Japanese National Burn Japan Society for Burn Injuries Agreed to
Registry participate
Kenya Burn Repository         Pilot register collaboration between Vanderbilt         No response
University and AIC Kijabe Hospital in Kenya.
Custodian identified from a recent publication.[269]
Norwegian Burn Registry/ Norwegian National Burn Center, Haukeland Agreed to
Norsk brannskaderegister         Oniversity Hospital, Bergen, Norway         participate           Courth Asia Burry Desister         Dilet register colleboration between John Hendring         Asneed to
South Asia Burn Registry Pilot register collaboration between John Hopkins Agreed to
Bioomberg school of Public Health, USA; Centre for participate
National Institute of Purp and Plastic Surgery
Rangladachi Aga Khan University, Dakistani and Civil
Hospital Karachi Dakistan
Ilkraine Burn Registry         Dilot study in Lyiy province Ukraine Custodian         No response
identified from a recent publication.[371]

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

Appendix B consists of five tables. These include:

Table 1. A full list of all variables from the burn register data dictionaries that include information on injury intent. A spreadsheet was created for the variables that relate to each of the clinical concepts of patient age, timing of injury, injury intent, injury mechanism, inhalational Injury, infection, and patient death. These were included as a supplementary spreadsheet file in manuscript submitted to the journal Burns. Only the variables relating to the concept of injury intent is included in this thesis due to the size of the other spreadsheets.

Table 2. Comparison of variables from the burn register data dictionaries on patient age.

Table 3. Comparison of variables from the burn register data dictionaries on timing of injury.

Table 4. Example of how current injury intent variables could be mapped to a new common variable.

Table 5. Example of how current inhalational injury variables could be mapped to a new common variable.

Abbreviations used in the tables: INID, Information not in data dictionary; NA, Not applicable.

## Table 1. Injury intent detailed variable information. Transcribed from data dictionaries.

Register	Field label	Field description/definition	Format	Conditional on	Categorical response options	Measurement (method / guidance / timing)
Burn Care Quality Platform	Circumstances of injury	This field is used to indicate the circumstances of injury. Choose the term that most closely approximates the circumstances, as you know them.	Categorical	NA	9 options: 1. Accidental injury: employment related; 2. Accidental injury: non-employment related;3. Accidental injury: recreation (that occurs while performing a recreational (sport and fitness) activity (includes Camping)); 4. Accidental injury: unknown circumstances; 5. Suspected arson (the term arson refers specifically to the malicious burning of property. If an individual sets the patients house on fire, that is Suspected arson. If an individual sets the patient on fire, that is Suspected assault.); 6. Suspected assault/abuse; 7. Suspected self-inflicted; 8. Other; 9. Not known/not recorded.	Choose the term that most closely approximates the circumstances, as you know them. It is often difficult to determine the intentionality of the injury. It is up to the user (and treating physician) to determine whether the injury should be reported as such or as Suspected abuse. The ABA has intentionally listed this choice as Suspected Abuse to avoid legal problems with proof. 1. Medical record 2. EMS documentation It is often difficult to determine the intentionality of the injury. It is up to the user (and treating physician) to determine whether the injury should be reported as such or as Suspected abuse. The ABA has intentionally listed this choice as Suspected Abuse to avoid legal problems with proof. Note that the term arson refers specifically to the malicious burning of property. If an individual sets the patients house on fire, that is Suspected arson. If an individual sets the patient on fire, that is Suspected assault. If the accidental injury occurred during paid employment (Accidental injury: employment related), one additional data variables must be completed: PATIENT'S OCCUPATIONAL INDUSTRY.
Burn Care Quality Platform	Report of Physical Abuse	A report of suspected physical abuse was made to law enforcement and/or protective services. This includes, but is not limited to, a report of child, elder, spouse, or intimate partner physical abuse.	Categorical	NA	2 options: Yes; No.	<ol> <li>Medical record</li> <li>EMS documentation</li> <li>This includes, but is not limited to, a report of child, elder, spouse, or intimate partner physical abuse</li> </ol>
Burn Care Quality Platform	Investigation of Physical Abuse	An investigation by law enforcement and/or protective services was initiated because of the suspected physical abuse.	Categorical	Only complete when REPORT OF PHYSICAL ABUSE is Yes. In patients where REPORT OF	3 options: Yes; No; Not applicable.	INID

				PHYSICAL ABUSE is No, select the null value Not applicable.		
Burn Care Quality Platform	Primary ICD-10 External Cause Code	ICD-10 code used to describe the mechanism (or external factor) that caused the injury event.	Relevant ICD-10-CM code value for injury event	NA	NA	The primary ICD-10 code should describe the main reason a patient is admitted to the hospital. ICD-10-CM codes are used as the accepted reference in the U.S. at time of publication. MULTIPLE CAUSE CODING HIERARCHY - If two or more events cause separate injuries, an external cause code should be assigned for each cause. The first- listed external cause code will be selected in the following order: Child and adult abuse take priority over all other external cause codes. Terrorism events take priority over all other external cause codes except child and adult abuse. Cataclysmic events take priority over all other external cause codes except child and adult abuse, and terrorism. Transport accidents take priority over all other external cause codes except cataclysmic events, and child and adult abuse, and terrorism. The first listed external cause code should correspond to the cause of the most serious diagnosis due to an assault, accident or self-harm, following the order of hierarchy listed above. Data Source Hierarchy: EMS run sheet; Triage form / trauma flow sheet ; Billing sheet / medical records coding summary sheet; ED nurses' notes; Patient report.
Burn Care Quality Platform	Caregiver at Discharge	The patient was discharged to a caregiver different than the caregiver at admission due to suspected physical abuse.	Categorical	Only complete when REPORT OF PHYSICAL ABUSE is Yes. Only complete for minors as determined by state/local definition, excluding emancipated minors	3 options: Yes; No; Not applicable .	Not applicable should be used for patients where REPORT OF PHYSICAL ABUSE is No, or where older than the set/local age definition of a minor, or if the patient expires prior to discharge.

Burn Centres Outcomes Registry the Netherlands	Not included in data di	ctionary - Retrieved from DBR-R	3 via data linka	age if required for anal	yses	
Burn Model System	Circumstances of injury	INID	Categorical	NA	9 options: 1-Non-intentional employment related; 2-Non- intentional non-work related (if employment and recreation do not apply); 3-Non-intentional recreation; 4-Non-intentional unspecified; 5-Suspected assault-domestic; 6-Suspected assault-non domestic; 7-Suspected self-inflicted/suicide; 8-Suspected arson; 99- Missing/Unknown	Collected via medical record abstraction or self-report, depending on which is the better data source. Discharge form. Instructions: Fill out these items by using the information from the participant's medical record. This should be within 7 days (before or after) of when Form I is filled out with or by the participant. If for any reason an item is gathered by self report, indicate that on this form.
Burn Model System	Source of circumstances of data (self-report or medical record)	INID	Categorical	Circumstances of injury answered	3 options: 1-Medical record; 2-Self report; 3-Both medical record and self report.	Discharge form. Instructions: Fill out these items by using the information from the participant's medical record. This should be within 7 days (before or after) of when Form I is filled out with or by the participant. If for any reason an item is gathered by self report, indicate that on this form.

Burns	3.7 Activity when	The execution of a task or	Categorical	NA	21 options (two relevant to intent):-1 Not	Report the first appropriate code listed in the
Registry of	Burn Injury Occurred	action by an individual	Ū		stated/inadequately described Data not retrievable; 0 Sports	table which best characterise the type of
Australia		when the burn injury			activity_Physical exercise with a described functional element	activity undertaken by the person at the time
and New		occurred			such as: golf, riding, jogging, skiing, school athletics,	when the injury occurred
Zealand					swimming, trekking, water skiing.; 10_Leisure activity	
					(excluding sporting activity)_Hobby activities; leisure time	
					activities with an entertainment element such as being at a	
					cinema, a dance or party; participating in activities of a	
					voluntary organisation.; 11_Playing_An activity which is	
					enjoyed alone or with others, most commonly associated with	
					children activities; 20_Working for income_Paid work for	
					salary (manual) (professional), bonus and other types of	
					income; transportation (time) to and from such activities.;	
					30_Cooking/preparing food/drink_Unpaid duties involving	
					cooking and/or preparation of food or drink;	
					31_Cleaning_Unpaid duties involving cleaning;	
					32_Gardening_Unpaid duties involving gardening;	
					33_Household maintenance_Unpaid duties involving	
					household maintenance (excluding cooking, cleaning and	
					gardening – coded separately); 34_Other types of unpaid	
					work (specify)_Unpaid domestic duties, such as: caring for	
					children and relatives. Other duties for which income is not	
					gained, such as: unpaid work in family business.; 35_Near	
					person preparing food/drink_Injury sustained as a result of	
					being near a person who is cooking and/or preparing food or	
					drink; 36_Vehicle maintenance_Unpaid duties involving	
					vehicle maintenance; 40_Bathing_Bathing;	
					41_Eating/drinking_Activities related to eating or drinking;	
					42_Sleeping/resting_Activities related to sleeping and resting;	
					43_Other vital activities (specify)_Other vital activities not	
					elsewhere classified. This includes Personal hygiene and other	
					personal activity.; 50_Education_Formal education, learning	
					activities, such as: attending school session or lesson,	
					university, undergoing education.;	
					91_Driving/Passenger_Activities related to driving a vehicle or	
					being a passenger in a vehicle; 92_Self-harming_Intentional,	
					direct injuring of body tissue; 93_Suspected illegal activity_An	
					activity that is suspected to be prohibited or not authorised by	
					law; 99_Other specified activities_Other activity not	
					elsewhere classified.	

Burns	3.9 Intent when burn	Clinician's assessment of	Categorical	NA	10 options: -1 Not stated/inadeguately described Data not	Clinicians' assessment. The intent to produce
Registry of	occured	the most likely human	Ũ		retrievable; 1 Accident - injury not intended A specific,	the injury, not the intent to undertake an
Australia		intent in the occurrence of			unpredictable, unusual or unintended external action which	activity, which resulted in injury. The most
and New		the burn injury			occurs in a particular time and place, with no apparent and	appropriate option should characterise the role
Zealand					deliberate cause but with marked effects. It implies a	of intent in the occurrence of the injury on the
					generally negative outcome which may have been avoided or	basis of the information available at the time it
					prevented had circumstances leading up to the accident been	is recorded. 99_Other specified intent_Other
					recognised, and acted upon, prior to its occurrence;	intent not elsewhere classified. Includes
					2_Intentional self-harm_Intentional, direct injuring of body	injuries due to operations of war and injuries
					tissue most often done without suicidal intentions, but could	inflicted by the police or other law-enforcing
					still result in death; 3_Suspected Sexual assault_Suspected (or	agents, including military on duty, in the course
					confirmed) assault of a sexual nature on another person, or	of arresting or attempting to arrest
					any sexual act committed without consent.; 4_Suspected	lawbreakers, suppressing disturbances,
					maltreatment by parent_Suspected (or confirmed) child	maintaining order, and other legal action.
					maltreatment includes abuse and neglect of a child under the	Note: lack of supervision or unintentional
					age of 18 by a parent or caregiver, resulting in the child	neglectful behaviour (vs. intentional
					sustaining the burn injury. Note: lack of supervision or	maltreatment) should be coded here.
					unintentional neglectful behaviour(vs. intentional	
					maltreatment) is normally coded as accident; unless there are	
					exceptional circumstances where it can be coded as 'other	
					specified intent' (requiring further description); 5_Suspected	
					maltreatment by spouse or partner_Maltreatment includes	
					abuse and neglect of a person by their spouse or partner,	
					resulting in the patient sustaining the burn injury;	
					6_Suspected other and unspecified assault_Includes homicide	
					and injuries inflicted by another person with intent to injure	
					or kill, by any means. Excludes injuries due to legal	
					intervention or operations of war.; 7_Event of undetermined	
					intent_Available information is insufficient to enable a	
					medical or legal authority to make a distinction between	
					accident, self-narm and assault. Follow legal rulings when	
					available.; 9_Adverse effect or complications of medical and	
					surgical care_includes complications of medical devices;	
					correct drug properly administered in therapeutic or	
					prophylactic dosage as the cause of any adverse effect;	
					surgical and medical procedures as the sause of abnormal	
					reaction of the national or of later complication without	
					mention of misadventure at the time of the procedure:	
					accidental overdose of drug or wrong drug given or taken in	
					error - 99 Other specified intent	
Burns	3 9 99 Intent - Other	Other intent (not	Text	If Intent = Other		To further describe the intent when it does not
Registry of	5.5.55 mene	elsewhere classified)	<i>ick</i>	(99)		meet one of pre-defined values
Australia		cise there elaberriedy		(00)		
and New						
Zealand						

Burns Registry of Australia and New Zealand	3.10 Injury Event Description	Patient's personal account or description of injury event	Text	NA	NA	Briefly and concisely describe the injury event. Include: Location - specific location of the person at the time the injury occurred. For example, in the bathroom of own home, workshop or local shops. Activity - specific activity the person was undertaking at the time the injury occurred. For example, playing, working on a forklift or playing competition football Product - specific product involved in the injury (where applicable). For example, 50mls brand name X medicine: Safety Equipment - safety devices in use or absent at the time the injury occurred (where applicable). For example, wearing steel capped work bootsAdditional Information to Include - nature of the injuries; what caused the injuries (subject), any other relevant information.ExamplesRefer to the VEMD Business Rules: Injury Surveillance (3-115) for examples of how the Injury Surveillance fields should be utilised.
Burns Registry of Australia and New Zealand	ICD-10 Diagnosis	ICD10-AM diagnosis codes and prefixes	Relevant ICD-10-AM code value	NA	NA	When the patient is discharged from hospital, Health Information Services assign ICD 10 codes to the episode of care.
Burn Unit Database Sweden	Intention	INID	categorical	NA	5 options: Accident at work; Accident leisure time; Self inflicted; Assault; Other.	Research data/reports. Admission
Care of Burns in Scotland	Case history	A case history record	Text	NA	NA	INID
Dutch Burn Repository R3	Description of agent, event	INID	Text (50 characters)	NA	NA	INID
Dutch Burn Repository R3	Details background	INID	Categorical	NA	3 options: 0_No; 1_Yes; 9_Unknown.	INID
Dutch Burn Repository R3	Careless behaviour of parents	INID	Categorical	Details background = yes	2 options: 0_No; 1_Yes.	INID
Dutch Burn Repository R3	Suicide attempt	INID	Categorical	Details background = yes	2 options: 0_No; 1_Yes.	INID

Dutch Burn Repository R3	Automutiliation / Psychiatric disorder	INID	Categorical	Details background = yes	2 options: 0_No; 1_Yes.	INID
Dutch Burn Repository R3	Violence/assault	INID	Categorical	Details background = yes	2 options: 0_No; 1_Yes.	INID
German Burn Registry	Accident context/ Unfallzusammenhang	INID	Categorical	NA	6 options:1 = accident at home / leisure time; 2 = accident at work / school; 3 = traffic accident; 4 = suicide; 5 = criminal / child abuse (allegedly victim of an intentional criminal act); 99 = other (with field for manual input).	Multiple answers possible
German Burn Registry	Unf-Zus TEXT	INID	Text	Accident Context = 99	NA	An accident context that falls under other (99) must be entered here as text. Otherwise the field remains empty.
Global Burn Registry	Related to	INID	Categorical	How the burn was caused = FLAME, and Occuring in which setting = HOUSEHOLD	8 options: (1 relevant to intent) Cooking; Heating; Lighting; House fire (single) - means a flame burn sustained in a household which results from a fire involving the house itself (as opposed to a fire in a cooking area, etc.); House fire (multiple)- means a flame burn sustained in a household which results from a fire involving multiple homes (e.g. shack fires, large apartment building fires etc.); Intentional flame burn; Playing with fire; Other - Use of the term "Other" – for a number of questions the response option "Other" has been included. The intent of this is to provide an option where really none of the other response options apply. Please instruct your colleagues to limit the use of the response option "Other" to the smallest number of cases possible, since it provides very little useful information in any subsequent analyses of the GBR data. For example, a hot bowl of soup spilled on someone and causing a scald burn would correctly be categorized as a "Hot liquid, steam or gas" burn, and then the option Related to should use the response option "Cooking" and NOT "Other". This is because the heat energy that caused the burn was energy originally expended for cooking. In short, if you or your colleagues are frequently using the response option "Other" you are probably taking a too literal interpretation of the response options available. You can always address any questions you may have to gbr@who.int.	This section is structured in such a way to get information about the cause of the burn and the circumstances leading to the burn. It includes more than one question and therefore needs to be filled out in sequence.Step 1: Indicate how the burn happened. Check the appropriate box in the top row. See list below. Step 2: For all burns, apart from those rare causes of burns in the far right hand end of the top row (Friction, Inhalation, Cooling, etc.), there are additional follow up questions which are located immediately below the checked box in the top row. For burns that resulted from Flame, Hot surface, Hot liquid, steam or gas, Electrical or Chemical, read the italicized prompt or prompts underneath the checked box and fill out all remaining follow-up questions for how the burn was caused. See the list below for the follow-up questions on how the burn occurred.
Global Burn Registry	Related to	INID	Categorical	How the burn was caused = FLAME, and Occuring in which setting = PUBLIC	8 options: (2 relevant to intent) Road traffic crash; Bonfires; Fireworks; Spilled liquids - would include flame burns arising in public places resulting from ignition of flammable liquids through events like tanker truck accidents, or siphoning of flammable or spilled liquids in and around major infrastructure such as gas pipelines etc.; Playing with fire; Assault; Terrorism or war; Other.	As above

Global Burn Registry	In one or two sentences briefly describe the circumstances that led to the patient being burned	This is a single question designed to provide a clear picture of how the patient became burned. Be brief and focus on identifying the preventable circumstances that immediately preceded the patient sustaining the burn.	Text	NA	NA	Be brief and focus on identifying the preventable circumstances that immediately preceded the patient sustaining the burn.
Global Burn Registry	Burn involved	What the burn incident involved or how it happened	Categorical	How the burn was caused = FLAME and occuring in which setting = HOUSEHOLD and related to = COOKING, OR How the burn was caused = FLAME and occuring in which setting = OCCUPATIONAL and type of occupation = FOOD PREPARATION, OR How the burn was caused = HOT SURFACE and related to = COOKING, OR How the burn was caused = HOT LIQUID STEAM OR GAS and related to = COOKING.	5 options: (2 relevant to intent) Deliberate movement (e.g. deliberate touch); Accidental movement (e.g. fall/spill etc.); Explosion; Fire in cooking area; Other.	Recall the previous guidance to limit use of the responseoption "Other" to as few cases as possible.

