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Harnessing Routinely Collected Health Data for Global Monitoring of Stroke: Roadmap and Vision for INSPIRE-STROKE

Lachlan L. Dalli[a] Muideen T. Olaiya[a] Amy Y.X. Yu[b] Mathew J. Reeves[c] Dominique A. Cadilhac[a, d] Lee Nedkoff[e, f] Valery Feigin[g] Bo Norrving[h] Moira K. Kapral[i] William Whiteley[j] Anne-Marie Schott[k] Julia Ferrari[l] Hanne Christensen[m] Brian Mac Grory[n] Eric E. Smith[o] Yannick Béjot[p] Manav Vyas[q] Nishant K. Mishra[r] Jong-Moo Park[s] Michael D. Hill[t] Christine Benn Christiansen[u, v] Seana L. Gall[w] Monique F. Kilkenny[a, d] on behalf of the INSPIRE-STROKE collaborators

[a]Stroke and Ageing Research, Department of Medicine, School of Clinical Sciences, Monash University, Clayton, VIC, Australia; [b]Department of Medicine (Neurology), University of Toronto, Sunnybrook Health Sciences Centre, Toronto, ON, Canada; [c]Department of Epidemiology and Biostatistics, Michigan State University, East Lansing, MI, USA; [d]Stroke and Critical Care Research, Florey Institute of Neuroscience and Mental Health, University of Melbourne, Heidelberg, VIC, Australia; [e]University of Western Australia, Perth, WA, Australia; [f]Victor Chang Cardiac Research Institute, Sydney, NSW, Australia; [g]National Institute for Stroke and Applied Neurosciences, Auckland University of Technology, Auckland, New Zealand; [h]Department of Clinical Sciences, Department of Neurology, Skåne University Hospital, Lund University, Lund, Sweden; [i]Department of Medicine (General Internal Medicine) and Institute of Health Policy, Management, and Evaluation, University of Toronto, Toronto, ON, Canada; [j]Institute of Cardiovascular and Neuroscience Research, University of Edinburgh; Usher Institute, University of Edinburgh; and Health Data Data Research UK, London, UK; [k]University Claude Bernard Lyon 1, RESHAPE, U.INSERM, Hospices Civils de Lyon, Lyon, France; [l]Department of Neurology, St. John's of God Hospital Vienna, Vienna, Austria; [m]Copenhagen University Hospital, Bispebjerg Hospital, Copenhagen, Denmark; [n]Department of Neurology and Duke Clinical Research Institute, Duke University, Durham, NC, USA; [o]Department of Clinical Neurosciences and Hotchkiss Brain Institute, University of Calgary, Calgary, AB, Canada; [p]Université Bourgogne Europe, CHU Dijon Bourgogne, Service de Neurologie, Dijon, France; [q]St. Michael's Hospital, Unity Health Toronto, Toronto, ON, Canada; [r]Department of Neurology, Yale University School of Medicine, West Haven, CT, USA; [s]Department of Neurology, Uijeongbu Eulji Medical Center, Eulji University, Uijeongbu, Republic of Korea; [t]Department of Clinical Neurosciences and Hotchkiss Brain Institute, Departments of Community Health Sciences, Medicine and Radiology, Cumming School of Medicine, University of Calgary, Calgary, AB, Canada; [u]Cardiovascular Research Unit, Nordsjaellands Hospital Hilleroed, Copenhagen, Denmark; [v]Department of Neurology, Bispebjerg Hospital, Gentofte, Denmark; [w]Menzies Institute for Medical Research, University of Tasmania, Hobart, TAS, Australia

Lachlan L. Dalli and Muideen T. Olaiya should be considered first authors.
Seana L. Gall and Monique F. Kilkenny should be considered senior authors.

