

INPLASY

A systematic review of current national hospital-based stroke registries that monitor access to evidence based care and patient outcomes

INPLASY202410062

doi: 10.37766/inplasy2024.1.0062

Received: 15 January 2024

Published: 15 January 2024

Corresponding author:

Gillian Mead

gillian.e.mead@ed.ac.uk

Author Affiliation:

University of Edinburgh.

Mead, GE¹; Cadilhac, DX²; Kim, J³; Lannin, N⁴; Dennis, M⁵; Kapral, M⁶; Pandian, J⁷; Hardianoto, Y⁸; Lin, B⁹; Meretoja, A¹⁰; Abd Aziz, N¹¹; Schwamm, L¹²; Norvving, B¹³; Thapa, L¹⁴; Dozier, M¹⁵; Kelavkar, S¹⁶; Shreyan, S¹⁷; Horne, A¹⁸; Leigh, C¹⁹; Gill, J²⁰; Razak, Z²¹.

ADMINISTRATIVE INFORMATION

Support - None.

Review Stage at time of this submission - Preliminary searches.

Conflicts of interest - None declared.

INPLASY registration number: INPLASY202410062

Amendments - This protocol was registered with the International Platform of Registered Systematic Review and Meta-Analysis Protocols (INPLASY) on 15 January 2024 and was last updated on 15 January 2024.

INTRODUCTION

Review question / Objective What are the characteristics of current national, hospital based stroke registries that are designed to monitor provision of, and quality, of stroke care?

‘Current’ means registries that are actively identifying patients-rather than old registries that have completed recruitment.

A ‘registry’ is defined as a data collection program (using a register, databank or database) for monitoring standardized indicators of care quality at multiple sites, in patients hospitalized with acute stroke. Only registries with at least a full year of prospective data collection will be included. We consider a stroke registry to be “national” if it reports an accepted country-wide system for data collection; carried the name of a country; or was titled as “national”. Our guiding principle will be to

define country as a United Nations (UN) member state or constituent country of a UN member state. If, however, there are devolved nations within the constituent country, with its own government, then those devolved nations will be included as separate nations.

The characteristics that we wish to describe will be a) Aims, governance and organisation of the registry. We want to report the coverage of the registry (by population and by geographical area and whether low, middle income or high income), who manages it (e.g. government-led, managed by an academic organisation or institution, or health service), who funds it (and the amount of funding available), and whether there are likely to be biases in the way that data are collected. For example, if registries allow constituent hospitals to collect their own data, it is possible that the data are collected in a way to maximise performance-particularly if

there are financial incentives for better performance.

b) Methods of the registry: We wish to know how cases are ascertained (including whether consent is needed), whether the variables collected align to national standards or clinical guidelines, how data are collected (manually, or imported from electronic medical records, and whether data importation is associated with less manual data collection) and how the data are fed-back or reported to clinical teams-frequency, real-time or not, data dashboards or the ability to download reports.

c) Data items collected. These will be divided up according to characteristics of the patients, process data in the acute and rehabilitation settings (including evidence based treatment delivery and, for time-dependent treatments, whether 'time to treatment' is recorded), and whether there is follow-up (and if so, what data items are collected, are they 'patient reported', timing of follow-up, and whether there is data linkage to routinely collected data).

We will report these characteristics in tables, divided according to low, high and middle income countries.

In our discussion, we will reflect on main features of the stroke registries and the considerations for developing new stroke registries in low, middle or high income settings.

Rationale The previous systematic review of stroke registries published in 2016 is now out of date.

We wish to update this review, and ensure that we capture information about whether registries are collecting data about new stroke treatments developed since then, in particular thrombectomy.

Condition being studied Stroke including ischaemic and intracranial haemorrhage. Not subarachnoid haemorrhage.

METHODS

Search strategy We will build on the search strategies in a previous review of stroke registries (Cadilhac et al, 2016) (to identify current national stroke registries being used in hospitals to monitor the quality of care). We will search Medline (Ovid), Embase (Ovid), Global Health (Ovid) and the WHO regional indices in Global Index Medicus. Searches will use two main concept areas, stroke and registries. Each concept area will be searched for using subject headings relevant to each database supplemented with free text search terms.