Global Burn Registry	Burn caused by	Incident involving lighting that caused the burn.	Categorical	How the burn was caused = FLAME and occuring in which setting = HOUSEHOLD and related to = LIGHTING, OR How the burn was caused = HOT SURFACE and related to = HOUSEHOLD LIGHTING	4 options: (2 relevant to intent) Lamp/lantern igniting surrounding material; Deliberate movement touching lamp/lantern; Accidental movement touching lamp/lantern; Other.	This section is a follow up question on burns involving: Cooking/food preparation; Household lighting; Household heating. For other types of burn injuries skip to Section 7. If the burn involved the Household lighting there are two (2) follow-up questions.
Global Burn Registry	Burn caused by	How the heating caused the burn.	Categorical	How the burn was caused = FLAME and occuring in which setting = HOUSEHOLD and related to = HEATING, OR #How the burn was caused = HOT SURFACE and related to = HOUSEHOLD HEATING	4 options: (2 relevant to intent)Heating source igniting surrounding material; Deliberate movement touching heating source; Accidental movement touching heating source; Other.	As above
Global Burn Registry	Burn caused intentionally?	Indicate the apparent intent of the event that caused the burn – whether self-inflicted, inflicted by another person(s) or accidental – as documented by the treating clinician	Categorical	NA	4 options: Intentional self-harm - Includes self-inflicted burns where the person's intent was to burn themselves.; Assault - includes burns determined to have been caused by other person(s), with the intent to injure or kill. (If there is doubt about intent, use the "undetermined intent" option.); Unintentional - Includes burns determined to have resulted from an unexpected or unintended act.; Undetermined intent - To be selected only when there is no information about the intent or when there is a pending legal investigation, or the apparent intent cannot be assigned to any of the above categories.	As documented by the treating clinician

Global Burn Registry	If 'undetermined intent' was selected above what is the degree of clinical suspicion that the burn was caused intentionally?	For burns which were indicated to be of "Undetermined intent", indicate the degree to which the treating clinician has a suspicion that the burn was caused intentionally	Categorical	Burn caused intentionally = UNDETERMINED INTENT	4 options:None - For situations where the treating clinician has no suspicion whatsoever that the burn was caused intentionally; Low - For situations where the treating clinician believes that the burn was most likely not caused intentionally, but an intentional burn cannot be ruled out completely.; Moderate - For situations where the treating clinician believes there is a realistic possibility the burn was caused intentionally, but they are not suspicious enough of an intentional burn to characterize their level of suspicion as "High".; High - For situations where the burn had to be recorded as "Undetermined intent" as per the guidance for Section 7, but where the treating clinician believes there is a strong likelihood that the burn was caused intentionally.	The degree to which the treating clinician has a suspicion that the burn was caused intentionally
International Burn Injury Database	Cause of Injury	Free text field to provide a description of the injury circumstances	Text	NA	NA	This is a free text and searchable field. Type in as much detail as possible regarding what caused the burn injury or episode. Once data is entered a search can be generated for keyword content. If the injury causation menus do not allow accurate characterisation of the injury, this text field allows a full description of the circumstances of the injury to be detailed. Analysis of this field allows improvement in the menu structures that describe the injury causations.
International Burn Injury Database	Intentional Inj Suspected	Is the injury regarded as potentially nonaccidental or in potentially cause?	Categorical	NA	3 options: Checked - Positive with a known value = 1; Unchecked - Negative with a known value = 0; Gray - Don't know with a value = null.	If it is suspected by the burn care team that the injury was intentionally caused by either the patient or another person, then this item should be checked. A searchable tick box to flag suspected intentional injury, for analysis and statistics.
International Burn Injury Database	Neglect Suspected	Is the injury regarded as potentially caused or contributed to by some form of neglect?	Categorical	NA	3 options: Checked - Positive with a known value = 1; Unchecked - Negative with a known value = 0; Gray - Don't know with a value = null.	If it is suspected by the burn care team that the injury was caused or contributed to by some form of neglect on behalf of the patient or some other person, then this item should be checked. If the burn service suspect that neglect has had a part to play in the burn injury, click into the field until a tick appears. This field is a searchable tick box to flag suspected neglect, for analysis and statistics.
International Burn Injury Database	Supervision Lapse	Did lapse in supervision of the casualty play a part in the mechanism of injury?	Categorical	NA	3 options: Checked - Positive with a known value = 1; Unchecked - Negative with a known value = 0; Gray - Don't know with a value = null.	INID

International Burn Injury Database	Category	Pick the most suitable type of injury	Categorical	NA	17 Options: 01 Accidental: Recreation; 02 Accidental: Work Related; 03 Accidental: Not Work Related; 04 Accidental: Unspecified; 05 Assault; 06 Self Inflicted; 07 Suicidal; 08 NAI of Child; 08.1 Suspected neglect of child or adult; 08.2 Suspected NAI of child or adult; 08.3 Confirmed neglect of child or adult; 08.4 Confirmed NAI of child or adult; 09 Arson; 10 Suspected Criminal activity; 11 Irresponsible act by other; 98 Other; 99 Unknown.	The most appropriate menu item that characterises the type of injury should be chosen from the menu. Additional detail can be added to the associated text box. Choose from the drop down list the item that best describes the category of the injury. If the information is not available it can be inserted at a later date.
Burn Injury Database	Category text	further details if known.	Text	NA		type further information about the activity
Japanese National Burn Registry	27. Notes	If there are any significant pre-existing history, injury mechanism and progress that should be noted, please describe them.	Text	NA	NA	INID
Norwegian Burn Registry	Activity	INID	Categorical	NA	22 options: -9 = Choose value; 0 = Sports activity; 10 = Leisure activity excluding sporting activity; 11 = Playing; 20 = Working for income; 30 = Cooking/Preparing food/drink; 31 = Cleaning; 32 = Gardening; 33 = Household maintenance; 34 = Other types of unpaid work (specify); 35 = Near person preparing food/drink; 36 = Vehicle maintenance; 40 = Bathing; 41 = Eating/Drinking; 42 = Sleeping/Resting; 43 = Other vital activities (specify); 50 = Education; 91 = Driving/Passenger; 92 = Self-harming; 93 = Suspected illegal activity; 99 = Other specified activities; -1 = Not stated / Inadequately described.	Single choice
Norwegian Burn Registry	Activity - Other	INID	Text	Activity = OTHER SPECIFIED ACTIVITIES	NA	INID
Norwegian Burn Registry	Intent	INID	Categorical	NA	11 options:-9 = Choose value; 1 = Accident - injury not intended; 2 = Intentional self-harm; 3 = Suspected sexual assault; 4 = Suspected maltreatment by parent; 5 = Suspected maltreatment by spouse or partner; 6 = Suspected other and unspecified assault; 7 = Event of undetermined intent; 9 = Adverse effect or complications of medical and surgical care; 99 = Other specified intent; -1 = Not stated / Inadequately described.	Single choice
Norwegian Burn Registry	Intent - Other	INID	Text	intent = OTHER SPECIFIED INTENT	NA	INID
Norwegian Burn Registry	Injury Event Description	INID	Text	NA	NA	INID
South Asia Burn Registry	suspected intent	INID	Categorical	NA	5 options:Unintentional; Suicide/attempted suicide; Assault; Unknown; Other (specify).	The data for this section is collected from patient/next of kin interviews and ED medical records

## Table 2. Patient age variable comparison

Register	Field label	Format	Handling of unknown data	
(i) Date of birth				
Burn Care Quality Platform	Date of Birth	YYYY-MM-DD	Complete age and age unit variables	
Burn Model System	Date of Birth	yyyy-mm-dd	09/09/1900	
Burns Registry of Australia and New Zealand	Date of Birth	DD/MM/CCYY	09/09/9999	
Burn Unit Database Sweden	Social security number	YYYYMMDD-####	INID	
Care of Burns in Scotland	Date of Birth	DD/MM/YYYY	INID	
Dutch Burn Repository R3	Birth date	YYYY-MM-DD	INID	
Global Burn Registry	Patient's date of birth	DD/MM/YYYY	Complete age variable	
International Burn Injury Database	Date of Birth	DD/MM/YYYY	INID	
South Asia Burn Registry	Date of Birth	dd/mm/yy	Complete age variable	
(ii) Age				
Burn Care Quality Platform	Age	1 - 3 numeric digits or Not known/Not recorded	Not known/not recorded	
Burn Care Quality Platform	Age Units	Categorical	Not known/not recorded	
Burn Model System	Year of Birth	уууу	9999	
German Burn Registry	Age	Numeric	INID	
Global Burn Registry	Age	Numeric	INID	
Japanese National Burn Registry	Age	Numeric	INID	
Norwegian Burn Registry	Patient Age	Numeric	INID	
South Asia Burn Registry	Age	months/years	INID	
Register	Variable name	Format	Handling of unknown data	
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(i) Date of injury				
Burn Care Quality Platform	Injury incident date	YYYY-MM-DD	INID	
Burn Model System	Date of burn injury	YYYY/MM/DD	09/09/1900	
Burns Registry of Australia and New Zealand	1.3 Date of injury	Numeric (DD/MM/CCYY)	09/09/9999	
Burn Unit Database Sweden	Date of injury	YYYYMMDD	INID	
Care of Burns in Scotland	Injury date	DD/MM/YYYY	INID	
Dutch Burn Repository R3	Date and time injury	jjjj-mm-dd hh:mm	INID	
German Burn Registry	Accident date	DD/MM/YYYY	Estimate	
German Burn Registry	DATE unsure	Categorical	This variable is used to indicate if date of injury is estimated	
Global Burn Registry	Date burn occured	DD/MM/YYYY	Estimate if necessary	
International Burn Injury Database	Date of injury	DD/MM/YYYY	INID	
Japanese National Burn Registry	Date of injury	YYYY/MM/DD	9999/99/99	
Norwegian Burn Registry	Date and time of injury	Date/time	Specific variable (below) for unknown date	
Norwegian Burn Registry	Unknown	checkbox	This variable is used to indicate if date of injury is unknown	
South Asia Burn Registry	Date of injury	dd/mm/yyyy	INID	
(ii) Time of injury				
Burn Care Quality Platform	Injury incident time	HH:MM	INID	
Burns Registry of Australia and New Zealand	1.4 Time of injury	Numeric (HH:MM:SS)	best estimate or 00:00:00	
Burn Unit Database Sweden	Time of injury	HH-MM	INID	
Care of Burns in Scotland	Injury Time	HH:MM	INID	
Dutch Burn Repository R3	Date and time injury	jjjj-mm-dd hh:mm	INID	
German Burn Registry	Accident time	HH:MM	Estimate	
German Burn Registry	TIME unsure	Categorical	This variable is used to indicate if time of injury is estimated	
Global Burn Registry	Hour of day burn injury occurred	HH:MM	Estimate or 12:00:00 if unknown	
International Burn Injury Database	Time of injury	HH:MM	INID	
Norwegian Burn Registry	Date and time of injury	Date/time	Specific variable (below) for unknown time	
Norwegian Burn Registry	Unknown	checkbox	This variable is used to indicate if time of injury is unknown	
South Asia Burn Registry	Time of injury	HH:MM	INID	

# Table 3. Timing of injury variable comparison

Register	Register         Variable for comparison         Variable response options		Example of how original variable response options could be mapped to the response options of a common variable		
Proposed common	Proposed common variable: Injury intent (response options: Unintentional, Self-harm/suicide, Violence/assault, Undetermined, Other, Unknown)				
Burn Care Quality Platform	"Circumstances of injury"	9 options: Accidental injury: employment related, Accidental injury: non-employment related, Accidental injury: recreation, Accidental injury: unknown circumstances, Suspected arson, Suspected assault/abuse, Suspected self-inflicted, Other, Not known/not recorded	<b>Unintentional</b> - if Accidental injury: employment related OR Accidental injury: non- employment related OR Accidental injury: recreation OR Accidental injury: unknown circumstances. <b>Self-harm/suicide</b> - if Suspected self-inflicted. <b>Violence/assault</b> - if Suspected assault/abuse. <b>Other</b> - if Suspected arson OR Other. <b>Unknown</b> - if Not known/not recorded.		
Burn Model System	"Circumstances of injury"	9 options: Non-intentional employment related, Non-intentional non- work related, Non-intentional recreation, Non-intentional unspecified, Suspected assault-domestic, Suspected assault-non domestic, Suspected self-inflicted/suicide, Suspected arson, Missing/Unknown.	Unintentional - if Non-intentional employment related OR Non-intentional non-work related OR Non-intentional recreation OR Non-intentional unspecified. Self-harm/suicide - if Suspected self-inflicted/suicide. Violence/assault - if Suspected assault-domestic OR Suspected assault-non domestic. Other - if Suspected arson. Unknown - if Missing/Unknown.		
Burns Registry of Australia and New Zealand	"Intent when burn occurred"	10 options: Not stated/inadequately described, Accident - injury not intended, Intentional self-harm, Suspected Sexual assault, Suspected maltreatment by parent, Suspected maltreatment by spouse or partner, Suspected other and unspecified assault, Event of undetermined intent, Adverse effect or complications of medical and surgical care, Other specified intent.	Unintentional - if Accident - injury not intended. Self-harm/suicide - if Intentional self-harm. Violence/assault - if Suspected Sexual assault OR Suspected maltreatment by parent OR Suspected maltreatment by spouse or partner OR Suspected other and unspecified assault. Undetermined - if Event of undetermined intent. Other - if Adverse effect or complications of medical and surgical care OR Other specified intent. Unknown - if Not stated/inadequately described.		
Burn Unit Database Sweden	"Intention"	5 options: Accident at work, Accident leisure time, Self inflicted, Assault, Other.	Unintentional - if Accident at work OR Accident leisure time. Self-harm/suicide - if Self inflicted. Violence/assault - if Assault. Other - if Other.		
Dutch Burn Repository R3	"Details background" and "Careless behaviour of parents" and "Suicide attempt" and "Automutiliation / Psychiatric disorder" and "Violence/assault"	"Details background" has 3 options: No, Yes, Unknown. The other variables have 2 options: No, Yes.	Unintentional - if "Details background" is Yes AND "Careless behaviour of parents" is No AND "Suicide attempt" is No AND "Automutiliation / Psychiatric disorder" is No AND "Violence/assault" is No. Self-harm/suicide - if "Details background" is Yes AND "Suicide attempt" is Yes OR "Automutiliation / Psychiatric disorder" is Yes. Violence/assault - if "Details background" is Yes AND "Careless behaviour of parents" is Yes OR "Violence/assault" is Yes. Unknown - if "Details background" is No OR Unknown.		
German Burn Registry	"Accident context"	6 options: Accident at home / leisure time, Accident at work / school, Traffic accident, Suicide, Criminal / child abuse, Other	Unintentional - if Accident at home / leisure time OR Accident at work / school OR Traffic accident. Self-harm/suicide - if Suicide. Violence/assault - if Criminal / child abuse. Other - if Other.		
Global Burn Registry	"Burn caused intentionally?"	4 options: Intentional self-harm, Assault, Unintentional, Undetermined intent.	Unintentional - if Unintentional. Self-harm/suicide - if Intentional self-harm. Violence/assault - if Assault. Undetermined - if Undetermined intent.		

International Burn Injury Database	"Category"	17 Options: Accidental: Recreation, Accidental: Work Related, Accidental: Not Work Related, Accidental: Unspecified, Assault, Self Inflicted, Suicidal, NAI of Child, Suspected neglect of child or adult, Suspected NAI of child or adult, Confirmed neglect of child or adult, Confirmed NAI of child or adult, Arson, Suspected Criminal activity, Irresponsible act by other, Other, Unknown.	Unintentional - if Accidental: Recreation OR Accidental: Work Related OR Accidental: Not Work Related OR Accidental: Unspecified. Self-harm/suicide - if Self Inflicted OR Suicidal. Violence/assault - if Assault OR NAI of Child OR Suspected NAI of child or adult OR Confirmed NAI of child or adult. Other - if Suspected neglect of child or adult OR Confirmed neglect of child or adult OR Arson OR Suspected Criminal activity OR Irresponsible act by other OR Other. Unknown - if Unknown.
Norwegian Burn Registry	"Intent"	11 options: Choose value, Accident - injury not intended, Intentional self-harm, Suspected sexual assault, Suspected maltreatment by parent, Suspected maltreatment by spouse or partner, Suspected other and unspecified assault, Event of undetermined intent, Adverse effect or complications of medical and surgical care, Other specified intent, Not stated / Inadequately described.	Unintentional - if Accident - injury not intended. Self-harm/suicide - if Intentional self-harm. Violence/assault - if Suspected Sexual assault OR Suspected maltreatment by parent OR Suspected maltreatment by spouse or partner OR Suspected other and unspecified assault. Undetermined - if Event of undetermined intent. Other - if Adverse effect or complications of medical and surgical care OR Other specified intent. Unknown - if Not stated/inadequately described, Choose value.
South Asia Burn Registry	"Suspected intent"	5 options: Unintentional, Suicide/attempted suicide, Assault, Unknown, Other.	Unintentional - if Unintentional. Self-harm/suicide - if Suicide/attempted suicide. Violence/assault - if Assault. Other - if Other. Unknown - if Unknown.