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Correspondence to:
Monique F. Kilkenny, monique.kilkenny@monash.edu

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Abstract
Introduction: Sustainable and low-cost data systems for national and global surveillance of stroke are urgently needed to address the growing burden of stroke. Routinely collected health data (including registries and administrative data) are proliferating at a rapid pace, offering promise for systematic and enduring global stroke surveillance. However, several challenges exist in utilising these routinely collected data from across the globe for global stroke surveillance, such as non-standardised definitions and coding, missingness of data, and lack of transparent or reproducible methods. We aim to describe the vision and methods for a new global collaboration to leverage and harmonise population-level health data for global stroke surveillance. ***Methods:*** The International Network for Standardised Population Insights and Real-world Evidence for STROKE (INSPIRE-STROKE) was established in October 2023 and currently includes 39 collaborators from 16 countries. The vision of INSPIRE-STROKE is to develop new methods that will harmonise and combine health databases across the world to facilitate reliable and robust multi-country stroke surveillance. Through this scientific community, we are initially collaborating to: (1) summarise existing methods for calculating and reporting measures of post-stroke outcomes using routinely collected health data; (2) develop consensus-based standards for analysing routinely collected health data on post-stroke outcomes; and (3) conduct proof-of-concept studies to align variables/definitions in routinely collected health data and create standardised statistical code to measure post-stroke outcomes (e.g., medication adherence, readmissions, and mortality) according to consensus-based definitions. ***Conclusion:*** INSPIRE-STROKE will support more reliable investigations into country-level trends in stroke incidence and outcomes, by leveraging routinely collected health data at a global scale. The large and diverse data compiled for INSPIRE-STROKE could facilitate exploration of rare stroke outcomes, particularly among under-represented groups (e.g., pregnant women, children). INSPIRE-STROKE will strengthen health policy and resource planning by providing high-quality evidence to improve access to stroke care and maximise patient outcomes.

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Advancing Data Systems for Stroke: The Time Is Now

Stroke is a leading cause of death and disability [1]. Despite coordinated global efforts to curb stroke incidence, age-standardised rates are increasing among people aged <55 years in several countries [2], and across low- and middle-income countries (LMICs) [1]. The global burden of stroke is projected to increase by 50% from 2020 to 2050, largely from population growth and ageing [3]. Recent recommendations from the World Stroke Organization-Lancet Neurology Commission are aimed at addressing this burden across four pillars (surveillance, prevention, acute care, and rehabilitation). Within the surveillance pillar, the Commission called for "governments to establish nationwide systems for monitoring the burden of stroke, through registries, electronic health records, and vital statistics systems." In this paper, we highlight current deficiencies in global stroke surveillance systems, and introduce the vision and methods for a new multi-country stroke surveillance initiative to leverage and systematically analyse Big Data to uncover new insights into stroke burden, treatments, and outcomes globally.

Current Landscape of Stroke Data Systems across the Globe

Several collaborations, including the Global Burden of Disease [1] and the Global Stroke Statistics [4], routinely report data on the worldwide burden of stroke (e.g., incidence and mortality). However, estimates reported for entire countries or regions tend to be based on smaller studies undertaken in a subset of the population, which may have different characteristics (e.g., differences in age, race/ethnicity, socio-economic status, rurality, time). Where population-wide incidence studies are available, they usually focus only on first-ever events, which limits the ability to determine the prevalence of recurrent stroke, important treatments and outcomes, and the real-world impacts of the disease. There is a need for more systematic and representative population-based analyses into the burden of stroke to evaluate complex patterns of healthcare use and outcomes in stroke.

Governments in many high-income countries have made recent progress in developing national systems to routinely monitor data on major stroke treatments and indicators of stroke burden (e.g., incidence, mortality) to support health policy, evaluation, and planning [3]. The Organisation for Economic Co-operation and

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Development (OECD) has reported data on in-hospital mortality due to stroke (26 countries), hospital readmissions after stroke (15 countries), and medication use post-stroke (e.g., antihypertensive; 7 countries) [5]. Similarly, within Europe, progress has been made to develop the Stroke Service Tracker, compiling standardised data on core stroke indicators from registries and other data sources across Europe [6, 7]. However, gaps remain in implementing similar surveillance activities at a global scale, particularly with representation from LMICs.

Benefits of Routinely Collected Health Data

In recent decades, systems have advanced to more seamlessly collect and link patient-level data across the healthcare system [8]. Routinely collected health data include a broad spectrum of health information, from electronic medical records, hospital administrative data, pharmaceutical claims data, quality assurance datasets, and death registrations [9]. Combining these different sources of data allows investigations into the entire continuum of stroke care [10] and facilitates low-cost prospective follow-up of patients to ascertain long-term outcomes [9]. Routinely collected health data have shown benefits in investigating novel and emerging stroke risk factors and outcomes [8], uncovering disparities for marginalised groups (e.g., migrants), understanding the real-world safety and effectiveness of interventions, and projecting the future heath and economic burden of stroke.