Grey literature will be identified by searching websites of key organisations in this stroke care including the World Stroke Organisation, European Stroke Organisation, African Stroke Organisation, American Heart Association.

We will also check existing websites that we were identified in the previous review of registries, to identify links or references to other registries.

For resource reasons we will not perform back or forward citation searching; thus our searches are described as 'rapid'.

The medline search is shown below

Ovid MEDLINE(R) and Epub Ahead of Print, In-Process, In-Data-Review & Other Non-Indexed Citations, Daily and Versions

<https://www.ezproxy.is.ed.ac.uk/login?url=http://ovidsp.ovid.com/ovidweb.cgi?T=JS&NEWS=N&PAGE=main&SHAREDSEARCHID=7liyEW74oG0gRt8UT6uethvI0xkloz7AFMzEtzknKdlwrMuLvdcuPqQSyNfm9ziwl>

1 Ischemic Attack, Transient/ 22007

2 exp Cerebral Hemorrhage/ 38191

3 exp Stroke/ 176630

4 ((ischemic adj2 (attack or stroke)) or acute stroke).ti,ab,kf. 88262

5 1 or 2 or 3 or 4 252528

6 Registries/ 109666

7 (((national or central*) adj5 stroke adj5 regist*) or (stroke and audit)).ti,ab,kf. 1427

8 ((stroke and (Internet or web)) adj2 data collection).ti,ab,kf. 84

9 5 and 6 5667

10 7 or 8 or 9 6880

11 limit 10 to dt=20150521-20240101 3913.

Participant or population Stroke (defined by American Heart Association). but not including subarachnoid haemorrhage.

Intervention Not applicable.

Comparator Not applicable.

Study designs to be included Stroke registries are defined as systems that collect and analyse data on stroke events in defined populations or settings. Stroke registries provide information on the epidemiology, diagnosis, management, and prevention of stroke, as well as the quality and effectiveness of stroke care, and outcomes. Stroke registries can help to understand the burden of stroke, monitor the trends and interventions, and improve the outcomes of stroke patients. To be included in this review, the registry must cover a

national population (as previously defined-Cadilhac et al 2016) and must, as a minimum, collect data for acute stroke care. If registries also follow up patients and report process variables for rehabilitation, we will include this information in our review. We will not include registries that focus *only* on patients admitted to rehabilitation units. Note that ongoing stroke audits might also fulfil the criteria for a 'registry' if the above characteristics are fulfilled, even though they might not be called 'a registry' in the text. Our inclusion criteria are the same as a previous systematic review (Cadilhac et al 2016).

Eligibility criteria Hospital based national stroke registries, which collect data on at least acute care. We will include low, middle and high income settings, and narratively compare and contrast registries in different settings. The term 'hospital based' will be used in a broad sense, including registering only hospital admitted cases (sometimes using an overnight stay to distinguish between those admitted, and those attending a clinic or other ambulatory care service). Hospital-based will also interpreted as simply being based in a hospital – not referring to whether the patients are seen there or not. If our searches find a national community-based registry that will be included too. We have decided not to specifically search for community-based registries as this would require a new search strategy for all databases from inception and we do not have the resources to do this. We will, however, comment on the whether the hospital-based registries are likely to 'miss' patients not admitted to hospital.

Information sources We will search Medline (Ovid), Embase (Ovid), Global Health (Ovid) and the WHO regional indices in Global Index Medicus. Grey literature will be identified by searching websites of key organisations in this stroke care including the World Stroke Organisation, European Stroke Organisation, African Stroke Organisation, American Heart Association. We will also check existing websites that we were identified in the previous review of registries, to identify links or references to other registries.

Main outcome(s) We are interested in three broad areas a) aims and organisation b) methods c) data items collected. We will design a data collection sheet for each of these three aspects; the data collection sheet will categorise the methodology prior to data extraction. These will be categorised according to the income setting (low, medium or high). We expect that the final results for each of these three broad areas will be reported in tables, with

the methodology as a column and the rows will list the stroke registry.

Data management Papers to include will be uploaded into a shared drive at University of Edinburgh. Data will be extracted into Word tables (also stored on the shared drive), and divided into low, middle and high income countries.