Register	Variable(s) for comparison	Variable(s) response options	Example of how original variable response options could be mapped to a common variable response option
(i) Proposed commo	on variable: Clinical suspicion of inhalational injury (respo	nse options: Yes, No, Unknown)	
Burn Care Quality Platform	"Inhalation injury"	3 options: No, Yes with cutaneous burn injury, Yes without cutaneous burn injury.	Yes - if Yes with cutaneous burn injury OR Yes without cutaneous burn injury. No - if No.
Burn Model System	"Inhalation injury""	3 options: 1-Yes, 2-No, 99- Missing/Unknown	Yes - if 1 Yes. No - if 2 No. Unknown - if 99 Missing/Unknown.
Burns Registry of Australia and New Zealand	"Documented inhalation injury"	3 options: Not stated/Inadequately described, No, Yes	Yes - if Yes. No - if No. Unknown - if not stated/inadequately described.
Care of Burns in Scotland	"Airways Burn"	3 options: Yes. No, Uncertain.	Yes - if Yes. No - if No. Unknown - if Uncertain.
Dutch Burn Repository R3	"Clinical inhalation injury according to file"	2 options: Yes, No.	Yes - if Yes. No - if No.
German Burn Registry	"Inhalational injury" and "Inhalation injury confirmed bronchoscopically"	2 options: Yes, No.	Yes - if "inhalational injury" is yes OR "Inhalation injury confirmed bronchoscopically" is yes. No - if "inhalational injury" is no AND "Inhalation injury confirmed bronchoscopically" is no.
Global Burn Registry	"Associated smoke inhalation injury"	2 options: Yes, No.	Yes - if Yes. No - if No.
International Burn Injury Database	"Inhale severity" and "Nostril burns/sooting" and "Mouth burns/sooting" and "stained sputum" and "hoarse voice" and "Uvula oedema" and "Epiglottis oedema" and "Vocal cord oedema" and "Dysponea" and "Stridor" and "Lung fields crackles" and "lung fields wheezes" and "No inhalation signs or symptoms".	"inhale severity" has 4 options: None, Mild, Moderate, Severe. The other varibles have 2 options: Yes, No.	Yes - if "inhale severity" is mild/moderate/severe OR "Nostril burns/sooting" is yes OR "Mouth burns/sooting" is yes OR "stained sputum" is yes OR "hoarse voice" is yes OR "Uvula oedema" is yes OR "Epiglottis oedema" is yes OR "Vocal cord oedema" is yes OR "Dysponea" is yes OR "Stridor" is yes OR "Lung fields crackles" is yes OR "lung fields wheezes" is yes. No - if "inhale severity" is none OR "No inhalation signs or symptoms" is yes.
Japanese National Burn Registry	"Inhalation burn"	3 options: Yes, No, Unclear	Yes - if Yes. No - if No. Unknown - if Unclear.
Norwegian Burn Registry	"Documented inhalation injury"	4 options: -9 = Choose value, 0 = No, 1 = Yes, -1 = Not stated / Inadequately described.	Yes - if 1 Yes. No - if 0 No. Unknown - if -1 Not stated / Inadequately described, -9 choose value.
South Asia Burn Registry	Evidence of inhalation injury at time of presentation or during hospital stay - "Mental confusion, unconciousness", "Facial burns", "Singing of facial hair", "Soot in mouth, around nares or in sputum", "Hoarseness, stridor".	3 options: Yes, No, Unknown.	Yes - if Evidence of inhalational injury at time of presentation or during hospital stay "mental confusion, unconciousness" is yes OR "facial burns" is yes OR "singing of facial hair" is yes OR "soot in mouth, around nares or in sputum" is yes OR "hoarseness, stridor" is yes. No - if Evidence of inhalational injury at time of presentation or during hospital stay "mental confusion, unconciousness" is no AND "facial burns" is no AND "singing of facial hair" is no AND "soot in mouth, around nares or in sputum" is no AND "hoarseness, stridor" is no.

# Table 5. Example of how current inhalational injury variables could be mapped to a new common variable.

(i) Proposed common variable: Bronchoscopic signs of inhalational injury (response options: Yes, No)			
Dutch Burn Repository R3	"Use of bronchoscopy" and "Inhalation injury confirmed by bronchoscopy"	2 options: Yes, No.	<b>Yes</b> - if "use of bronchoscopy" is yes AND "Inhalation injury confirmed by bronchoscopy" is yes. <b>No</b> - if "use of bronchoscopy" is yes AND "Inhalation injury confirmed by bronchoscopy" is no
German Burn Registry	"Inhalation injury confirmed bronchoscopically"	2 options: Yes; No.	Yes - if "Inhalation injury confirmed bronchoscopically" is yes No - if "Inhalation injury confirmed bronchoscopically" is no
International Burn Injury Database	"Bronchoscopy changes - upper airway" and "Bronchoscopy changes - carina" and "Bronchoscopy changes - bronchi" and "Upper airway erythema" and "Carina erythema" and "Bronchi erythema" and "Upper airway bleeding" and "Carina bleeding" and "Bronchi bleeding" and "Upper airway pallor" and "Carina pallor" and "Bronchi pallor" and "Upper airway ulceration" and "Carina ulceration" and "Bronchi ulceration" and "Upper airway oedema" and "Carina oedema" and "Bronchi oedema" and "Upper airway contamination" and "Carina contamination" and "Bronchi contamination"	3 options: Checked, Unchecked, Null.	Yes - if "Bronchoscopy changes - upper airway" is checked OR "Bronchoscopy changes - carina" is checked OR "Bronchoscopy changes - bronchi" is checked OR Upper airway erythema "Carina erythema" is checked OR "Bronchi erythema" is checked OR "Upper airway bleeding" is checked OR "Carina bleeding" is checked OR "Bronchi bleeding" is checked OR "Upper airway pallor" is checked OR "Carina pallor" is checked OR "Bronchi pallor" is checked OR "Upper airway ulceration" is checked OR "Carina ulceration" is checked OR "Bronchi pallor" is checked OR "Upper airway ulceration" is checked OR "Carina ulceration" is checked OR "Bronchi ulceration" is checked OR "Upper airway oedema" is checked OR "Carina oedema" is checked OR "Bronchi oedema" is checked OR "Upper airway contamination" is checked OR "Carina contamination" is checked OR "Bronchi contamination" is checked OR "Bronchi oedema" is unchecked AND "Bronchoscopy changes - upper airway" is unchecked AND "Bronchoscopy changes - carina" is unchecked AND "Bronchoscopy changes - bronchi" is unchecked AND "Bronchoscopy changes - carina" is unchecked AND "Bronchoscopy changes - bronchi" is unchecked AND "Upper airway erythema "Carina erythema" is unchecked AND "Bronchi erythema" is unchecked AND "Upper airway bleeding" is unchecked AND "Carina bleeding" is unchecked AND "Bronchi bleeding" is unchecked AND "Bronchi pallor" is unchecked AND "Bronchi is unchecked AND "Bronchi pallor" is unchecked AND "Bronchi ulceration" is unchecked AND "Carina ulceration" is unchecked AND "Carina ulceration" is unchecked AND "Bronchi ulceration" is unchecked AND "Upper airway oedema" is unchecked AND "Bronchi ulceration" is unchecked AND "Upper airway contamination" is unchecked AND "Bronchi ulceration" is unchecked AND "Upper airway contamination" is unchecked AND "Bronchi ulceration" is unchecked AND "Upper airway contamination" is unchecked AND "Bronchi ulceration" is unchecked AND "Upper airway contamination" is unchecked AND "Bronchi ulceration" is unchecked AND "Bronchi coedema" is unche

## Appendix C: Database search strategies.

#### MEDLINE search strategy

Ovid MEDLINE(R) and In-Process, In-Data-Review & Other Non-Indexed Citations <1946 to XXXX>

#	Query
1	exp Burns/
2	burn*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
3	scald*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
4	thermal* injur*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
5	smoke inhalation.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
6	1 or 2 or 3 or 4 or 5
7	exp Heartburn/
8	heartburn.mp.
9	heart burn.mp.
10	exp Burnout, Psychological/
11	burnout.mp.
12	burn* out.mp.
13	burnet*.mp.
14	burnish.mp.
15	7 or 8 or 9 or 10 or 11 or 12 or 13 or 14
16	6 not 15
17	exp Afghanistan/
18	exp Bangladesh/
19	exp Bhutan/

20	exp India/
21	exp Sri Lanka/
22	Indian Ocean Islands/
23	exp Nepal/
24	exp Pakistan/
25	afghan*.mp.
26	bangladesh*.mp.
27	bhutan*.mp.
28	india*.mp.
29	Sri lanka*.mp.
30	maldiv*.mp.
31	nepal*.mp.
32	pakistan*.mp.
33	17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32
34	comoros/ or madagascar/ or mauritius/ or reunion/ or seychelles/
35	afghan* hound.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
36	india* ink.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
37	Indiana*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
38	amerindian.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
39	34 or 35 or 36 or 37 or 38
40	33 not 39
41	exp Burn Units/
42	Hospitalization/
43	Inpatients/

44	Patient Admission/
45	Registries/
46	burn unit*.mp.
47	admit*.mp.
48	admission.mp.
49	hospital*.mp.
50	inpatient.mp.
51	registry.mp.
52	registries.mp.
53	register.mp.
54	41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53
55	16 and 40 and 54
56	limit 55 to (english language and humans)

#### Embase search strategy

Embase <1974 to 2022 July 14>

#	Query
1	exp burn/
2	exp burn patient/
3	burn*.mp.
4	scald*.mp.
5	thermal* injur*.mp.
6	smoke inhalation.mp.
7	1 or 2 or 3 or 4 or 5 or 6
8	exp heartburn/
9	heartburn.mp.
10	heart burn.mp.
11	exp burnout/
12	burnout.mp.
13	burn* out.mp.
14	burnet*.mp.
15	burnish.mp.
16	8 or 9 or 10 or 11 or 12 or 13 or 14 or 15
17	7 not 16
18	exp Afghanistan/
19	exp Bangladesh/
20	exp Bhutan/
21	exp India/
22	exp Sri Lanka/
23	exp Maldives/
24	exp Nepal/
25	exp Pakistan/
26	afghan*.mp.
27	bangladesh*.mp.

28	bhutan*.mp.
29	india*.mp.
30	sri lanka.mp.
31	maldiv*.mp.
32	nepal*.mp.
33	pakistan*.mp.
34	18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33
35	afghan* hound.mp.
36	india* ink.mp.
37	indiana*.mp.
38	amerindian.mp.
39	35 or 36 or 37 or 38
40	34 not 39
41	exp burn care hospital/
42	exp hospitalization/
43	exp hospital patient/
44	exp hospital admission/
45	exp register/
46	burn unit*.mp.
47	admit*.mp.
48	admission.mp.
49	hospital*.mp.
50	inpatient.mp.
51	registry.mp.
52	registries.mp.
53	register.mp.
54	41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53
55	17 and 40 and 54
56	limit 55 to (human and english language)

#### PsycInfo search strategy

APA PsycInfo <1806 to July Week 2 2022>

#	Query
1	exp Burns/
2	burn*.mp.
3	scald*.mp.
4	thermal* injur*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
5	smoke inhalation.mp.
6	1 or 2 or 3 or 4 or 5
7	exp gastrointestinal ulcers/
8	heartburn.mp.
9	heart burn.mp.
10	exp occupational stress/
11	burnout.mp.
12	burn* out.mp.
13	burnet*.mp.
14	burnish.mp.
15	7 or 8 or 9 or 10 or 11 or 12 or 13 or 14
16	6 not 15
17	afghan*.mp.
18	bangladesh*.mp.
19	bhutan*.mp.
20	india*.mp.
21	sri lanka*.mp.
22	maldiv*.mp.
23	nepal*.mp.
24	pakistan*.mp.
25	17 or 18 or 19 or 20 or 21 or 22 or 23 or 24
26	afghan* hound.mp.

27	india* ink.mp.
28	indiana*.mp.
29	amerindian.mp.
30	26 or 27 or 28 or 29
31	25 not 30
32	exp Hospitalization/
33	exp Hospitalized Patients/
34	exp Hospital Admission/
35	burn unit*.mp.
36	admit*.mp.
37	admission.mp.
38	hospital*.mp.
39	inpatient.mp.
40	registry.mp.
41	registries.mp.
42	register.mp.
43	32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42
44	16 and 31 and 43
45	limit 44 to (human and english language)

#	Query	Limiters/Expanders
S56	S17 AND S41 AND S54	Limiters - Human; Language: English Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S55	S17 AND S41 AND S54	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S54	S42 OR S43 OR S44 OR S45 OR S46 OR S47 OR S48 OR S49 OR S50 OR S51 OR S52 OR S53	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S53	"register"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S52	"registries"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S51	"registry"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S50	"inpatient"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S49	"hospital*"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S48	"admission"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S47	"admit*"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S46	"burn unit*"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S45	(MH "Patient Admission")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S44	(MH "Inpatients")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S43	(MH "Hospitalization")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S42	(MH "Burn Units")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase

S41	S34 NOT S40	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S40	S35 OR S36 OR S37 OR S38 OR S39	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S39	"amerindian"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S38	"indiana*"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S37	"india* ink"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S36	"afghan* hound"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S35	(MH "Madagascar")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S34	S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S33	"pakistan*"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S32	"nepal*"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S31	"maldiv*"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S30	"sri lanka*"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S29	"india*"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S28	"bhutan*"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S27	"bangladesh*"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S26	"afghan*"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase

S25	(MH "Pakistan")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S24	(MH "Nepal")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S23	(MH "Indian Ocean Islands")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S22	(MH "Sri Lanka")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S21	(MH "India")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S20	(MH "Bhutan")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S19	(MH "Bangladesh")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S18	(MH "Afghanistan")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S17	S7 NOT S16	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S16	S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S15	"burnish"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S14	"burnet*"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S13	"burn* out"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S12	"burnout"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S11	(MH "Burnout, Professional+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S10	"heart burn"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S9	"heartburn"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase

S8	(MH "Heartburn")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S7	S1 OR S2 OR S3 OR S4 OR S5 OR S6	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S6	smoke inhalation	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S5	"thermal* injur*"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S4	"scald*"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S3	"burn*"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S2	(MH "Burn Patients")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S1	(MH "Burns+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase

#### PakMediNet search strategy

Only the keyword 'burn' was used to search the Pak MediNet database because during trial searches it was found that Boolean operators did not work. The term 'burn' was chosen as the most inclusive term required for the eligibility criteria.

#### Appendix D: Screening advice document.

# Terminology and methods used to differentiate injury intent of hospital burn patients in South Asia: A systematic scoping review

Below are instructions for authors undertaking screening to help determine which articles should be included and excluded at the title and abstract screening phase, and the full text screening phase of the systematic scoping review.

# **Title and abstract screening**

#### • Has the article already been screened?

**Yes** – All duplicates should have been removed before being uploaded into Covidence. If you believe the article is a duplicate of another article please add a 'note' on Covidence stating that it is a duplicate and this will be checked by the lead reviewer. If the article is verified by the lead reviewer as a duplicate then please exclude the article.

No – Move to next criteria.

#### • Are the title and abstract written in English?

Yes – Move on to next criteria.

**No** – Exclude article.

#### • Does the article study humans?

Yes – Move on to next criteria.

No – Exclude article [Example: lab based studies on human or non-human tissue, animal studies].

#### • Is the article from a journal?

Yes – Move on to next criteria. Check journal homepage to ensure a peer-review process is used.
 No – Exclude article [Example: thesis, book].

#### • Is original data presented?

**Yes** – Move on to next criteria [Example: quantitative studies, qualitative studies, case series, case report].

No – Exclude article [Example: review article, opinion piece, personal practice].

#### • Are cutaneous burns the focus of the study?

**Yes** – Move on to next criteria [Example: burns to the skin from heat (thermal burn), chemicals (acid burn), radiation, electricity, friction].

No – Exclude article [Example: not related to a burn injury such as heartburn or professional burnout; focuses exclusively on non-cutaneous burns such as burns to the eye (ocular), internal burns (e.g. from ingestion of corrosive substances), or inhalational burns; multiple causes of injury discussed in which burns are not the main focus of the article (under 50% of cases)].

#### • Has the study been conducted in a South Asian country?

Yes – Move on to next criteria. We have defined 'South Asia' to include the countries of
Afghanistan, Bangladesh, Bhutan, India, Sri Lanka, Maldives, Nepal, and Pakistan in this review.
No – Exclude article.

#### • Does the study include hospital patients?

Yes – Move on to next criteria. [Example: use of the word burn unit, hospital, secondary care, tertiary care, or inferred that data has been collected from a hospital].
No – Exclude article [Example: studies that do not focus exclusively on hospital patients such as autopsy studies, post-mortem studies, coroner's studies, medicolegal death studies, forensic department studies, data collected from primary care, community studies].

#### • Was the study conducted on patients who had sustained burns during combat?

Yes – Exclude article [Example: burn sustained during combat].

**No** – Move on to next criteria [Example: military hospital that also treat civilians, no discussion of whether the burns were sustained during combat].

#### • Is a term used that relates to intent of the burn or its classification?

Yes – Include article [Example: intent, motive, unintentional, intentional, accidental, homicidal, suicidal, self-immolation, undetermined intent, or other term that the reviewer infers to relate to intent]. If an ambiguous term is used in the title or abstract [example: aetiology, cause, circumstances of the injury] then include the article for full text screening.
No – Exclude article.

## Full text screening

#### 1. Has the article already been screened?

Yes – All duplicates should have been removed at the title and abstract screening phase. If you believe the article is a duplicate of another article please add a 'note' on Covidence stating that it is a duplicate and this will be checked by the lead reviewer. If the article is verified by the lead reviewer as a duplicate then please exclude the article choosing the exclusion reason as 'duplicate'.
No – Move to next criteria.

#### 2. Is the full text article written in English?

Yes – Move on to next criteria.

No – Exclude the article choosing the exclusion reason as 'Not in English'.

#### 3. Does the article study humans?

Yes – Move on to next criteria.

**No** – Exclude the article choosing the exclusion reason as 'non-human study' [Example: lab based studies on human or non-human tissue, animal studies].

#### 4. Is the full text article peer reviewed?

Yes – Move on to next criteria.

**No** – Exclude the article choosing the exclusion reason as 'not a peer reviewed publication' [Example: conference abstract, thesis, book, not from a peer reviewed journal].

#### 5. Are original data presented in the results section?

**Yes** – Move on to next criteria [Example: quantitative studies, qualitative studies, case series, case report].

**No** – Exclude the article choosing the exclusion reason as 'no original data presented' [Example: review article, opinion piece, personal practice].

#### 6. Are cutaneous burns the focus of the study?

**Yes** – Move on to next criteria [Example: burns to the skin from heat (thermal burn), chemicals (acid burn), radiation, electricity, friction].

**No** – Exclude the article choosing the exclusion reason as 'cutaneous burns not studied' [Example: not related to a burn injury such as heartburn or professional burnout; focuses exclusively on non-cutaneous burns such as burns to the eye (ocular), internal burns (e.g. from ingestion of corrosive substances), or inhalational burns; multiple causes of injury discussed in which burns are not the main focus of the article (under 50% of cases)].

#### 7. Has the study been conducted in a South Asian country?

Yes – Move on to next criteria. We have defined 'South Asia' to include the countries of Afghanistan, Bangladesh, Bhutan, India, Sri Lanka, Maldives, Nepal, Pakistan in this review.
No – Exclude the article choosing the reason as 'study not from a country in South Asia'.

#### 8. Does the study include hospital patients?

**Yes** – Move on to next criteria. [Example: In methods section it is made explicit that data has been collected from a hospital].