Implementing Analytical Protocols at a Global Scale

Standardising the analysis of routinely collected health data between regions also allows distributed (or federated) data network analyses to be undertaken at a global or multinational scale. In these analyses, a single standardised protocol is executed by each participating collaborator in their healthcare dataset and the resultant summary outputs are then pooled (or meta-analysed) by a central coordinating team [11]. This approach overcomes privacy concerns associated with sharing person-level identifiers between countries and increases statistical power to examine rare treatments or outcomes [11]. Multi-country collaborations have been successfully established in other diseases and disciplines (e.g., pharmacoepidemiology [11], diabetes [12], myocardial infarction [13]), highlighting the feasibility of leveraging global routinely collected for multi-country analyses into stroke care and outcomes.

Overcoming the Challenges of Routinely Collected Health Data

To fully harness the power of routinely collected health data to supplement and augment existing global stroke surveillance efforts, the following important challenges must be overcome.

Non-Standardised Definitions and Coding Algorithms

There is a lack of uniformity in definitions, vocabularies, coding algorithms, and technical processes required to prepare and analyse routinely collected data for health research. Even within a country, stroke events are often ascertained using different methods between states/jurisdictions (e.g., federated data models in Australia and Canada) [14, 15]. These differences can substantially affect the reliability of estimates on stroke burden [16, 17], and contribute to the siloing of health data with limited ability for reuse in research. There is a need to develop a set of standardised definitions, vocabularies and coding algorithms to facilitate more transparent and reliable big data research in stroke. Adding to this complexity is the need to carefully understand local clinical coding practices and policies [18], including any changes over time with revisions to international coding systems (e.g., ICD-11). To facilitate distributed network analyses in stroke, we urgently need consensus at national and international levels on the technical definitions for stroke and related indicators (e.g., mortality, acute treatments, rehabilitation, and medication adherence). Ideally, these definitions should be validated against high-quality measures in population-based samples to ensure they are valid and robust.

Balancing Data Diversity and Achieving Harmonisation

While the diversity of routinely collected health data offers great potential for granular patient-level analyses, it also increases the complexity of combining variables and definitions between databases. Establishing a Common Data Model is central to overcoming many of these inherent issues with data diversity. A Common Data Model is an informational model that allows the transformation of data from different databases into a common (harmonised) format, in which all coding and vocabulary are pre-specified and standardised [19]. Because each database typically has its own primary purpose, data structure, and terminology, data specificity is often compromised when establishing a Common Data Model [19].

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Gaps in Clinical Information

Given routinely collected administrative health data are typically collected for billing purposes, and codes are assigned based on health system funding criteria and standards, important patient-level clinical information may not be captured [20]. Particularly, data relating to stroke severity and deficits (e.g., disability, cognitive impairment, mood, pain) are often not available in administrative health data, which can limit risk adjustment of models [20]. Using a defined lookback period and multiple data sources (e.g., registries, admissions, and dispensing) can improve the sensitivity to detect past medical events or patient comorbidities [21]. Natural language processing and other machine learning methods may enhance the capture of important clinical characteristics not routinely available via billing codes [22].

Lack of Transparent and Reproducible Methods

Observational studies using routinely collected health data have received criticism for having poor external validity and reproducibility [23]. These issues often arise from inadequate disclosure of methods in sufficient detail for replication, or from jurisdictional differences in databases and coding standards [23]. Researchers and journal editors are ethically responsible for ensuring their methods are adequately reported to facilitate replication. In addition to adhering to recommended manuscript reporting checklists [24], authors should strive to make their study protocols, detailed methods (including covariate definitions), and exact statistical coding publicly available via open-access repositories.

Limited Data in LMICs

The dearth of population-based data in LMICs represents a major deficiency in global surveillance efforts. Investment into infrastructure is urgently needed in these settings to advance the systems to collect, link, and utilise health data at the population level [25]. The World Stroke Organization recently indicated that only 31/216 (14%) WHO member countries had a population-based stroke registry, including only seven LMICs [3]. A recent USD 74.5 million investment in Africa – the DS-I Africa project – is a pivotal first step in accelerating health research using big data in the region [26]. Funding should be prioritised for population-based electronic health data systems in LMICs to increase the coverage and quality of population-level health data for research and quality improvement.