Quality assessment / Risk of bias analysis There are no standardised validated tools to assess the risk of bias for stroke registries. In our discussion we will refer to a narrative review article which describes the key features of stroke improvement programmes based on registries/audits (Measuring Stroke Quality: Methodological Considerations in Selecting, Defining, and Analyzing Quality Measures | Stroke (ahajournals.org).

Strategy of data synthesis Each national registry will be described based on the main characteristics. We will report on aims/governance, methods and data collected. We will create three tables in Word, that list each registry in a row, and the relevant data items in columns. Each cell will contain text to indicate if, and how, the method listed in the column title is described in the publication. In the text we will then summarise if/how the registries include the respective data items.

Subgroup analysis We will categorise the registries according the geographic setting (low, middle, high income). We will also comment on whether the registries collect data from the acute phase only, or rehabilitation too.

Sensitivity analysis Not applicable.

Language restriction We will attempt to include all languages that the team is fluent in. If there is an English abstract but the full text is not in English, we will include the study and contact the authors and ask for them to provide, in English, the data items that we wish to extract.

Country(ies) involved United Kingdom, Australia, Canada, India, China, Finland, Malaysia, Sweden, Nepal, Bangladesh, US.

Keywords stroke; ischaemic stroke; intracranial haemorrhage; guidelines, audit, registries.

Dissemination plans Dissemination plan: we will publish this review in a peer reviewed journal, and present at conferences. We will also provide a plain language summary, which we will share with

Stroke Support Organisations, with whom we have links through the World Stroke Organisation. One of our authors Professor Pandian is President Elect of the World Stroke Organisation.

Contributions of each author

Author 1 - Gillian Mead - Coordination of the team and supervision of three University of Edinburgh BSc students.

Email: gillian.e.mead@ed.co.uk

Author 2 - Dominique Cadilhac - Providing information about methodology from the previous 2016 review.

Email: dominique.cadilhac@monash.edu

Author 3 - Joosup Kim - Contributing to development of the search strategy, providing previous search results and previously included studies.

Email: joosup.kim@monash.edu

Author 4 - Natasha Lannin - Contributing methodological and topic expertise.

Email: natasha.lannin@monash.edu

Author 5 - Martin Dennis - contributing experience in setting up national stroke registries.

Email: martin.dennis@ed.co.uk

Author 6 - Moira Kapral - Topic and methodological expertise.

Email: moira.kapral@uhn.ca

Author 7 - Jeyaraj Pandian - Topic expertise in stroke especially low income settings, and the global context of stroke.

Email: jeyarajpandian@hotmail.com

Author 8 - Yudi Hardianoto - Topic and methodological expertise.

Email: yudi.hardianto@monash.edu

Author 9 - Beilei Lin - Topic and methodological expertise.

Email: beilei.lin@monash.edu

Author 10 - Atte Meretoja - Topic and methodological expertise.

Email: atte.meretoja@hus.fi

Author 11 - Noorazah Abd Aziz - Topic and methodological expertise.

Email: azah@ppukm.ukm.edu.my

Author 12 - Lee Schwamm - Topic and methodological expertise.

Email: lee.schwamm@yale.edu

Author 13 - Bo Norrving - Topic and methodological expertise.

Email: bo.norrving@med.lu.se

Author 14 - Lekhjung Thapa - Topic and methodological expertise that is relevant to a low income country.

Email: drlekhjung@gmail.com

Author 15 - Marshall Dozier - Information specialist-search strategy.

Email: marshall.dozier@ed.ac.uk

Author 16 - Shyam Kelavkar - Topic expertise.

Email: shyam@kelavkar.com

Author 17 - Shirsho Shreyan - Expertise in stroke from low income countries.

Email: shreyanshirsho83rmc@gmail.com

Author 18 - Andrew Horne - Expertise in using AI to perform literature searches.

Email: andrew.horne2@ed.ac.uk

Author 19 - Chloe Leigh - BSc student-performing searches, extracting data and writing up part of the review.

Email: c.j.leigh@sms.ed.ac.uk

Author 20 - Jodie Gill - BSc student-performing searches, extracting data and writing up part of the review.

Email: j.gill-13@sms.ed.ac.uk

Author 21 - Zainab Razak - BSc student-performing searches, extracting data and writing up part of the review.

Email: z.razaq@sms.ed.ac.uk