No – Exclude the article choosing the reason as 'study not based on hospital patients' [Example: studies that do not focus exclusively on hospital patients such as autopsy studies, post-mortem studies, coroner's studies, medicolegal death studies, forensic department studies data collected from primary care, community studies].

#### 9. Was the study conducted on patients who had sustained burns during combat?

**Yes** – Exclude the article choosing the reason as 'burns sustained during combat' [Example: burn sustained during combat].

**No** – Move on to next criteria [Example: Burns not sustained during combat, burns sustained by civilians not engaged in combat].

# **10.** Does the methods or results section refer to the intent of the burn, its classification, or how intent has been determined?

**Yes** – Include article [Example: use of a stem term or classifier for intent such as intent, motive, unintentional, intentional, accidental, homicidal, suicidal, self-immolation, undetermined intent, or other term that the reviewer infers to relate to intent]; method of determination of intent described.]

**No** – Exclude the article choosing the reason as 'intent terminology or method of differentiation not discussed'.

Section	Variable prompt	Format	Response options (categorical only)	Notes
Publication	Title	Imported	NA	NA
Publication	Year of publication	Free text	NA	NA
Publication	Journal	Free text	NA	NA
Publication	Lead author	Free text	NA	NA
Study information	Dates of study	Free text	NA	Dates of data collection. If two date put 'to' between them.
Study information	Dates of data collection	Free text	NA	If two dates put 'to' between them.
Study information	Country/countries of study	Categorical	9 options: Afghanistan; Bangladesh; Bhutan; India; Sri Lanka; Maldives; Nepal; Pakistan; Other.	If multiple countries included in the study please select all that apply. Include countries outside of South Asia in 'other'.
Study information	Type of study	Free text	NA	NA
Study information	Study aim	Free text	NA	NA
Study information	Number of participants	Free text	NA	NA
Study information	Age of population under study	Categorical	4 options: Paediatrics; Adults; Paediatrics and adults; Other.	NA
Study information	Details about age included	Free text	NA	Include details about if there are any restrictions to the ages included in the study.
Terminology	Stem term	Free text	NA	E.g. intent, motive. Use lower case. Use a new row for each term. If none used, put 'NA' in first column.
Terminology	Any definition(s) given for stem term(s)	Categorical	4 options: Yes; No, but examples given; No; Not applicable.	NA
Terminology	Definition(s) of stem terms	Free text	NA	NA
Terminology	Unintentional classifier term	Free text	NA	e.g. unintentional, accidental. Use lower case. Use a new row for each term. If none used put 'NA' in first column.
Terminology	Intentional classifier term	Free text	NA	e.g. intentional, suicide, homicide. Use lower case. Use a new row for each term. If none used put 'NA' in first column.

# Appendix E: Data dictionary of the variables for which data were sought from included articles.

Terminology	Other classifier term	Free text	NA	Use this option if the term does not obviously fall into intentional or unintentional. Use lower case. Use a new row for each term. If none used put 'NA' in first column.
Terminology	Any definitions given for classifier terms?	Categorical	3 options: Yes; No, but examples given; No.	NA
Terminology	Definition/examples of classifier terms	Free text	NA	NA
Terminology	Is a term used that is typically associated with intent used in a different context?	Categorical	2 options: Yes; No.	NA
Terminology	Details about the term used in a different context	Free text	NA	e.g. burn accident vs burn injury
Method	Is a method of differentiation of intent included in the methods section of the manuscript?	Categorical	3 options: Yes explicit: specific to intent; Yes Inferred: general method given but not specifically related to intent; No: No methods given relating to how information of variables collected.	NA
Method	Method of differentiation of intent	Free text	NA	Complete if answered yes or maybe to previous question
Other methods	Is a method for determining any other variable given in the methods section of the manuscript?	Categorical	2 options: Yes; No.	e.g. Lund and Browder chart for total body surface area of the burn
Other methods	Details about the other variable(s) and method of measurement	Free text	NA	NA

Robustness	ASSAULT: method of	Categorical	7 options: NA: no cases in the study reported as	Adapted from Maguire et al (2008).
assessment	determination		assault/abuse; 1: assault confirmed at court proceeding or	
			admitted by perpetrator; 2: assault confirmed by stated	
			criteria including multidisciplinary assessment; 3: diagnosis	
			of assault defined by stated criteria; 4: assault stated as	
			occurring but no supporting detail given as to how it was	
			determined; 5: assault stated as "suspected" with no details	
			given on whether it was confirmed or not; Other.	
Robustness	ACCIDENT: method of	Categorical	5 options: NA: no cases in the study reported as accidental;	Adapted from Maguire et al (2008).
assessment	determination		A: scene of incident recreated or forensic police	
			investigation of scene or criminal investigation ruled out	
			assault as a cause; B: efforts specifically made to exclude	
			assault as a cause for burn through multidisciplinary	
			investigation; C: no discussion about how burn was deemed	
			to be accidental; Other.	
Final	Any other	Free text	NA	NA
thoughts	notes/observations			

# Appendix F: Study characteristics.

Reference	Location	Data collection duration	Study design	Number of participants	Age of study population
Adil 2016	Karachi,	6 months (August 2013	Data collection: Administered questionnaire completed prospectively. Inclusion: All	384	Adults
[372]	Pakistan	to February 2014)	admitted patients with a burn injury. Location: Tertiary government teaching hospital burn department.		(18 years and over)
Adil 2016	Karachi,	6 months (August 2013	Data collection: Administered questionnaire completed prospectively. Inclusion:	324	Adults
[373]	Pakistan	to February 2014)	Admitted patients with unintentional burn injury. Location: Tertiary government teaching hospital burn department.		(18 years and over)
Agrawal 1990 [374]	Bokaro Steel City, India	5 years (January 1980 to December 1984)	<b>Data collection:</b> Not stated. <b>Inclusion:</b> Patients who sustained burn injuries at a local steel plant. <b>Location:</b> Government hospital burn department.	270	Adults
Ahmad	Peshawar,	1 year	Data collection: Proforma completed on admission by taking history from	242	Paediatrics and
2015 [375]	Pakistan	(July 2013 to June 2014)	patient/family. Inclusion: All admitted patients with a burn injury. Location: Tertiary teaching hospital surgical unit.		adults
Ahmed	Rawalpindi,	9 years	Data collection: Proforma completed retrospectively using admission details. Inclusion:	178	Paediatrics and
2009 [197]	Pakistan	(April 1999 to April	All patients with a burn injury presenting to casualty or admitted to burn department.		adults (11 years
		2008)	Location: Charitable hospital casualty department and burn department.		and over)
Ahmed	Rawalpindi,	12 years	Data collection: Proforma completed on admission by taking history from	139	Adults
2014 [376]	Pakistan	(April 1997 to March 2009)	patient/family. Inclusion: Female patients with a burn injury presenting to casualty department or admitted to burns department. Location: Tertiary charitable hospital burn department.		(15 years and over)
Ahmed 2016 [377]	Abbottabad, Pakistan	4 years (July 2011 to June 2015)	<b>Data collection:</b> Proforma completed prospectively. <b>Inclusion:</b> All admitted patients with a burn injury. <b>Location:</b> Tertiary government teaching hospital burn department.	678	Paediatrics and adults
Ahuja 2002 [378]	Delhi, India	8 years (January 1993 to December 2000)	<b>Data collection:</b> From patient records. <b>Inclusion:</b> All admitted patients with a burn injury. <b>Location:</b> Government teaching hospital burn department.	11196	Paediatrics and adults
Ahuja 2009 [379]	Delhi, India	15 years (January 1993 to December 2007)	<b>Data collection:</b> Retrospectively from patient records. <b>Inclusion:</b> All admitted patients with a burn injury. <b>Location:</b> Government teaching hospital burn department.	16762	Paediatrics and adults

Ahuja 2011 [302]	Delhi, India	16 months (1 January 2009 to 21 May 2010)	<ul> <li>Data collection: Prospectively from clinical database of patient admissions. Inclusion:</li> <li>Admitted patients with a burn injury caused by liquefied petroleum gas or kerosene.</li> <li>Location: Government teaching hospital burn department.</li> </ul>	991	Paediatrics and adults
Alibran 2012 [380]	Karachi, Pakistan	4 years (2006 to 2010)	<b>Data collection:</b> Retrospective review of patient records. <b>Inclusion:</b> All admitted patients with a burn injury. <b>Location:</b> Tertiary government teaching hospital burn department.	3972	Paediatrics and adults
Allbran 2013 [381]	Karachi, Pakistan	2 years (1 January 2010 to 31 December 2011)	<b>Data collection:</b> Prospectively completed questionnaire. <b>Inclusion:</b> All admitted patients with a burn injury. <b>Location:</b> Tertiary government teaching hospital burn department.	1979	Adults (15 years and over)
Aslam 2012 [382]	Peshawar, Pakistan	1 year (January 2009 to December 2009)	<b>Data collection:</b> Prospectively completed proforma. <b>Inclusion:</b> All patients presenting with an acute burn injury. <b>Location:</b> Hospital burn department.	758	Paediatrics and adults
Aslam 2017 [190]	Peshawar, Pakistan	1 year (January 2015 to December 2015)	<b>Data collection:</b> Prospectively completed proforma. <b>Inclusion:</b> Paediatric patients presenting with an acute burn injury. <b>Location:</b> Hospital burn department.	3947	Paediatrics (10 years and under)
Aslam 2020 [383]	Kharian, Pakistan	2 years (September 2017 to August 2019)	<b>Data collection:</b> Retrospective review of patient records. <b>Inclusion:</b> Paediatric patients admitted with an acute burn injury. <b>Location:</b> Military hospital burn department.	1011	Paediatrics (12 years and under)
Baranwal 2021 [384]	Delhi, India	3 years (1 October 2016 to 1 October 2019)	<b>Data collection:</b> Prospectively collected validated questionnaire administered to patients and relatives by a researcher. <b>Inclusion:</b> Admitted patients with a burn injury caused by liquefied petroleum gas. <b>Location:</b> Tertiary government teaching hospital burns department.	401	Paediatrics and adults
Belur 2014 [74]	Delhi and Mumbai, India	2 months (May 2012 to June 2012)	<ul> <li>Data collection: Semi structured interviews using purposive sampling. Inclusion:</li> <li>Women admitted with a burn injury or their relatives, healthcare providers, and police.</li> <li>Location: Two major burn departments.</li> </ul>	59 (33 patients, 14 HCP, 14 police)	Not stated
Bhandari 2019 [385]	Nepal	2 months (May 2016 to June 2016)	<b>Data collection:</b> Key informant interviews and focus groups. <b>Inclusion:</b> Key informants include medical superintendents, burn unit medical staff, and medical recorder, and focus groups conducted with people in the community. <b>Location:</b> 10 referral hospitals of 8 districts in Nepal.	146 (40 key informants, 18 focus groups)	Not stated
Chakrabort y 2010 [198]	Kolkata, India	2 months (July 2008 to August 2008)	<b>Data collection:</b> Proforma completed prospectively using patient notes and interviews. <b>Inclusion:</b> All admitted patients with a burn injury. <b>Location:</b> Tertiary government teaching hospital burns department.	83	Paediatrics and adults

Daruwalla	Delhi and	3 months	Data collection: Semi-structured and key informant interviews using purposive	59 (33	Adults
2014 [189]	Mumbai, India	(June 2012 to August	sampling. Inclusion: Women admitted with flame burns or their relatives, healthcare	patients, 26	
		2012)	providers, and police. Location: Two major tertiary hospital burn departments.	key	
				informants)	
Das 1983	Bangalore, India	Disaster occurred in	Data collection: Not stated. Inclusion: Patients who sustained a burn injury at a local	190	Paediatrics and
[386]		1981	circus. Location: Tertiary government teaching hospital burns department.		adults
Das 2013	Dhaka,	7 years	Data collection: Retrospective review of patient records. Inclusion: Inpatients and	311	Paediatrics and
[199]	Bangladesh	(April 2004 to May	outpatients who sustained a burn injury due to assault. Location: Tertiary government		adults
		2011)	teaching hospital burns department.		
Das 2015	Dhaka,	8 years	Data collection: Not stated. Inclusion: Patients with a burn injury caused by acid who	126	Paediatrics and
[387]	Bangladesh	(July 2004 to	presented to hospital in 24 hours. Location: Tertiary government teaching hospital		adults
		December 2012)	burns department.		
Dash 2021	Delhi, India	4 years	Data collection: Retrospective review of patient records. Inclusion: Inpatients and	15	Adults
[388]		(March 2015 to March	outpatients with cryogenic burns caused by refrigerants. Location: Tertiary government		
		2019)	teaching hospital burns department.		
Faired 2016	Karaah i	Creantha	Data callections Duran actively administered synaptic maxim to convenience completef	100	۵ ماریا <del>ن</del> ه م
Faisal 2016	Karachi,	6 months	<b>Data collection:</b> Prospectively administered questionnaire to convenience sample of	100	Adults
[389]	Pakistan	(2013)	patients. <b>Inclusion:</b> Patients with 25% of greater TBSA burns involving face and neck		(15 years and
	Davida la indi	1	sustained 9 months to 3 years earlier. Location: Tertiary hospital burns department.	1400	over)
Farooq	Rawaipindi,	L year	<b>Data collection:</b> WHO injury surveillance questionnaire prospectively completed	1498	Paediatrics and
2011 [390]	Pakistan	(1 July 2007 to 30 June	through patient interview and use of patient records. <b>Inclusion:</b> All patients presenting		adults
		2008)	with a burn injury. Location: Inree tertiary government teaching hospital emergency		
Canadama	Devediebeww	1	departments.	222	De e districe e red
Ganesamo	Ponaicherry,	I year	Data collection: Prospectively completed proforma. Inclusion: Admitted patients with	222	Paediatrics and
ni 2010	India	(April 2006 to April	major burn injuries. Location: Tertiary government teaching nospital surgical		adults
[391]		2007)	department.		
Goval	Rishikesh, India	17 months	Data collection: Prospectively maintained Trauma Registry. Inclusion: Admitted	8	Paediatrics and
2021 [392]	,	(May 2019 to	patients with high voltage electrical injuries. Location: Tertiary government teaching		adults
		September 2020)	hospital trauma surgery department.		
Gupta	Jaipur, India	1 year	Data collection: Prospectively completed proforma. Inclusion: Admitted paediatric	127	Paediatrics
1992 [191]	. ,	(January 1990 to	patients with accidental burn injuries. Location: Tertiary government teaching hospital		(14 years and
		December 1990)	burns department.		under)
Curata	lainun India	10 mantha	Data collections Duran actively completed weeks use the lysions All educities duration to	<b>C</b> 20	De e districe e red
Gupta	Jaipur, mula		with a burn injury <b>Location</b> : Tertiany government teaching besnital burns department	029	raeulatrics and
1222 [122]		(January 1000)	with a burn injury. <b>Location.</b> Tertiary government teaching nospital burns department.		audits
		August 1990)			

Gupta	Jaipur, India	2 months	Data collection: Not stated. Inclusion: All patients with a burn injury due to distribution	303 (40	Paediatrics and
1996 [393]		(February 1994 to April	of kerosene mixed with petrol. Location: Tertiary government teaching hospital burns	treated at the	adults
		1994)	department.	study hospital)	
Hafooz	Laboro Bakistan	19 months	<b>Data collection:</b> Potrospectively from bespital records. <b>Inclusion:</b> All admitted patients	20	Adulta
2010 [200]	Lanore, Pakistan	10 months (May 2016 to	with a hurn injury caused by acid <b>Location:</b> Government teaching hospital burns	20	(18 years and
2019 [200]		(May 2010 (0 November 2017)	department		
Honnogow	Maninal India	0 months (Sontombor	Deta collection: Drospostively completed admission record book from	727	Dver)
do 2010	iviallipal, illula	2012 to June 2012)	patients (relatives, Inclusion: All admitted patients with a burn injury, Incation: Drivate	/5/	Paeulatrics anu
[204]		2012 (0 Julie 2013)	tooching hospital hurns department		auuits
[594]					
lqbal 2013	Islamabad,	3 years	Data collection: Prospectively completed proforma. Inclusion: All patients with a burn	13295	Paediatrics and
[395]	Pakistan	(January 2008 to	injury presenting within 24 hours of injury. Location: Tertiary government teaching		adults
		December 2010)	hospital burns department.		
Jayaraman	Chennai, India	1 year	Data collection: Prospectively completed WHO proforma. Inclusion: All patients	1368	Paediatrics and
1993 [396]		(1 May 1987 to 30 April	presenting with a burn injury. Location: Government teaching hospital burns		adults
		1988)	department.		
Jeevaratna	Afghanistan	1 year	Data collection: Retrospective review of patient records of those with a burn injury	88	Paediatrics and
m 2014		(1 January 2010 to 31	code in a trauma registry. Inclusion: All patients with a coding of a burn injury.		adults
[397]		December 2010)	Location: NATO role 3 medical treatment facility.		
Karunadas	Colombo, Sri	18 months	Data collection: Retrospective review of burns registry, patient records, operation	46	Paediatrics and
a 2010	Lanka	(1 January 2008 to 30	registers, and rehabilitation registers by departmental staff. Inclusion: All patients with		adults
[398]		June 2009)	a burn injury due to assault with acid. Location: Tertiary government teaching hospital		
			burns department.		
Kim 2012	Mumbai, India	10 days	Data collection: Retrospective questionnaire administered to patients about initial burn	31	Paediatrics and
[399]		(8 January 2010 to 18	care, and review of patient demographic details from hospital records. Inclusion:		adults
		January 2010)	Patients treated at surgical mission. Location: Specialised burns hospital.		
Kumar	Ahmedabad,	1 year	<b>Data collection:</b> Prospectively completed proforma by patient or relative interviews.	112	Paediatrics and
1994 [400]	India	(1 January 1991 to 31	Inclusion: Admitted paediatric and adolescent patients with a burn injury. Location:		adults (19 years
		December 1991)	Government teaching hospital burns department.		and under)
Kumar	Manipal, India	10 years	Data collection: Retrospective (no further detail stated). Inclusion: Admitted paediatric	309	Paediatrics
2000 [401]		(1989 to 1998)	patients with a burn injury. Location: Private teaching hospital burns department.		(10 years and
					under)
Kumar	Manipal, India	Steel converter blast	Data collection: Not stated. Inclusion: Admitted patients with burn injuries from a local	30 (6 treated	Adults
2010 [402]		on 30 July 2003	steel works. Location: Private teaching hospital burns department.	at the study	
				hospital)	