Introducing INSPIRE-STROKE

To maximise the use of routinely collected population-level health data for global stroke surveillance [7], collaboration is needed to harmonise datasets and standardise methods. In 2022, we: (a) advocated for better use of routinely collected individual-level health data to monitor the burden of stroke to drive improvements in stroke outcomes; and (b) recommended the development and application of standardised methods to ensure reliable comparison of stroke data between countries [8]. In response to this problem, the International Network for Standardised Population Insights and Real-world Evidence for STROKE (INSPIRE-STROKE) was established in October 2023. While multi-country data collaborations are not a new concept, prior to the establishment of INSPIRE-STROKE, there was no multi-country initiative for the standardised analysis of person-level routinely collected health data to investigate stroke outcomes. INSPIRE-STROKE has several other unique features, as outlined in Table 1.

Vision

The overarching vision of INSPIRE-STROKE is to create a sustainable and valid system to support reliable analyses of routinely collected data on stroke, with a focus on measures that are not available in current surveillance systems (e.g., stroke unit care, recanalisation treatments, rehabilitation, readmissions, recurrent stroke, medication adherence).

Governance

The day-to-day operations of INSPIRE-STROKE are led by a central coordination team at Monash University, comprising the Director, Program Managers, and Secretariat. An International Steering Committee provides strategic oversight and governance, responsible for collaboratively establishing the research priorities, supporting collaboration, and monitoring activity progress (https://inspire-stroke.bigdatacvd.com).

Membership

INSPIRE-STROKE collaborators were identified following a systematic process. Firstly, a comprehensive literature review was undertaken to identify all published studies involving big data (N = 1,000+ adults) to ascertain post-stroke outcomes, between January 2019 and August 2021 [8]. From this review, we compiled a list of first and last authors and retrieved their contact information from public sources. Our International Steering Committee (initially comprising A.Y.X.Y., B.N., D.A.C., L.L.D., L.N.,

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Table 1. Comparison of data pooling initiatives to monitor and compare stroke metrics between countries[a]

	GBD study [1]	GSS [4, 30]	Europe stroke action plan SST [7]	OECD integrated Care [5]	INSPIRE-STROKE (proposed)
Year established	1990	2013	2020	2022	2023
Number of collaborators	>12,000	>15	>120	>20	>35
Coverage					
Countries	>200	>200	>50	>14	>14
Continents	5	5	1	3	4
Data and methods					
Aggregated, non-linked data	✓	✓	✓	✓	✗
Collaborators have access to person-level source data	✗	✗	✓[d]	✓	✓
Common data model	✗	✗	✗	?	✓
Published protocol outlining data standards and definitions of metrics	✓	✗	✓	✓	✓
Use of standardised statistical coding to derive estimates from each individual dataset	✗	✗	✗	✗	✓
Meta-analysis to pool data from different regions	✓	✓ (mortality only)	✓	✗	✓
Reported metrics					
Stroke burden (outcomes)					
Incidence	✓	✓[b]	✓	✗	✓
Prevalence	✓	✓[b]	✗	✗	✓
Readmissions	✗	✗	✗	✓	✓
Recurrent stroke	✗	✗	✓	✓	✓
Mortality	✓	✓[c]	✓	✓	✓
Disability	✓	✗	✗	✗	✓
Treatments					
Acute care interventions	✗	✓[b]	✓	✗	✓
Primary care visits	✗	✗	✗	✗	✓
Specialist visits	✗	✗	✗	✗	✓
Medication dispensing	✗	✗	✓	✓	✓
Vaccination	✗	✗	✗	✗	✓

GBD, Global Burden of Disease; GSS, Global Stroke Statistics; OECD, Organisation for Economic Co-operation and Development; SST, Stroke Service Tracker; ✓, yes; ✗, no; ?, and unclear. [a]Information sourced from recent publications or correspondence with relevant senior authors. Data correct as at December 2024. [b]Data sourced from undertaking a systematic review of existing literature [28]. [c]Data sourced from the World Health Organization. [d]Access granted only to national coordinators in certain countries due to General Data Protection Regulation reasons.

M.K.K., M.T.O., M.R., S.G., V.F.) reviewed the list of potential collaborators and selected 1–3 lead researcher(s) from each country to be invited. A total of 74 potential collaborators were invited from 28 countries, of whom 39 from 16 countries have since joined (as of August 2025). We are actively working to include additional collaborators from under-represented countries, including from LMICs. Interested persons are recommended to contact the INSPIRE-STROKE Secretariat (inspire-stroke@monash.edu) or visit our website (https://inspire-stroke.bigdatacvd.com) for more information on joining.

Recruitment Survey

As part of the onboarding process, collaborators completed a short survey and confirmed their access to administrative data from their country for a cohort of people with stroke. During the recruitment survey, information was collected on the datasets available to collaborators in their country and their preferences to participate in studies investigating specific stroke outcomes. Of the 39 current collaborators, the majority indicated they had access to stroke-related data on hospital admissions, emergency department presentations, mortality, and pharmaceutical

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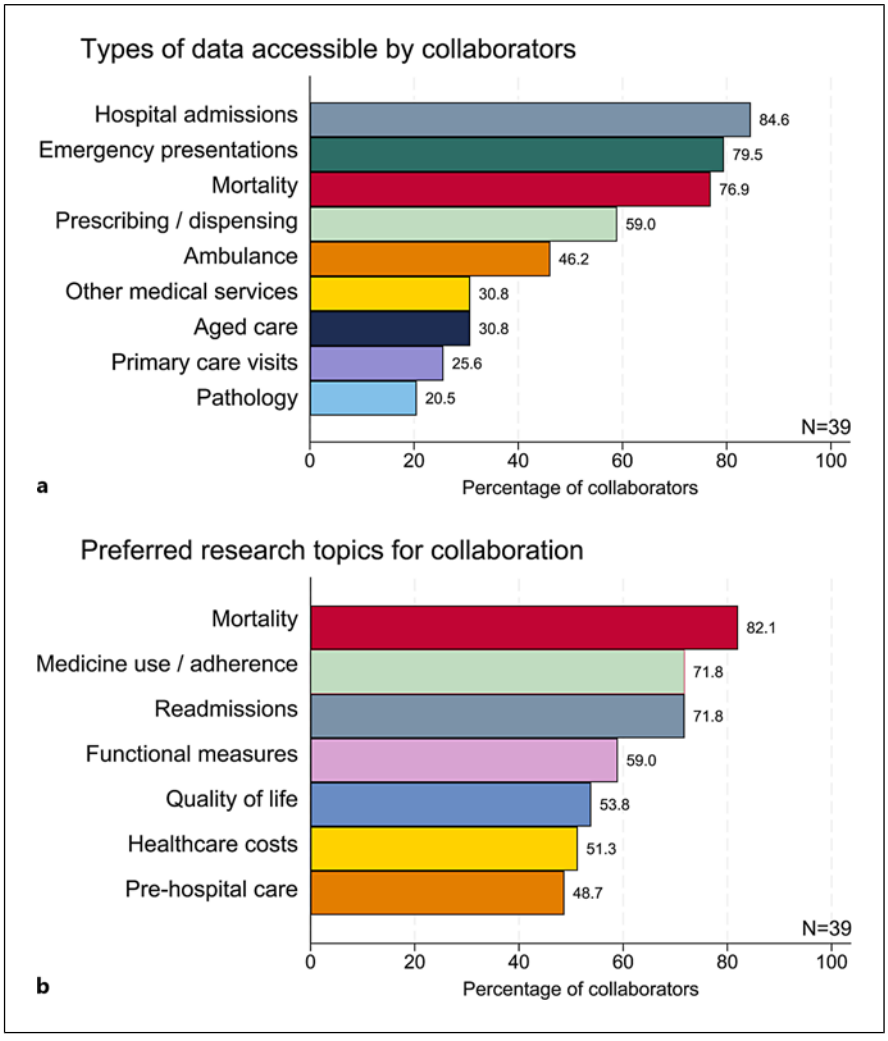


Fig. 1. a, **b** Responses to the INSPIRE-STROKE Recruitment Survey. Collaborators could select more than one response for each question.

prescription or dispensation (Fig. 1a). Collaborators were also mostly interested in collaborating in INSPIRE-STROKE to investigate post-stroke mortality, medication use/adherence, and readmissions (Fig. 1b).

Pilot Standardisation and Harmonisation Projects

Through this scientific community, we aim to advance the standardisation of methods used for measuring and reporting stroke outcomes using routinely collected health data. Based on the information collected in our registration survey, and through further workshops with INSPIRE-STROKE collaborators (in-person and via Zoom), we have developed short-term projects to guide the network's collaborative activities over the next 1–2 years.