Kumar	Manipal, India	Steel furnace blast on	Data collection: Not stated. Inclusion: Admitted patients with burn injuries from a local	3	Adults
2010 [403]		12 July 1996	steel works. Location: Private teaching hospital burns department.		
Kumar	Mangalore,	1 year	Data collection: Proforma completed retrospectively using patient notes. Inclusion: All	101	Paediatrics and
2012 [305]	India	(January 2009 to	admitted patients with a burn injury. Location: Tertiary government teaching hospital		adults
		December 2009)	burns department.		
Kumar	Manipal, India	Tanker explosion on	Data collection: Data collected by medical professional through site visits and	41 (6 treated	Paediatrics and
2013 [404]		27th August 2012	interviews with the media, eye witnesses, rescuers, district collector, and district	at the study	adults
			medical officer. Inclusion: Patients with burn injuries from the explosion of a liquified	hospital)	
			petroleum gas tanker. Location: Private teaching hospital burns department.		
Laloe 2002	Batticaloa, Sri	2 years	Data collection: Prospective completed proforma. Inclusion: All admitted patients with	345	Paediatrics and
[195]	Lanka	(1 July 1999 to 30 June	a burn injury with a focus on those with self-inflicted injuries. Location: Government		adults
		2001)	teaching hospital surgical department.		
Laloe 2002	Batticaloa, Sri	2 years	Data collection: Prospectively completed proforma. Inclusion: All admitted patients	345	Paediatrics and
[196]	Lanka	(1 July 1999 to 30 June	with a burn injury. Location: Government teaching hospital surgical department.		adults
		2001)			
Lama 2015	Kathmandu,	11.5 years	Data collection: Secondary analysis of deidentified patient data. Inclusion: All admitted	1148	Paediatrics and
[281]	Nepal	(1 January 2002 to 31	patients with a burn injury. Location: Tertiary government teaching hospital burns		adults
		August 2013)	department.		
Learmonth	Delhi, Pune,	Delhi 1971	Data collection: Retrospective review of patient records. Inclusion: All paediatric	1486	Paediatrics
1979 [336]	Hyderabad, and	Pune 1976-77	patients admitted with a burn injury. Location: 4 government teaching hospital burns		(11 years and
	Bangalore, India	Hyderabad 1974-77	department.		under)
		Bangalore 1977			
Marsh	Karachi,	1 year	Data collection: Review of admissions register and interview of sample of patients.	832 (47	Adults
1996 [201]	Pakistan	(1 November 1992 to	Inclusion: All patients admitted with a burn injury. Location: 2 government teaching	interviews)	
		31 October 1993)	hospital burns department.		
Masood	Quetta City,	1 year	Data collection: Proforma completed using patient records, police records, and enquiry	68	Paediatrics and
2016 [405]	Pakistan	(January 2003 to	reports. Inclusion: All patients presenting with a burn injury. Location: Hospital casualty		adults (11 years
		December 2003)	and burns department.		and over)
Mehboob	Faisalabad,	1 year	Data collection: Not stated. Inclusion: All patients with acute burn injuries. Location:	566	Paediatrics and
2021 [406]	Pakistan	(August 2019 to August	Government teaching hospital burns department.		adults
		2020)			-
Mukerji	Indore, India	7 years	Data collection: Prospectively collected burn treatment registry. Inclusion: All admitted	110	Paediatrics
2001 [193]		(1993 to 1999)	paediatric patients with burn injuries. Location: Tertiary charitable hospital burns		(14 years and
			department.		under)

Natarajan 2014 [213]	Delhi, India	Registry data: 4 months (15 July to 22 November 2011) Interviews: 6 months (15 July to 22 November 2011, and 10 January to 30 March 2012)	Data collection: Prospectively collected hospital registry and semi-structured interviews. Inclusion: All patients with burn injuries in register, and interviews with female inpatients. Location: Government hospital burns department.	768 (60 interviews)	Paediatrics and adults (Interviews 19 years and over only)
Naumeri 2019 [407]	Lahore, Pakistan	6 months (July 2017 to January 2018)	<b>Data collection:</b> Questionnaire completed prospectively by duty doctor after interviewing parents. <b>Inclusion:</b> Parents of admitted children with burn injuries. <b>Location:</b> Tertiary government hospital burns department.	310	Paediatrics
Newberry 2019 [202]	Andhra Pradesh, Assam, Gujarat, Karnataka, and Telangana, India	4 months (May 2015 to August 2015)	<b>Data collection:</b> Questionnaire completed by research assistants prospectively from emergency medical technicians. <b>Inclusion:</b> Patients with a burn injury who call an ambulance using 108. Chemical, electrical, transfers, and treatment refusals were excluded. <b>Location:</b> 5 states in India using prehospital emergency medical services.	439	Paediatrics and adults
Padovese 2010 [408]	Kabul, Afghanistan	16 months (1st March 2007 to 30th June 2008)	<b>Data collection:</b> Retrospective review of patient records. <b>Inclusion:</b> All admitted patients with a burn injury. <b>Location:</b> Tertiary government hospital burns department.	532	Paediatrics and adults
Paliwal 2014 [409]	Delhi, India	1 year (September 2011 to August 2012)	<b>Data collection:</b> Proforma completed prospectively by medical professional. <b>Inclusion:</b> Patients with reliable history of a burn injury caused by liquefied petroleum gas. <b>Location:</b> Tertiary government teaching hospital burns department.	182	Paediatrics and adults
Parray 2015 [410]	Jammu, India	17 years (January 1994 to September 2010)	<b>Data collection:</b> Proforma completed used information from burn ward database, ward register, and patient records. <b>Inclusion:</b> All admitted patients with a burn injury. <b>Location:</b> Tertiary government teaching hospital burns department.	2230	Paediatrics and adults
Puri 2009 [411]	Mumbai, India	10 years (1997 to 2006)	<b>Data collection:</b> Prospective data collection 2000-2006 from patient or accompanying person, retrospective 1997-1999. <b>Inclusion:</b> All patients presenting with a burn injury caused by fireworks. <b>Location:</b> Tertiary government teaching hospital burns department.	157	Paediatrics and adults
Ramakrish nan 1991 [412]	Chennai, India	17 years (1973 to 1990)	<b>Data collection:</b> Retrospective analyses (not further detail stated). <b>Inclusion:</b> All admitted patients with an electrical burn injury. <b>Location:</b> Tertiary government teaching hospital burn intensive care unit.	923	Paediatrics and adults
Rao 1966 [413]	Delhi, India	6 months (1 December 1962 to 31 May 1963)	<b>Data collection:</b> Not stated. <b>Inclusion:</b> All admitted paediatric patients with burn injuries. <b>Location:</b> Tertiary government teaching hospital burn department.	91	Paediatrics (15 years and under)

Rao 1989 [203]	Madurai, India	7 months (16 March 1988 to 15 October 1988)	<b>Data collection:</b> Proforma completed prospectively by research staff, and psychological autopsy for fatal cases. <b>Inclusion:</b> Admitted female patients with flame burns sustained in a domestic environment. <b>Location:</b> Tertiary government teaching hospital burn	166	Adults (15 years and over)
Rashid 2014 [414]	Srinagar, India	1 year (year not stated)	Data collection: Not stated. Inclusion: Patients with burn injuries caused by assault with a Kangri. Location: Tertiary government teaching hospital emergency ward and burn department.	20	Paediatrics and adults
Raza 2009 [188]	Krachi, Pakistan	Not stated	<b>Data collection:</b> Not stated. <b>Inclusion:</b> Patients with burn injuries caused by branding. <b>Location:</b> Tertiary government teaching hospital.	4	Adults
Razzaque 2020 [415]	Pakistan	6 months (June 2017 to November 2017)	<b>Data collection:</b> Self-administered questionnaire using convenience sampling. <b>Inclusion:</b> Patients with healing burn injury over a joint aged 15-50. <b>Location:</b> Burn institutes, clinics, and hospitals.	100	Adults (15 years and over)
Sakya 2018 [416]	8 districts in Nepal	2 months (May 2016 to June 2016)	<b>Data collection:</b> Key informant interviews and focus group discussions. <b>Inclusion:</b> Health service providers (interviews) and community people (focus groups). <b>Location:</b> Ten referral hospitals and their catchment areas of eight districts across Nepal.	146 (40 key informants, 18 focus groups)	Not stated
Saleem 2001 [417]	Karachi, Pakistan	1 year (January 1999 to December 1999)	<b>Data collection:</b> Proforma completed prospectively. <b>Inclusion:</b> Admitted acute paediatric thermal burns. <b>Location:</b> Tertiary government teaching hospital burns department.	198	Paediatrics (12 years and under)
Sarma 1994 [418]	Digboi, India	10 years (March 1980 to March 1990)	<b>Data collection:</b> Retrospective (further detail not stated). <b>Inclusion:</b> Admitted patients with burn injuries. <b>Location:</b> Indian Oil Corporation hospital general surgical department.	348	Paediatrics and adults
Sawhney 1989 [419]	Chandigarh, India	5 years (1982 to 1987)	<b>Data collection:</b> Retrospective review of patient records. <b>Inclusion:</b> Admitted patients with burn injuries caused by stove accidents. <b>Location:</b> Tertiary government teaching hospital burns department.	198	Paediatrics and adults
Segu 2016 [204]	Bangalore, India	5 years (2009 to 2013)	<b>Data collection:</b> Proforma completed prospectively by discussion with patient and family. <b>Inclusion:</b> Acute paediatric admissions with suicidal burn injuries. <b>Location:</b> Tertiary government teaching hospital burns department.	89	Paediatrics (18 years and under)
Shankar 2012 [420]	Belgaum, India	1 year (April 2004 to March 2005)	<b>Data collection:</b> Administered questionnaire completed prospectively. <b>Inclusion:</b> Patient admissions with suicidal or homicidal burn injuries. <b>Location:</b> Two tertiary hospital burns department.	58	Paediatrics and adults
Shankar 2012 [421]	Bagalkot, India	1 year (1 January 2010 to 31 December 2010)	<b>Data collection:</b> Retrospective review of admission register, hospital computer database, and patient records. <b>Inclusion:</b> Patient admissions with burn injuries. <b>Location:</b> Tertiary private teaching hospital burns department.	64	Paediatrics and adults

Shankar 2014 [187]	South India	1 year (2009)	<b>Data collection:</b> Proforma completed prospectively through interviewing patients or their relatives. Data collected from patient records if interview not possible. <b>Inclusion:</b> Admitted pregnant patients with burn injuries. <b>Location:</b> Two tertiary hospital burns department.	10	Adults
Shankar 2015 [422]	Belgaum, India	1 year (2009)	<b>Data collection:</b> Proforma completed prospectively (no further detail stated). <b>Inclusion:</b> Admitted patients with burn injuries aged 60 or over. <b>Location:</b> Two tertiary hospital burns department.	16	Adults (60 years and over)
Sharma 2015 [423]	Kathmandu, Nepal	11.5 years (1 January 2002 to 31 August 2013)	<b>Data collection:</b> Review of deidentified patient records. <b>Inclusion:</b> Admitted patients with unintentional burn injuries. <b>Location:</b> Tertiary government teaching hospital burns department.	819	Paediatrics and adults
Siddiqui 1998 [424]	Karachi, Pakistan	1 year (January 1996 to December 1996)	<b>Data collection:</b> Review of patient records. <b>Inclusion:</b> Admitted patients with acute burn injuries. <b>Location:</b> Tertiary government teaching hospital burns department.	716	Paediatrics and adults (paediatrics in OP only)
Siddiqui 2015 [159]	Karachi, Rawalpindi, Peshwar, Lahore, Quetta, and Islamabad, across Pakistan	4 months (November 2010 to March 2011_	<b>Data collection:</b> Pretested proforma completed prospectively by researchers through interviewing patients or their family. <b>Inclusion:</b> Patients presenting to emergency department with a burn injury. <b>Location:</b> 2 private and 5 government tertiary hospitals emergency departments.	403	Paediatrics and adults
Singh 2012 [425]	Chandigarh, India	1 year (year not stated)	<b>Data collection:</b> Prospectively collected data by interviewing patients or their family. <b>Inclusion:</b> Patients with burn injuries admitted for over 48 hours or died in hospital. <b>Location:</b> Tertiary government teaching hospital.	116	Paediatrics and adults
Singh 2012 [426]	Mullana, India	19 months (1 May 2010 to 31 December 2011)	<b>Data collection:</b> Questionnaire completed prospectively by interviewing patients or their family. Outcomes captured by reviewing personal history, inquest report, or dying declaration. <b>Inclusion:</b> Admitted patients with suicidal or homicidal burn injuries. <b>Location:</b> Tertiary private teaching hospital.	127	Paediatrics and adults
Srinivasulu 2014 [427]	Khammam, India	1 year (October 2006 to September 2007)	<b>Data collection:</b> Proforma completed prospectively. <b>Inclusion:</b> Admitted patients with burn injuries. <b>Location:</b> Tertiary private teaching hospital.	55	Paediatrics and adults
Subrahma nyam 1996 [194]	Solapur, India	8 months (June 1993 to February 1994)	<b>Data collection:</b> Prospective (no further detail stated). <b>Inclusion:</b> Patients with burn injuries treated at the hospital. <b>Location:</b> Government district hospital burn department.	175	Paediatrics and adults
Sunder 1998 [428]	Jamshedpur, India	4 years (January 1993 to December 1996)	<b>Data collection:</b> Not stated. <b>Inclusion:</b> Patients with burn injuries treated at the hospital. <b>Location:</b> Secondary private hospital burn department.	815 (142 inpatients,	Not stated

				673	
				outpatients)	
Tahir 2010	Jamshoro,	8 years	Data collection: Review of patient records. Inclusion: Admitted patients with self-	1572 (154 self	Paediatrics and
[186]	Pakistan	(January 2001 to	inflicted burn injuries treated at the hospital. Location: Tertiary government teaching	inflicted)	adults
		December 2008)	hospital burns department.		
Tiwari	Delhi, India	1 year	Data collection: Retrospective (no further detail stated). Inclusion: Admitted paediatric	6	Paediatrics
1999 [429]		(1998)	patients with burn injuries due to kite flying. Location: Tertiary government teaching		
			hospital burns department.		
Wagle	Mumbai, India	3 months (October	Data collection: Proforma and presumptive stressful life event scale completed	50	Not stated
1999 [205]		1994 to January 1995)	prospectively through interviews with patient and family. Inclusion: Admitted patients		
			with acute burn injuries. Location: Tertiary government teaching hospital burns		
			department.		
Waqas	Punjab	4 months (August 2016	Data collection: Validated questionnaire completed prospectively through patient	343	Adults
2018 [430]	province,	to December 2016)	interview by medical students. <b>Inclusion:</b> Admitted patients with acute burn injuries.		(18 years and
	Pakistan		Location: 4 government hospitals burns or surgical departments.		over)
Yar 2011	Rahim Yar Khan,	8 months	Data collection: Review of patient records. Inclusion: Admitted patients with burn	109	Paediatrics and
[431]	Pakistan	(1 February 2010 to 30	injuries. Location: Tertiary government teaching hospital burns department.		adults
		September 2010)			
Yerpude	Mumbai, India	6 months	Data collection: Proforma completed prospectively through interview with patients or	278	Paediatrics and
2011 [206]		(March 2007 to August	their relatives, and review of patient records, admission register, and referral notes.		adults
		2007)	Inclusion: Admitted patients with burn injuries. Location: Tertiary government teaching		
			hospital burns department.		
Zopate	Sevagram, India	3 years	Data collection: Proforma completed prospectively through interview with patients or	300	Paediatrics and
2017 [207]		(dates not stated)	their relatives, and review of police records and dying declarations. Inclusion: Admitted		adults
			patients with accidental burn injuries. Location: Tertiary government teaching hospital		
			burns department.		

Reference	Stem terms	Stem term definition	Unintentional classifier terms	Intentional classifier terms	Other classifier terms	Classifier term definition
Adil 2016 [372]	intent	No	self incurred, non intentional	self harm, assault, intentional	-	No
Adil 2016 [373]	-	-	unintentional, accident	intentional, suicide, homicide	-	No
Agrawal 1990 [374]	-	-	Accident	-	-	No
Ahmad 2015 [375]	-	-	accident	suicide	-	No
Ahmed 2009 [197]	nature	No	accident	homicide, suicide	-	No
Ahmed 2014 [376]	type	No	accident	homicide, suicide	-	No
Ahmed 2016 [377]	manner	No	accident	homicide, suicide	-	No
Ahuja 2002 [378]	mode	No	accident	homicide, suicide	miscellaneous	No
Ahuja 2009 [379]	mode	No	non intentional, accident	homicide, suicide	miscellaneous/ not known	Νο
Ahuja 2011 [302]	mode	No	accident, non intentional, mishap	suicide, homicide	-	No
Alibran 2012 [380]	cause, acquisition	No	accident	suicide, homicide	-	No
Allbran 2013 [381]	cause	No	accident	homicide, suicide	-	No
Aslam 2012 [382]	-	-	accident	-	-	No

# Appendix G: Stem and classifier terms, and their definitions found in included articles. '-' means that no term was included in the article.