Activity 1: Summarise published literature on methods used to calculate and report measures of post-stroke readmissions and mortality using routinely collected health data.

Methods: A scoping review will be undertaken in accordance with the PRISMA Extension for Scoping Reviews (PRISMA-ScR) 2020 [28]. The full methods for this scoping review are published elsewhere [29]. Briefly, two academic databases will be searched to retrieve articles reporting measures of "readmissions" or "mortality" in "routinely collected data" after "stroke" or "intracerebral haemorrhage." Data will be extracted from each article on bibliographic details, type of stroke, population (age group), data source, mortality measures (e.g., within 30, 90 days, 365 days), numerators and denominators, and variables for risk adjustment (age, sex, comorbidities, others). This activity will elucidate the impact of different methodological decisions on the estimates of mortality and hospital readmissions. These

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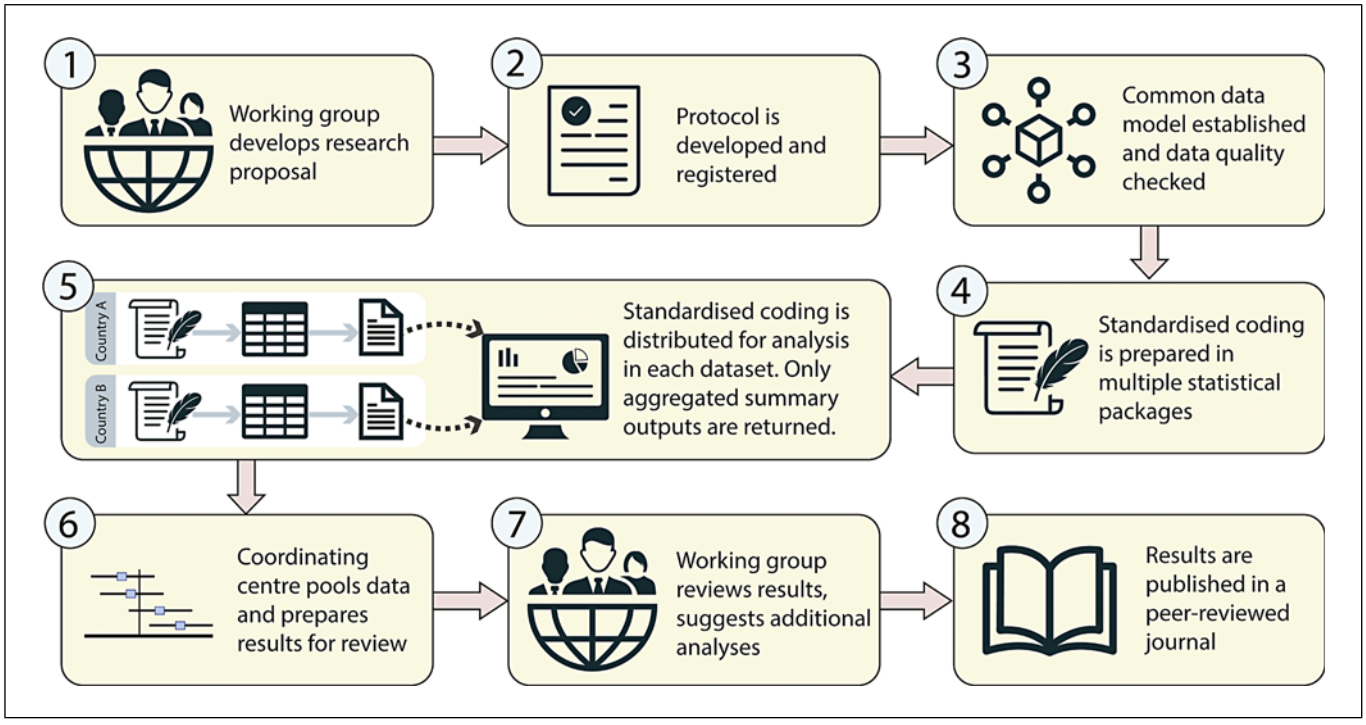


Fig. 2. Proposed methods for distributed network analysis of INSPIRE-STROKE.

findings, along with those from our previous scoping review on medication adherence methods [23], will inform the subsequent development of consensus-based methods for measuring post-stroke outcomes using routinely collected health data.