Aslam 2017 [190]	-	-	accident	-	-	Example only. Accident: e.g. "Most common patterns in our study were falling of child in to hot water pan meant for washing cloth, falling into hot food utensil and spillage of hot food. In all these scenarios, the common factor was an unsupervised child left with hot liquid. These accidents reflect the lapses in child supervision and need behavioral changes on the part of caregivers."
Aslam 2020 [383]	-	-	accident	-	-	Example only. Accident: e.g. "In infants and very young, the commonest cause was immersion in boiled milk or water by slipping from hands of elder into the pot or immersion of a playing or standing toddler in the pot lying on the floor."
Baranwal 2021 [384]	-	-	accident	suicide, homicide	-	No
Belur 2014 [74]	classification, circumstances, cause	Yes. Classification: flow chart with the official procedure for women who have died from a burn injury in hospital	accident	suicide, homicide, dowry, intentional, unnatural death	-	Yes. Accident: No victim allegations or findings in police report.; Suicide: Victim allegations of harassment and police use of legal sanction 498A IPC or 306 IPC.; Homicide: Victim allegations of harassment and police use of legal sanction 498A IPC or 302 IPC.; Dowry death: Victim allegations of dowry related harassment and police use of legal sanction 304B IPC or 304B IPC.
Bhandari 2019 [385]	-	-	unintentional, accident	homicide, suicide, attack, intentional	-	No
Chakraborty 2010 [198]	cause	No	accident	homicide, suicide	-	No
Daruwalla 2014 [189]	classification, cause	No	accident	suicide, homicide, dowry, self immolation, self harm, non accidental, attempted murder	unstated	Example only. Homicide: e.g. "in two cases a husband told his wife to set herself on fire and, when she refused, lit the match himself (a drunken suitor did a similar thing and accidentally set himself alight). The reality of setting a woman on fire and the rapidity of spread usually unnerved the aggressor, who then helped to put it out". Accident: "My dupatta was hanging and caught fire, slowly, slowly, burning more and more, while I was paying attention

						to the milkwe throw it behind us and then we dont pay attention to it".
Das 1983 [386]	-	-	disaster, victim	-	-	Example only. Fire disaster: The paper gives an in depth description of events leading to the fire disaster.
Das 2013 [199]	intent	No	accident, non intentional	intentional, self mutilation, suicide, assault, torture, non accidental, homicide	-	Example only. Homicide: e.g. "Three cases of forced ingestion of a chemical were the result of attempted homicide"
Das 2015 [387]	-	-	accident	attack, intentional, victim	-	No
Dash 2021 [388]	-	-	work related	-	-	Example only. Work related: "In all cases, patients had failed to follow standard precautions or wear personal protective equipmentall reported being unaware of the possibility of cold-related injuries and the appropriate first aid procedures"
Faisal 2016 [389]	reason	No	accident	-	incidental	No
Farooq 2011 [390]	intent	No	unintentional	self harm, assault, intentional	-	No
Ganesamoni 2010 [391]	cause	No	non intentional, accident	suicide, homicide	-	No
Goyal 2021 [392]	mode	No	accident, recreational, occupational	-	-	No
Gupta 1992 [191]	-	-	accident	-	-	Example only. Accident: e.g. "Thirty-three children either crawled to or reached up to vessels containing hot liquids which had been placed either on the floor or on a slightly raised platform. These children managed to tip the contents of the container over themselves."

Gupta 1993 [192]	type	No	accident	suicide, homicide	-	Example only. Suicide: suicide: "In our series all the suicidal burns were married females and they burned themselves by pouring kerosene oil on their clothes and setting themselves afire. Their ages varied between 20 and 80 years. The single case of suicide in an 80-year-old woman was the result of a feeling of being unwanted and lonely."
Gupta 1996 [393]	-	-	accident	-	-	Example only. Accident: "the lowered flash point of the petrol-kerosene mixture (to below room temperature) caused the accidents."
Hafeez 2019 [200]	-	-	-	assault, victim	-	Νο
Honnegowda 2019 [394]	-	-	accident	-	-	Example only. Accident: accident: "the stated cause for alleged accidental burn injury in females (63.7%) was ignition of their clothing, and males (33.4%) received burn injury while attempting to save other victims"
lqbal 2013 [395]	-	-	accident	intentional, self inflicted, assault	-	Νο
Jayaraman 1993 [396]	-	-	accident	non accidental, homicide, suicide	-	Νο
Jeevaratnam 2014 [397]	-	-	accident	-	-	No
Karunadasa 2010 [398]	-	-	-	assault	-	Νο
Kim 2012 [399]	-	-	accident	suicide	-	No
Kumar 1994 [400]	-	-	accident	-	-	Example only. Accident: "Young girls are mainly introduced to wearing the traditional saree (long piece of cloth loosely wrapped around the lower half of body with a flowing tail over one shoulder, the tail is called pallu and the pallu accidentally catches on fire when they get up and it slips from the shoulder onto the stove."
Kumar 2000 [401]	-	-	accident	-	-	No
Kumar 2010 [402]	-	-	accident, victim	-	-	Example only. Accident and victims: In depth description of the circumstances leading to the blast and resulting injuries of the victims.
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Kumar 2010 [403]	clinical forensic study	No	accident, victim	-	-	Example only. Accident: "On July 12, 1996, 11.0 p.m., when three workers were mixing petroleum coke in the molten metal of the ladle refining furnace, suddenly flame and hot gases emerged, inflicting severe burns."
Kumar 2012 [305]	manner	No	accident	suicide, homicide	not ascertained	No
Kumar 2013 [404]	-	-	accident, victim, disaster	-	-	Example only. Disaster: "An Indian Oil Corporation LPG tanker rammed a divider in an attempt to overtake a vehicle at the Chala bypass near Bhagavathy Temple at 11 p.m. The tanker containing LPG The LPG vapour was seen to flow slowly all around at the ground level like cloud of white colour gas (as described by eye witness) that burst into flames within 20 min. The blast was soon followed by two more blasts at 3 min interval."
Laloe 2002 [195]	circumstances	No	accident	self inflicted, homicide, assault, suicide, self injury	doubtful	No
Laloe 2002 [196]	circumstances, cause	No	accident	self inflicted, assault, suicide, violence, self harm	doubtful	Example only. Suicide related: "attempts by the husband to rescue his wife attempting suicide"
Lama 2015 [281]	intent	No	unintentional	assault, intentional, self inflicted, self harm	-	No
Learmonth 1979 [336]	-	-	accident, non intentional	suicide, non accidental	-	No
Marsh 1996 [201]	circumstances	No	unintentional, mishap	suicide, homicide, assault	-	No
Masood 2016 [405]	manner	No	accident	suicide, homicide	-	No
Mehboob 2021 [406]	-	-	accident	-	-	No

Mukerji 2001 [193]	mode	No	accident	suicide	-	Example only. Accident: e.g. "Four cases accidentally poured hot water when left unattended in the bathroom". Suicide: e.g. "A 9- year-old female committed suicide by pouring kerosene over herself and setting herself on fire after a quarrel with her brother. She was most probably influenced by a similar recent incident in her neighbourhood"
Natarajan 2014 [213]	-	-	non intentional, accident	intentional, suicide, homicide	burn were suffered by someone who tried to intervene	No
Naumeri 2019 [407]	-	-	accident	-	-	No
Newberry 2019 [202]	-	-	accident	non accidental, self inflicted	-	No
Padovese 2010 [408]	aetiology	No	accident	self immolation	-	No
Paliwal 2014 [409]	-	-	accident, incident	-	-	Example only. Accident: "one accident occurred during unauthorised refilling of the smaller cylinder from a larger one involving 2 victims, one accident occurred from LPG geyser at home and one was due to a leaking gas cylinder thrown in the sewerage causing a major fire accident"
Parray 2015 [410]	circumstances, cause	No	accident	suicide, homicide	-	No
Puri 2009 [411]	-	-	accident	-	-	No
Ramakrishnan 1991 [412]	-	-	accident	-	-	Example only. Accident: "Low tension accidents were usually domestic accidents, particularly in children - invariably as a result of poking their moist fingers into power sockets and plug points within their reach."
Rao 1966 [413]	-	-	accident	-	-	No
Rao 1989 [203]	nature	No	accident	suicide, homicide	unclassifiable	No

Rashid 2014 [414]	-	-	-	assault, victim	-	No
Raza 2009 [188]	-	-	-	-	branding	Example only. Branding: "A 35-year-old Pakistani male with a history of chronic malaria, progressive splenomegaly and a complaint of severe left sided abdominal pain was treated by branding with a hot metal rod 7 days prior to admission."
Razzaque 2020 [415]	demographic feature	No	accident	-	-	No
Sakya 2018 [416]	type	No	unintentional	intentional, suicide	-	No
Saleem 2001 [417]	-	-	accident	-	-	No
Sarma 1994 [418]	-	-	accident	suicide, homicide, dowry	-	No
Sawhney 1989 [419]	nature	No	accident	homicide, suicide	-	No
Segu 2016 [204]	-	-	-	suicide, self immolation	-	No
Shankar 2012 [420]	-	-	-	suicide, homicide	-	No
Shankar 2012 [421]	-	-	accident	-	-	No
Shankar 2014 [187]	cause, mode	Example only. External cause: response options include either intentional (homicidal or suicidal) or unintentional(accidental)	unintentional, accident	intentional, homicide , suicide	-	No
Shankar 2015 [422]	-	-	accident	-	-	No
Sharma 2015 [423]	-	-	unintentional	-	-	No
Siddiqui 1998 [424]	human behaviour	No	carelessness, accident	intentional, homicide, suicide	-	Example only. Accident: "Most of the females acted clumsily during cooking, for instance pouring kerosene in a burning stove and lighting match in the

						presence of leaking gas. Accidental burns were commonly prevalent among males (19.6%) relative to those in females (3.5%) - p<0.001 and were mostly inflicted at their places of work."
Siddiqui 2015 [159]	intent	No	unintentional	self inflicted, assault, intentional	-	Νο
Singh 2012 [425]	-	-	accident	suicide, homicide	-	No
Singh 2012 [426]	cause, mode	No	unintentional, accident	intentional, homicide, suicide	-	No
Srinivasulu 2014 [427]	nature	No	accident	suicide, homicide	-	No
Subrahmanyam 1996 [194]	cause, intent	No	accident	suicide, homicide	-	Example only. Homicide: "One case of branding by the husband on his wife was a homicidal attempt triggered by suspected infidelity."
Sunder 1998 [428]	-	-	industrial, occupational	-	-	No
Tahir 2010 [186]	-	-	accident	self burns, self inflicted, self immolation, suicide	incidental	Yes
Tiwari 1999 [429]	-	-	accident	-	-	Example only. Accident: e.g. "In the first two cases current passed directly through the string of kite, which was wet due to rain showers just before the accident, when the kite got entangled in the electrical wires."
Wagle 1999 [205]	-	-	accident	suicide	-	No
Waqas 2018 [430]	aetiology	No	accident	assault	-	No
Yar 2011 [431]	nature	No	accident	suicide	-	No
Yerpude 2011 [206]	cause	No	accident	homicide, suicide	-	No
Zopate 2017 [207]	-	-	accident	-	-	No

Reference	Method of	Method of differentiation of intent as described in the article	Assessment	Other variable method of measurement described in
	differentiation		rigour	the article
Adil 2016	Inferred	Administered questionnaire completed prospectively.	-	-
Adil 2016 [373]	Inferred	Administered questionnaire completed prospectively.	-	-
Agrawal 1990 [374]	Not stated	-	-	-
Ahmad 2015	Inferred	Proforma completed on admission by taking history from	-	TBSA: Percentage of burn was determined using rule
[375]		patient/family.		of nines
Ahmed 2009	Explicit	"Patients less then ten years of age were excluded from the study	Assault: 5	-
[197]	-	because medico-legal aspect is least likely in these patients. Patients	Accident: C	
		and their relatives/attendants were carefully interviewed by medical		
		officer and in charge nurse repeatedly regarding the circumstances		
		and nature of accident, complete profile of the patient and their		
		family etc was recorded carefully. All these informations were		
		gathered in complete secrecy and by repeated informal interviews		
		and discussions."		
Ahmed 2014	Inferred	"All patients and their first relatives (parents, husband, siblings etc)	-	-
[376]		were interviewed by our team member and in charge nurse		
[]		repeatedly regarding the circumstances of accident."		
Ahmed 2016	Inferred	Proforma completed prospectively	-	TBSA: Lund and Browder chart or Rule of Nines.
[377]				
Ahuja 2002	Inferred	Patient records	-	-
[378]				
Ahuja 2009	Inferred	Retrospectively from patient records.	-	-
[379]				
Ahuja 2011	Inferred	Prospectively from clinical database of patient admissions	-	Socioeconomic status: Kuppuswamy scale.
[302]				Literacy level: A patient was considered as literate if
				he/she could read and write with understanding in
				any language.
				In accidental burn injury the exact mechanism of
				injury: gas leak/cylinder blast/stove
				malfunction/negligence. A gas leak was recorded
				when the mishap occurred due to a direct leak caused
				'

## Appendix H: Method of differentiation of injury intent and other variables. Abbreviations: TBSA – Total body surface area of the burn injury.

				by damage to connecting tube. An
				indirect/indovertent leak resulting from person fault
				refilling of cylinder or working while wearing loose
				fitting clothes was considered to be negligence
				Negligence also included keeping the stove close to
				inflammable material or cooking in a utencil much
				larger than the stove base. Any technical defect like a
				faulty cylinder regulator or stove valve leading to the
				mishan was considered as stove malfunction
				Inhalation injury component based only on clinical
				features like: History of fire in enclosed space, burns
				around mouth and/or nose, soot in mouth or nostrils
				singed nasal hairs intraoral hurns intraoral swelling
				hoarseness of voice and inspiratory stridor
				Bronchoscopy to assess inhalation injury was not
				possible for all patients because of large number of
				burn patients coming to our center.
Alibran 2012	Inferred	Retrospective review of patient records.	-	-
[380]				
Allbran 2013	Inferred	Prospectively completed questionnaire.	-	-
[381]				
Aslam 2012	Inferred	Prospectively completed proforma.	-	TBSA: Lund and Browder chart
[382]				
Aslam 2017	Inferred	Prospectively completed proforma.	-	TBSA: Lund and Browder chart
[190]				
Aslam 2020	Inferred	Retrospective review of patient records.	-	TBSA: Lund and Browder chart
[383]				
Baranwal 2021	Inferred	The information for the study was obtained from burn victims and/or	-	Socioeconomic status: Kuppuswamy scale
[384]		family members present during the mishap through a pre-validated		
		questionnaire and detailed physical examination.		
Belur 2014 [74]	Explicit	Semi-structure interviews with women admitted with a burn injury or	Assault: 5	-
		their relatives, healthcare providers, and police as part of qualitative	Accident: C	
		study. "Clinicians at the frontline in emergency or burns wards take an		
		initial history from the patient or her relatives, register a medico-legal		

		case and inform the police stationed in the casualty ward."" his involvement was restricted to taking down the history or cause of burns as narrated by the patient or relatives; he did not usually delve into the details of the incident."" even when doctors find that the narrative they have been given and the burn patterns do not accord with one another, they seldom have the time or inclination to follow it up in order to try to ascertain the sequence of events that led up to the human"		
Bhandari 2019 [385]	Inferred	Key informant interviews about their views on burns, not specifically about how intent is determined.	-	-
Chakraborty 2010 [198]	Explicit	"The data were collected by interview of patients and / or their relatives with the help of pre-designed and pre-tested schedule. The bed head tickets, admission register and the referral note were also reviewed. The medico legal aspects were obtained by interviewing the patients or their relatives with the help of the schedule and also by reviewing the relevant records like admission register and bed tickets."	Assault: 5 Accident: C	TBSA: Lund and Browder chart
Daruwalla 2014 [189]	Explicit	Clinicians document intent based on what the patient or relatives said e.g. "My job is merely to document what I have got from the patient in the patient's own words". Clinicians often thought accidental burns were intentional. This information is included in the medicolegal case notes. The police then investigate the burn further. More detail of the process included in the study.	Assault: 5 Accident: C	-
Das 1983 [386]	Not stated	-	-	-
Das 2013 [199]	Explicit	Patient reported injury as assault, and claims believed to be consistent with history and clinical picture. "Included in the study were both outpatients and inpatients who made specific complaints about the intentional nature of the injury to police and who requested injury certificates for litigation purposes." "Included in the study were both outpatients and inpatients who made specific complaints about the intentional nature of the injury to police and who requested injury certificates for litigation purposes." "Although the health-care team was suspicious of intent in some cases, the absence of investigation by the local authorities left no option but to categorise those as accidental."	Assault: 2 Accident: C	-

Das 2015 [387]	Not stated	-	-	-
Dash 2021 [388]	Inferred	Retrospective review of outpatient and inpatient medical records	-	Socioeconomic status: Modified Kuppuswamy Scale
Faisal 2016 [389]	Inferred	Prospectively administered questionnaire to convenience sample of patients.	-	self esteem: Linkert State Self Esteem Scale (reference given)
Farooq 2011 [390]	Inferred	WHO injury surveillance questionnaire prospectively completed through patient interview and use of patient records.	-	-
Ganesamoni 2010 [391]	Inferred	A detailed clinical examination was done, and a detailed history was recorded according to the questionnaire created	-	TBSA: Lund and Browder chart Inhalational injury: assessed by the history of smoke exposure and presence of hoarseness, stridor, tachyponea, wheezing or rhonchi. Singed nasal hairs or carbonaceous sputum were considered objective signs of inhalation injury. Bronchoscopic assessment of airway injury was not done
Goyal 2021 [392]	Inferred	Retrospective review of trauma registry	-	TBSA: Lund and Browder
Gupta 1992 [191]	Inferred	Prospectively completed proforma.	-	-
Gupta 1993 [192]	Inferred	Prospectively completed proforma.	-	-
Gupta 1996 [393]	Not stated	-	-	-
Hafeez 2019 [200]	Explicit	"Data was retrieved manually from the hospital records of individual files of every victim using purposive samplingDemographic questionnaire was developed in the light of literature and it included gender, age, education, marital status, area of residence, total burn surface area (TBSA), assaulted body parts, assaulted by, and the reason of assault."	Assault: 5 Accident: NA	-
Honnegowda 2019 [394]	Inferred	"On admission, data were collected according to the burns ward protocol from the patients themselves or their relative". The article uses the term "alleged accidental" suggesting that intent is based on what the patient/relative state.	-	TBSA: rule of nines Resuscitation: Parkland Formula

lqbal 2013 [395]	Inferred	Prospectively completed proforma	-	TBSA: rule of nines in adults and Lund and Browder in children up to 12 years old. Initial management: Advance Burn Life Support protocols of the American burn Association Fluid resuscitation: Mount Vernon formula
Jayaraman 1993 [396]	Inferred	Prospectively completed WHO proforma		Fluid resuscitation: parkland formula
Jeevaratnam 2014 [397]	Inferred	Retrospective review of patient records.	-	-
Karunadasa 2010 [398]	Inferred	Retrospective review of burns registry, patient records, operation registers, and rehabilitation registers by departmental staff.	-	Fluid resuscitation: Parkland formula
Kim 2012 [399]	Inferred	Retrospective questionnaire administered to patients about initial burn care, and review of patient demographic details from hospital records.	-	-
Kumar 1994 [400]	Inferred	Prospectively completed proforma by patient or relative interviews.	-	TBSA: body surface area charts modified from Lund and Browder and Carvajal.
Kumar 2000 [401]	Not stated	-	-	-
Kumar 2010 [402]	Not stated	-	-	-
Kumar 2010 [403]	Not stated	-	-	-
Kumar 2012 [305]	Inferred	Proforma completed retrospectively using patient notes.	-	-
Kumar 2013 [404]	Inferred	Data collected by medical professional through site visits and interviews with the media, eye witnesses, rescuers, district collector, and district medical officer.	-	
Laloe 2002 [195]	Explicit	Based upon what was reported by the patient or relatives and clinical assessment. "Deliberate self-harm, acknowledged by patient or relatives during the course of hospitalisation, was classified as such. Suspected but unconfirmed cases, either because of the distribution of the burns or the behaviour of the patient or the relatives, were classified as doubtful."	Assault: 5 Accident: C	TBSA: rule of nines

Laloe 2002	Explicit	Based upon report of patient and relatives combined with clinical	Assault: 5	TBSA: adults - rule of nines, children - Lund and
[196]		assessment. "We have classified as self-inflicted those cases	Accident: C	Browder
		acknowledged by patient or relatives during the course of		
		hospitalisation. Doubtful cases were those where the distribution of		
		the burns or the behaviour of the patient or her relatives suggested		
		that they were not accidental" "doubtful origin [burns] (allegedly		
		accidental but thought to be self-inflicted or due to violence)"		
Lama 2015	Inforred	Secondary analysis of deidentified nations data	_	_
[201]	interreu	Secondary analysis of dedentified patient data.	_	
[201]	Informed	Detrespective review of notiont records		
Learmonth	Interred	Retrospective review of patient records.	-	-
1979[336]				
Marsh 1996	Explicit	Patient interview about circumstances of injury	Assault: 5	-
[201]			Accident: C	
Masood 2016	Inferred	Proforma completed using patient records, police records, and	-	-
[405]		enquiry reports.		
Mehboob 2021	Not stated	-	-	-
[406]				
Mukerji 2001	Inferred	Prospectively collected burn treatment registry.	-	-
[193]				
Natarajan 2014	Inferred	Prospectively collected hospital registry and semi-structured	-	-
[213]		interviews.		
Naumeri 2019	Inferred	Questionnaire completed prospectively by duty doctor after	-	-
[407]	interred	interviewing parents		
Newberry 2019	Explicit	"Data included demographics medical history physical exam care	Assault: 5	-
[202]	LAplicit	rendered by the EMT and whether the injury was accidental or non-	Assault. 5	
[202]		assidental (nor patient or caller report) "	Accident. C	
Dedayaaa 2010	Informed	Detrespective review of retient records		
Padovese 2010	Interred	Retrospective review of patient records.	-	IBSA: Rule of nines
Paliwal 2014	Inferred	Proforma completed prospectively by medical professional.	-	-
[409]	-			
Parray 2015	Inferred	Proforma completed using information from burn ward database,	-	-
[410]		ward register, and patient records.		
Puri 2009 [411]	Inferred	The history of injury was obtained from the patient or accompanying	-	-
		persons (in the case of children).		
Ramakrishnan	Not stated	-	-	-
			1	

Rao 1966 [/13]	Not stated		_	_
Na0 1900 [413]			-	
Rao 1989 [203]	Explicit	Data collected on proformas by staff. "Psychological autopsy was	Assault: 4	-
		performed on fatal cases.""Each case was discussed by the research	Accident: C	
		team and the decision on the nature of the burns was arrived at		
		(accidental, suicidal or homicidal)."		
Rashid 2014	Not stated	-	-	-
[414]				
Raza 2009	Not stated	-	-	-
[188]				
Pazzague 2020	Inferred	Self-administered questionnaire		TRSA: rule of nines
[415]	interreu			TBSA. Tule of filles
Sakya 2018	Inferred	Key informant interviews and focus group discussions.	-	-
[416]				
Saleem 2001	Inferred	Proforma completed prospectively.	-	-
[417]				
Sarma 1994	Not stated	-	-	-
[418]				
Sawhney 1989	Inferred	Retrospective review of patient records.	-	-
[419]				
Segu 2016	Explicit	"A Performa was prepared to document sociodemographic data which	NA	TBSA: Lund and Browder
[204]	Explicit	included age gender education type of family and per capita income		Fluid resuscitation: Parkland's formula
[204]		Information reporting the size metanage surrounding the incident		Depression: Back's Depression Inventory
		mormation regarding the circumstances surrounding the incident,		Contraction and a state of the second state of
		burn severity, cause of suicide and any associated linesses was also		Socioeconomic state: Kuppuswamy scale
		collected. During history taking particular emphasis was given to know		
		the intent of suicide by talking to patients/relatives/friends."		
Shankar 2012	Inferred	Administered questionnaire completed prospectively. The terms	-	-
[420]		"alleged suicidal and homicidal burn injuries" are used suggesting the		
		intent was as reported by the patient or family.		
Shankar 2012	Inferred	Retrospective review of admission register, hospital computer	-	
[421]		database, and patient records.		
Shankar 2014	Inferred	Proforma completed prospectively through interviewing patients or	-	-
[197]	interred	their relatives. Data collected from patient records if interview not		
[107]		nossible		
Shankar 2015	Inforrad	Proforma completed prospectively		
	merred	From the completed prospectively	-	-
Sharma 2015	Interred	Review of deidentified patient records.	-	Caste - as per reference (Bennett L, Dahal D,
[423]				Govindasamy P. Caste, Ethnic and Regional Identity in

				Nepal: Further Analysis of the 2006 Nepal Demographic and Health Survey)
Siddiqui 1998 [424]	Inferred	Review of patient records.	-	-
Siddiqui 2015 [159]	Inferred	Pretested proforma completed prospectively by researchers through interviewing patients or their family.	-	-
Singh 2012 [425]	Inferred	Prospectively collected data by interviewing patients or their family.	-	-
Singh 2012 [426]	Inferred	Questionnaire completed prospectively by interviewing patients or their family. Outcomes captured by reviewing personal history, inquest report, or dying declaration. Inclusion: Admitted patients with suicidal or homicidal burn injuries.	-	-
Srinivasulu 2014 [427]	Inferred	Proforma completed prospectively.	-	TBSA: rule of nines
Subrahmanyam 1996 [194]	Not stated	-	-	-
Sunder 1998 [428]	Not stated	-	-	-
Tahir 2010 [186]	Inferred	Review of patient records.	-	-
Tiwari 1999 [429]	Not stated	-	-	fluid therapy: Parkland formula
Wagle 1999 [205]	Explicit	"All the patients and their relatives were seen one to three times in the first week post-burns. When possible, friends and neighbours were interviewed. All of the initial interviews were carried out by a female psychiatrist (SW) The main purpose was to gather information about the socio-demographic details and also to find out whether or not the injuries resulted because of a suicide attempt. The patients were divided into two groups depending on the presence or absence of a suicidal intent. The information about the suicidal intent was obtained by speaking to patients, their blood relatives and by referring to case notes."	Assault: NA Accident: C	Life stress: Presumptive Life Event Scale
Waqas 2018 [430]	Inferred	Validated questionnair completed prospectively through patient interview by medical students.	-	PTSD symptomatology: Impact of Events Revised Scale. Ego resiliency: Ego Resiliency Scale

				Perceived social support: Multidimensional Scale of
				Perceived Social Support
Yar 2011 [431]	Inferred	Review of patient records.	-	-
Yerpude 2011	Explicit	"The medico legal aspects were obtained by interviewing the patients	Assault: 5	TBSA: Lund and Browder chart
[206]		or their relatives with the help of the schedule and also by reviewing	Accident: C	
		the relevant records like admission register and bed tickets."		
Zopate 2017	Explicit	"The detailed history was obtained from the patients close relatives or	Assault: NA	-
[207]		friends available and the person who was present at the time of	Accident: B	
		incidence or the one accompanying the victim. Information was also		
		collected from the relatives, maternal as well as in laws, neighbours		
		and police investigation reports. In doubtful cases, the dying		
		declaration given by the patient in presence of the magistrate was		
		compared with the statement given by the patient at the time of		
		admission."		

## Appendix I: Data dictionary code book for the burn register database.

#	Variable / Field Name	Field Label Field Note	Field Attributes (Field Type, Validation, Choices, Calculations, etc.)				
Instr	ument:SASHI_B data en	try form(sashi_b_data_entry_form) Collapse					
1	[sashi_eid]	SASHI Event ID Found in the event ID spreadsheet	text	text			
2	[reg_year]	Section Header: Burns register information Register book year Check this matches the first four digits of the SASHI Event ID. Found in 'D.O.A.' (date of admission) column.	text (number, Mi	n: 1990, Max: 2030), Required			
3	[reg_month]	Register book month	radio, Required				
		Found in 'D.O.A.' (date of admission) column.	January	January			
			February	February			
			March	March			
			April	April			
			May	Мау			
			June	June			
			July	July			
			August	August			
			September	September			
			October	October			
			November	November			
			December	December			
4	[reg_page]	Register book page Use page number on top left hand side of page.	text (integer, Min: 0, Max: 1000), Required				
5	[sl_no]	SL number numerator (sl_num) SL number denominator Check this matches the final digits of the SASHI Event ID. (sl_den)	descriptive				
6	[sl_num]	'SL no.' numerator This is the numerator of the value found in the 'SL no.' column. It corresponds to the number the patient presented to the burns unit that month. <i>e.g. for 7/64, enter the number 7</i>	text (integer, Mir	n: 0, Max: 1000)			
7	[sl_num_nrc]	If you do not have a response to 'SL no	radio, Required				
	Show the field ONLY if:	numerator', please state why.	unreadable	Unreadable			
	[sl_num] = ''		INIR	Information not in records			
			notapp	Not applicable			
8	[sl_den]	'SL no.' denominator. This is the denominator of the value found in the 'SL no.' column. It corresponds to the number the patient presented to the burns unit that year. <i>e.g. for 7/64, enter the number 64</i>	text (integer, Min: 0, Max: 1000)				
9	[sl_den_nrc]	If you do not have a response to 'SL no	radio, Required				
	if:	denominator , please state why.	unreadable	Unreadable			
	[sl_den] = ''		INIR	Information not in records			
			notapp	Not applicable			
10	[ip_no]	Inpatient number	text (integer), Ide	entifier			
11	[ip_no_nrc]	If you do NOT have a response for 'Inpatient	radio, Required				
	Show the field ONLY if:	number', please state why	unreadable	Unreadable			

	[ip_no] = ''		INIR	Informatio	on not in records	
			notapp	Not applic	able	
12	[ad_full]	Section Header: Patient address Patient address as written in the burns register This field is for free text entry. Get from 'address data' spreadsheet.	text, Identifier			
13	[ad_full_nrc]	If you do NOT have a response for 'Patient	radio, Required	T		1
	if:	address free text , please state why	unreadable	Unreadab	le	
	[ad_full] = ''		INIR	Informatio	on not in records	
			notapp	Not applic	able	
14	[ad_country]	Patient address: Country	radio India India Other Other			
15	[ad_country_nrc]	If you do NOT have a response for 'Country',	radio, Required	I		1
	Show the field ONLY if:	please state why	unreadable	Unreadab	le	
	[ad_country] = ''		INIR	Informatio	on not in records	
			notapp	Not applic	able	
16	[ad_state]	Patient address: State in India	radio		T	
	Show the field ONLY if:		Andaman_Nicob	oar_Islands	Andaman & Nico	obar Islands
	[ad_country] = 'India'		Andhra_Pradesh	1	Andhra Pradesh	
			Arunachal_Prade	esh	Arunachal Prade	esh
			Assam		Assam	
			Bihar		Bihar	
			Chandigarh		Chandigarh	
			Chhattisgarh		Chhattisgarh	
			Dadra_Nagar_Ha	aveli	Dadra & Nagar H	Haveli
			Daman_Diu		Daman & Diu	
			Goa		Goa	
			Gujarat		Gujarat	
			Haryana		Haryana	
			Himachal_Prade	sh	Himachal Prades	sh
			Jammu_Kashmir	•	Jammu & Kashm	nir
			Jharkhand		Jharkhand	
			Karnataka		Karnataka	
			Kerala		Kerala	
			Lakshadweep		Lakshadweep	
			Madhya_Pradesh		Madhya Pradesh	1
			Maharashtra		Maharashtra	
			Manipur		Manipur	
			Meghalaya		Meghalaya	
			Mizoram		Mizoram	
			Nagaland		Nagaland	
			NCT_Delhi		NCT Of Delhi	
			Odisha		Odisha	
			Puducherry		Puducherry	

			Punjab		Punjab	
			Raiasthan		Raiasthan	_
			Sikkim		Sikkim	
			Tamil Nadu		Tamil Nadu	
			Tripura		Tripura	
			Uttar Pradesh		Uttar Pradesh	_
			Uttarakhand		Uttarakhand	-
			West Bengal		West Bengal	-
			Other		Other	-
			Custom alignment	· 1 H	other	J
17	[ad state prc]	If you do NOT have a response for 'State'	radio Required			
1/	Show the field ONLY	please state why	unreadable	Unreadab	le	
	if: [ad_country] = 'India'		INIR	Informatio	on not in records	
	and [ad_state] = "		notapp	Not applic	able	
10	[ad table]	Patient addross: District Patient addross:	doscriptivo			
10	[au_table]	Taluk/Tehsil (ad_district) (ad_tq_cnagar) (ad_tq_hassan) (ad_tq_kodagu) (ad_tq_mandya) (ad_tq_mysore) (ad_tq_rnagara)	uescriptive			
19	[ad_district]	Patient address: District of Karnataka State	radio			
	Show the field ONLY if:	e.g. Mysore District	Bagalkot	Baga	lkot	
	[ad_state] =		Bangalore	Bangalore Bangalore		
	Kalilataka		Bangalore_Rural Bangalore Rural			
			Belgaum Belgaum		ium	
			Bellary	Bella	ry	
			Bidar	Bidar		
			Bijapur	Bijap	ur	
			Chamarajanagar	Cham	narajanagar	
			Chikkaballapura	Chikk	aballapura	
			Chikmagalur	Chikr	nagalur	
			Chitradurga	Chitra	adurga	
			Dakshina_Kanna	da Daksl	hina Kannada	
			Davanagere	Dava	nagere	
			Dharwad	Dhar	wad	
			Gadag	Gada	g	
			Gulbarga	Gulba	arga	
			Hassan	Hassa	an	
			Haveri	Have	ri	
			Kodagu	Koda	gu	
			Kolar	Kolar		
			Koppal	Корр	al	
			Mandya	Mano	dya	
			Mysore	Myso	ore	
			Raichur	Raich	iur	
			Ramanagara	Rama	anagara	

			1			
			Shimoga	Shimoga		
			Tumkur	Tumkur		
			Udupi	Udupi		
			Uttara_Kannada	Uttara Kann	ada	
			Yadgir	Yadgir		
			Other	Other		
			Custom alignment	t: LV		_
20	[ad_district_nrc]	If you do NOT have a response for 'District of	radio, Required	I		1
	show the field ONLY if:	Karnataka State', please state why	unreadable	Unreadable		
	[ad_state] = 'Karnataka' and		INIR	Information not	in records	
	[ad_district] = "		notapp	Not applicable		
21	[ad_tq_cnagar]	Patient address: Taluk (Tq) of	radio			
	Show the field ONLY if:	Chamarajanagar District, Karnataka State	Chamarajanagar	Chamarajanag	gar	
	[ad_district] =		Gundlupet	Gundlupet		
	Chamarajanagar		Kollegal	Kollegal		
			Yelandur	Yelandur		
22	[ad_tq_cnagar_nrc]	If you do NOT have a response for 'Taluk (Tq)	radio, Required			_
	Show the field ONLY if:	of Chamarajanagar District', please state why	unreadable	Unreadable		
	[ad_district] =		INIR	Information not	in records	
	[ad_tq_cnagar] = "		notapp	Not applicable		
23	[ad_tq_hassan]	Patient address: Taluk (Tq) of Hassan District,	radio			
	Show the field ONLY if:	Karnataka State	Alur	Alur		
	[ad_district] =		Arkalgud	Arkalgud		
	Hassan		Arsikere	Arsikere		
			Belur	Belur		
			Channarayapatn	a Channarayapa	atna	
			Hassan	Hassan		
			Hole_Narsipur	Hole Narsipur		
			Sakleshpur	Sakleshpur		
			Other	Other		
24	[ad_tq_hassan_nrc]	If you do NOT have a response for 'Taluk (Tq)	radio, Required			
	Show the field ONLY if:	of Hassan District', please state why	unreadable	Unreadable		
	[ad_district] =		INIR	Information not	in records	
	[ad_tq_hassan] = "		notapp	Not applicable		J
25	[ad_tq_kodagu]	Patient address: Taluk (Tq) of Kodagu District,	radio			
	Show the field ONLY if:	Karnataka State.	Madikeri	Madikeri		
	[ad_district] =		Somvarpet	Somvarpet		
	KOUABN		Virajpet	Virajpet		
			Other	Other		
26	[ad_tq_kodagu_nrc]	If you do NOT have a response for 'Taluk (Tq)	radio, Required			_
	Show the field ONLY if:	of Kodagu District', please state why	unreadable	Unreadable		
	[ad_district] =		INIR	Information not	in records	
	kodagu' and [ad_tq_kodagu] = ''		notapp	Not applicable		
1	1	1				

27	[ad_tq_mandya] Show the field ONLY	Patient address: Taluk (Tq) of Mandya District. Karnataka State	radio				
	if:		Krisnnarajpet	Kr	Isnnarajpet		
	[ad_district] = 'Mandya'		Maddur	M	addur		
			Malavalli	M	alavalli		
			Mandya	M	andya		
			Nagamangala	Na	agamangala		
			Pandavapura	Pa	ndavapura		
			Shrirangapattan	ia Sh	rirangapattana		
			Other	Ot	her		
28	[ad_tq_mandya_nrc]	If you do NOT have a response for 'Taluk (Tq)	radio, Required				
	Show the field ONLY if:	of Mandya District', please state why	unreadable	Unre	adable		
	[ad_district] =		INIR	Infor	mation not in re	cords	
	[ad_tq_mandya] = ''		notapp	Not a	applicable		
29	[ad_tq_mysore]	Patient address: Taluk (Tq) of Mysore	radio				
	Show the field ONLY	District, Karnataka State	Heggadadevank	ote	Heggadadevar	nkote	
	[ad_district] =		Hunsur		Hunsur		
	'Mysore'		Krishnarajanaga	ra	Krishnarajana	gara	
			Mysore		Mysore		
			Nanjangud		Nanjangud		
			Piriyapatna		Piriyapatna		
			Tirumakudal_Na	arsipur	Tirumakudal -	Narsipur	
			Other		Other		-
20	[ad ta mysoro pro]	If you do NOT have a response for 'Taluk (Ta)	radio Poquirod				
50	Show the field ONLY	of Mysore District', please state why	unreadable	Unre	adable		
	if: [ad_district] =		INIR	Infor	mation not in re	cords	
	'Mysore' and		notapp	Nota	applicable		
31	[ad_tq_rnagara] Show the field ONLY	Patient address: Taluk (Tq) of Ramanagara District, Karnataka State	Channanatna	Ch	annanatna	7	
	if: [ad_district] =		Kanakanura	Ka Ka			
	'Ramanagara'		Magadi	NA NA			
			Domonogoro	Do			
			Ramanagara	Ra	Imanagara	_	
			Other	Ut	ner		
32	[ad_tq_rnagara_nrc]	If you do NOT have a response for 'Taluk (Tq) of Ramanagara District' please state why	radio, Required			]	
	if:		unreadable	Unre	adable		
	[ad_district] = 'Ramanagara' and		INIR	Infor	mation not in re	cords	
	[ad_tq_rnagara] = ''		notapp	Not a	applicable		
33	[age]	Section Header: Patient demographics Patient age If age < 1 year please put 0.	text (integer, Min	i: 0, Ma	x: 130)		
34	[age_months] Show the field ONLY if: [age] = '0'	If age under 1 year please specify age in months	text (integer, Min	i: 0, Ma	x: 11)		
35	[age_nrc]	If you do not have a response to 'patient	radio, Required	T			
	Show the field ONLY if:	age', please state why.	unreadable	Unre	adable		
	[age] = ''		INIR	Infor	mation not in re	cords	

-						
			notapp	Not	applicable	
36	[age_months_nrc]	If you do not have a response to 'age in	radio. Required	1		
	Show the field ONLY	months for patient age under 1 year', please	unreadable	Unre	adable	
	if: [age] = '0' and	state why.	INIR	Infor	mation not in records	
	[age_months] = "		notapp	Not	applicable	
37	[sex]	Patient sex	radio	omolo	1	
					-	
			Male Ma	lale	-	
			Other Ot	ther		
38	[sex_nrc]	If you do not have a response to 'patient sex',	radio, Required			l
	if:	please state why.	unreadable	Unre	adable	
	[sex] = ''		INIR	Infor	mation not in records	
			notapp	Not	applicable	
39	[unit]	Hospital unit	radio			
			Plastic_surgery	у	Plastic surgery	
			Other		Other	
40	[unit_nrc]	If you do not have a response to 'hospital	radio, Required			
	Show the field ONLY	unit', please state why.	unreadable	Unre	adable	
	[unit] = ''		INIR	Infor	mation not in records	
			notapp	Not	applicable	
/1	lincomel	Income	text (number M	din: 0 M	av: 1000000)	
12	[income_prc]	If you do NOT have a response for 'Income'	radio Required		ux. 1000000,	
42	Show the field ONLY	please state why	unreadable	Unre	adable	
	if: [income] = ''		INIR	Infor	mation not in records	
			notapp	Not	applicable	
42	[]	Contraction Administra		<u> </u>		
43	[doa]	Date of admission (D-M-Y):	text (date_dmy)	")		
44	[doa_nrc]	If you do NOT have a response for 'Date of	radio, Required			I
	show the field ONLY if:	admission', please state why	unreadable	Unre	adable	
	[doa] = ''		INIR	Infor	mation not in records	
			notapp	Not	applicable	
45	[toa_casualty]	Time of admission (HH:MM - 24 hour clock):	text (time, Min:	: 00:00, N	Лах: 23:59)	
46	[toa_casualty_nrc]	If you do NOT have a response for 'Time of	radio, Required			I
	if:	admission , please state why	unreadable	Unre	adable	
	[toa_casualty] = ''		INIR	Infor	mation not in records	
			notapp	Not	applicable	
47	[doa_ward]	Date of patient received to ward (D-M-Y):	text (date_dmy)	·)		
48	[doa_ward_nrc]	If you do NOT have a response for 'Date	radio, Required			
	Show the field ONLY if:	patient received to ward', please state why	unreadable	Unre	adable	
	[doa_ward] = ''		INIR	Infor	mation not in records	
			notapp	Not	applicable	
49	[toa_ward]	Time patient received to ward (HH:MM - 24	text (time, Min:	: 00:00, N	Лах: 23:59)	
		hour clock)				

50	[too word pro]	If you do NOT have a response for 'Time of	radio Roquire	h			
50	Show the field ONLY	admission to ward', please state why	unreadable	eu	Unreadable		
	if: [toa_ward] = ''		INIR		Information not in reco	rds	
			notapp		Not applicable		
51	[hurn_intent]	Section Header: Iniury	chockbox				1
51	[buin_intent]	Intent of burn injury	Accidental	bur	rn_intentaccidental	Aco	cidental
			Suicidal	bur	rn_intentsuicidal	Sui	cidal
			Homicidal	bur	rn_intenthomicidal	Но	micidal
			Electrical	bur	rn_intentelectrical	Ele	ctrical
			Old_burns	bur	rn_intentold_burns	Olc	l burns
			Other	bur	rn_intentother	Oth	ner
52	[burn_intent_other] Show the field ONLY	If other, please specify	text, Requirec	ł			-
	if: [burn_intent(Other)] = '1'						
53	[burn_intent_nrc]	If you do NOT have a response for 'Intent of	radio, Require	ed			
	Show the field ONLY	burn injury', please state why	unreadable		Unreadable		
	[burn_intent(Acciden		INIR		Information not in reco	rds	•
	tal)] = '0' and [burn_intent(Suicidal)		notapp		Not applicable		
	] = '0' and [burn_intent(Homicid al)] = '0' and [burn_intent(Electric al)] = '0' and [burn_intent(Old_bur ns)] = '0' and [burn_intent(Other)]						J
	= '0'						
54	[burn_tbsa]	TBSA burn lower limit (%) (burn_tbsa_low) TBSA burn upper limit (%) (burn_tbsa_up)	descriptive				
55	[burn_tbsa_low]	Percentage of total body surface area (TBSA) of the burn (0% - 100%) lower limit	text (integer, Custom alignr	Min: ment:	0, Max: 100) : RH		
56	[burn_tbsa_low_nrc]	If you do NOT have a response for 'TBSA burn lower limit' please state why	radio, Require	ed			1
	if:	lower mint, please state why	unreadable		Unreadable		
	[burn_tbsa_low] = "		INIR		Information not in reco	rds	
			notapp		Not applicable		
57	[burn_tbsa_up]	Percentage of total body surface area (TBSA) of the burn (0% - 100%) upper limit	text (integer, Custom alignr	Min: ment:	0, Max: 100) : RH		
58	[burn_tbsa_up_nrc]	If you do NOT have a response for 'TBSA burn	radio, Require	ed			1
	if:	upper mint, please state wity	unreadable		Unreadable		
	[burn_tbsa_up] = "		INIR		Information not in reco	ords	
			notapp		Not applicable		
59	[discharge_status]	Section Header: <i>Outcome</i> Discharge status	radio				
			Discharged	Dise	charged		
			DAMA	Dise –	charged against medical	adv	ice (DAMA)
			Transferred	Tra	insterred		
			Death	Dea	ath		
60	[discharge_status_nr c]	If you do NOT have a response for 'Discharge status', please state why	radio, Require unreadable	ed	Unreadable		
	if:						]

	[discharge_status] = "		INIR	Information not in records
			notapp	Not applicable
61	[dod]	Date of discharge/ transfer/ death (D-M-Y):	text (date_dmy)	
62	[dod_nrc]	If you do NOT have a response for 'Date of	radio, Required	
	Show the field ONLY if:	discharge/ transfer/ death', please state why	unreadable	Unreadable
	[dod] = ''		INIR	Information not in records
			notapp	Not applicable
63	[tod]	Time of discharge/ trasnfer/ death (HH:MM - 24 hour clock):	text (time, Min: 0	0:00, Max: 23:59)
64	[tod_nrc]	If you do NOT have a response for 'Time of	radio, Required	
	Show the field ONLY if:	discharge or death', please state why	unreadable	Unreadable
	[tod] = ''		INIR	Information not in records
			notapp	Not applicable
65	[burn_intent_overwri tten]	Section Header: Observations from data entry Was the intent of the burn overwritten? If yes, please include details in the notes box. Based on observation by the person completing data entry e.g. suicidal crossed out and overwritten with accidental.	radio, Required Yes Yes No No	
66	[linked]	Does this appear to be a linked case? If yes, please include details in the notes box. Based on observation by the person completing data entry e.g. patients have same address and time of admission and close IP numbers.	radio, Required Yes Yes No No	
67	[notes]	Notes or observations from data entry.	notes	
68	[sashi_b_data_entry_ form_complete]	Section Header: <i>Form Status</i> Complete?	dropdown 0 Incomplete 1 Unverified 2 Complete	

## Appendix J: India Census data used to create categorical response options for address information.

A spreadsheet was published as supplementary material by the journal Burns. This spreadsheet includes detailed geographic information compiled from the 2011 Indian Census (https://www.censusindia2011.com) on the villages, towns, and taluks of districts that are closest to KR hospital. These districts include Chamarajanagar, Hassan, Kodagu, Mandya, Mysore, and Ramanagara. It is not practicable to include all information from the spreadsheet, so an extract is included here. The full spreadsheet can be downloaded at https://doi.org/10.1016/j.burns.2023.08.007. The spreadsheet can be used by readers of the article to improve coding of address data. Filters can be used to find correct district/ taluk/ town/ village combinations.

State	District	Taluk/ Tehsil	Town/Village	Туре
Karnataka	Chamarajanagar	Chamarajanagar	Chamarajanagar (CMC)	Town
Karnataka	Chamarajanagar	Chamarajanagar	Achattipura	Village
Karnataka	Chamarajanagar	Chamarajanagar	Aldur	Village
Karnataka	Chamarajanagar	Chamarajanagar	Alur	Village
Karnataka	Chamarajanagar	Chamarajanagar	Amachavadi	Village
Karnataka	Chamarajanagar	Chamarajanagar	Ammanapura	Village
Karnataka	Chamarajanagar	Chamarajanagar	Ankanasettypura	Village
Karnataka	Chamarajanagar	Chamarajanagar	Arakalavadi	Village
Karnataka	Chamarajanagar	Chamarajanagar	Aralikatte	Village
Karnataka	Chamarajanagar	Chamarajanagar	Attagulipura	Village
Karnataka	Chamarajanagar	Chamarajanagar	Ayyanapura	Village
Karnataka	Chamarajanagar	Chamarajanagar	Badagalapura	Village
Karnataka	Chamarajanagar	Chamarajanagar	Badanaguppe	Village
Karnataka	Chamarajanagar	Chamarajanagar	Bagali	Village
Karnataka	Chamarajanagar	Chamarajanagar	Banahalli	Village
Karnataka	Chamarajanagar	Chamarajanagar	Bandigere	Village
Karnataka	Chamarajanagar	Chamarajanagar	Bandigowdanahalli	Village
Karnataka	Chamarajanagar	Chamarajanagar	Basavanapura	Village
Karnataka	Chamarajanagar	Chamarajanagar	Basavapura	Village
Karnataka	Chamarajanagar	Chamarajanagar	Basavatti	Village
Karnataka	Chamarajanagar	Chamarajanagar	Basthipura	Village
Karnataka	Chamarajanagar	Chamarajanagar	Bedaguli	Village

## Appendix K: RECORD statement checklist.

The RECORD statement – checklist of items, extended from the STROBE statement, that should be reported in observational studies using routinely collected health data.

	ltem No.	STROBE items	Location in manuscript where items are reported	RECORD items	Location in manuscript where items are reported
Title and abstract	1	1			
	1	(a) Indicate the study's design with a commonly used term in the title or the abstract (b) Provide in the abstract an informative and balanced summary of what was done and what was found		RECORD 1.1: The type of data used should be specified in the title or abstract. When possible, the name of the databases used should be included. RECORD 1.2: If applicable, the geographic region and timeframe within which the study took place should be reported in the title or abstract. RECORD 1.3: If linkage between databases was conducted for the study, this should be clearly stated in the title or abstract.	Cover page
Introduction	1				
Background rationale	2	Explain the scientific background and rationale for the investigation being reported			Body of introduction
Objectives	3	State specific objectives, including any prespecified hypotheses			End of introduction
Methods	1				
Study Design	4	Present key elements of study design early in the paper			Start of methods
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection			"Setting and participants" section

Participants	6	(a) Cohort study - Give the eligibility	RECORD 6.1: The methods of study	"Setting and
		criteria, and the sources and	population selection (such as codes or	participants"
		methods of selection of	algorithms used to identify subjects)	section
		participants. Describe methods of	should be listed in detail. If this is not	
		follow-up	possible, an explanation should be	
		Case-control study - Give the	provided.	
		eligibility criteria, and the sources		
		and methods of case ascertainment	RECORD 6.2: Any validation studies of the	
		and control selection. Give the	codes or algorithms used to select the	
		rationale for the choice of cases	population should be referenced. If	
		and controls	validation was conducted for this study	
		Cross-sectional study - Give the	and not published elsewhere, detailed	
		eligibility criteria, and the sources	methods and results should be provided.	
		and methods of selection of		
		participants	RECORD 6.3: If the study involved linkage	
			of databases, consider use of a flow	
		(b) Cohort study - For matched	diagram or other graphical display to	
		studies, give matching criteria and	demonstrate the data linkage process,	
		number of exposed and unexposed	including the number of individuals with	
		Case-control study - For matched	linked data at each stage.	
		studies, give matching criteria and		
		the number of controls per case		
Variables	7	Clearly define all outcomes,	RECORD 7.1: A complete list of codes and	"Variables and
		exposures, predictors, potential	algorithms used to classify exposures,	method of
		confounders, and effect modifiers.	outcomes, confounders, and effect	assessment"
		Give diagnostic criteria, if	modifiers should be provided. If these	section
		applicable.	cannot be reported, an explanation should	
			be provided.	
Data sources/	8	For each variable of interest, give		"Variables and
measurement		sources of data and details of		method of
		methods of assessment		assessment"
		(measurement).		section
		Describe comparability of		
		assessment methods if there is		
		more than one group		
Bias	9	Describe any efforts to address		No adjustments
		potential sources of bias		made to data for
				bias. But the study

				aimed to
				understand sources
				of bias in the data.
Study size	10	Explain how the study size was		"Data access and
		arrived at		cleaning" section
Quantitative	11	Explain how quantitative variables		"Variables and
variables		were handled in the analyses. If		method of
		applicable, describe which		assessment"
		groupings were chosen, and why		section
Statistical methods	12	(a) Describe all statistical methods,		"Statistical
		including those used to control for		methods" section
		confounding		
		(b) Describe any methods used to		
		examine subgroups and		
		interactions		
		(c) Explain how missing data were		
		addressed		
		(d) <i>Cohort study</i> - If applicable,		
		explain how loss to follow-up was		
		addressed		
		Case-control study - If applicable,		
		explain how matching of cases and		
		controls was addressed		
		<i>Cross-sectional study</i> - If applicable,		
		describe analytical methods taking		
		account of sampling strategy		
		(e) Describe any sensitivity analyses		
Data access and			RECORD 12.1: Authors should describe the	"Data access and
cleaning methods			extent to which the investigators had	cleaning" section
-			access to the database population used to	-
			create the study population.	
			RECORD 12.2: Authors should provide	
			information on the data cleaning methods	
			used in the study.	
Linkage			RECORD 12.3: State whether the study	"Data access and
			included person-level, institutional-level,	cleaning" section

				or other data linkage across two or more	
				databases. The methods of linkage and	
				mothods of linkage quality evaluation	
				chevild be provided	
				snould be provided.	
Results	T	[	<b></b>		
Participants	13	(a) Report the numbers of		RECORD 13.1: Describe in detail the	Start of results
		individuals at each stage of the		selection of the persons included in the	
		study (e.g., numbers potentially		study ( <i>i.e.,</i> study population selection)	
		eligible, examined for eligibility,		including filtering based on data quality,	
		confirmed eligible, included in the		data availability and linkage. The selection	
		study, completing follow-up, and		of included persons can be described in	
		analysed)		the text and/or by means of the study	
		(b) Give reasons for non-		flow diagram.	
		participation at each stage.		0	
		(c) Consider use of a flow diagram			
Descriptive data	14	(a) Give characteristics of study			Body of results
		participants ( <i>e.g.</i> , demographic,			,
		clinical social) and information on			
		exposures and notential			
		confounders			
		(b) Indicate the number of			
		participants with missing data for			
		participants with missing data for			
		(a) Cohort study, superpositor			
		(c) <i>Conort study</i> - summarise			
		follow-up time ( <i>e.g.</i> , average and			
		total amount)			
Outcome data	15	Cohort study - Report numbers of			NA
		outcome events or summary			
		measures over time			
		Case-control study - Report			
		numbers in each exposure			
		category, or summary measures of			
		exposure			
		Cross-sectional study - Report			
		numbers of outcome events or			
		summary measures			

Main results	16	(a) Give unadjusted estimates and,		NA
		if applicable, confounder-adjusted		
		estimates and their precision (e.g.,		
		95% confidence interval). Make		
		clear which confounders were		
		adjusted for and why they were		
		included		
		(b) Report category boundaries		
		when continuous variables were		
		categorized		
		(c) If relevant, consider translating		
		estimates of relative risk into		
		absolute risk for a meaningful time		
		period		
Other analyses	17	Report other analyses done—e.g.,		Body of results
		analyses of subgroups and		
		interactions, and sensitivity		
		analyses		
Discussion				
Key results	18	Summarise key results with		Body of discussion
		reference to study objectives		
Limitations	19	Discuss limitations of the study,	RECORD 19.1: Discuss the implications of	End of discussion
		taking into account sources of	using data that were not created or	
		potential bias or imprecision.	collected to answer the specific research	
		Discuss both direction and	question(s). Include discussion of	
		magnitude of any potential bias	misclassification bias, unmeasured	
			confounding, missing data, and changing	
			eligibility over time, as they pertain to the	
			study being reported.	
Interpretation	20	Give a cautious overall		Discussion
		interpretation of results		
		considering objectives, limitations,		
		multiplicity of analyses, results		
		from similar studies, and other		
		relevant evidence		

Generalisability	21	Discuss the generalisability (external validity) of the study		End of discussion
Other Information		lesuits		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based		"Funding" section
Accessibility of protocol, raw data, and programming code			RECORD 22.1: Authors should provide information on how to access any supplemental information such as the study protocol, raw data, or programming code.	

\*Reference: Benchimol EI, Smeeth L, Guttmann A, Harron K, Moher D, Petersen I, Sørensen HT, von Elm E, Langan SM, the RECORD Working Committee. The REporting of studies Conducted using Observational Routinely-collected health Data (RECORD) Statement. *PLoS Medicine* 2015; in press.

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