Activity 2: Develop consensus-based standards for best-practice analyses of routinely collected health data for stroke, with specific focus on methods for deriving measures of readmissions and mortality.

Methods: A modified Delphi process will be undertaken with an international panel, comprising INSPIRE-STROKE collaborators and additional stroke experts recruited via the World Stroke Organization and European Stroke Organization networks. Multiple Delphi rounds will be undertaken with participants to identify best practices for the collection and analysis of routinely collected health data to measure stroke outcomes. Participants will anonymously review and rate a range of different analytical approaches for the measurement of stroke outcomes (e.g., mortality and readmissions), as identified from Activity 1. Feedback will be sought on exact numerators, denominators, exclusions, technical definitions and algorithms. The process will be undertaken using online survey tools and virtual workshops and reported using the ACCORD Delphi reporting guideline [30]. The final consensus-based definitions and standards will be published and underpin future INSPIRE-STROKE multi-country projects.

Activity 3: Conduct proof-of-concept studies to align variables/definitions in routinely collected health data and create standardised statistical code to measure post-stroke outcomes, including medication adherence, readmissions, and mortality.

Methods: Proof-of-concept studies will be undertaken between a subset of INSPIRE-STROKE countries (Australia, Canada, Denmark) to harmonise administrative datasets to measure prioritised post-stroke outcomes (readmissions, mortality, and medication adherence). Firstly, an evaluation will be undertaken to compare data dictionaries, local data collection protocols, and reimbursement practices in each country. Synonymous variables will be identified, and response categories will be aligned to enable cross-country comparability. A detailed protocol and dataset creation plan will be developed, specifying cohort inclusion and exclusion criteria, study timeframes, follow-up periods, and medications of interest. Diagnostic and pharmaceutical coding systems will be mapped to ensure consistency across jurisdictions. Descriptive

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analyses will be performed to assess differences in coding practices, prevalence estimates, and reimbursement patterns. Following dataset standardisation, the INSPIRE-STROKE coordinating centre will develop a single standardised statistical program to calculate post-stroke outcomes, adhering to best-practice consensus-based standards established through the modified Delphi process. Aggregated summary statistics from each country will be securely shared, tabulated, and pooled using random-effects meta-analysis. This activity will provide critical insights into the feasibility of international collaboration within the INSPIRE-STROKE network, highlighting challenges related to cost, time, data interoperability, and healthcare system variability.

Large-Scale Distributed Network Analysis Projects

Successful completion of the pilot standardisation and harmonisation projects will be essential for demonstrating the feasibility of INSPIRE-STROKE, including any facilitators and barriers to multi-country distributed network analyses. For example, ascertaining the impact of differences in healthcare and reimbursement systems (e.g., private vs. public vs. dual systems) and population demographics (e.g., age structure, ethnicity, migration, gender inequality) will be critical for ensuring comparisons between countries are robust [18]. The evidence generated from these projects will be critical for demonstrating the feasibility of standardising methods used for measuring and reporting stroke outcomes between countries, using routinely collected health data, and provide a methodological framework for scale-up to other countries. The large and diverse data harmonised for INSPIRE-STROKE will enable (i) standardised statistical coding to be applied to generate reliable insights on the global burden of stroke (Fig. 2); and (ii) more granular investigations in under-represented groups (e.g., pregnant women), and on emerging risk factors (e.g., infection), which would otherwise not be possible within single or multi-centre studies.

Summary

Routinely collected health data are proliferating at a rapid pace. Opportunities exist to fully harness these data for more impactful research of stroke. We propose a new collaboration, INSPIRE-STROKE, to develop and implement new methods to harmonise and leverage fragmented health databases for reliable and robust multi-country stroke research. Evidence from this collaboration will enhance the generation and exchange of reliable information on disparities in stroke treatments and outcomes to better target prevention and quality improvement programs.

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Statement of Ethics

The INSPIRE-STROKE Coordinating Centre has been approved by Monash University Human Research Ethics Committee (Approval No. 41990) to conduct this project. As part of the distributed network analyses proposed for INSPIRE-STROKE, each collaborator will be responsible for ensuring they have obtained necessary ethics approvals and permissions from data custodians to analyse person-level data and share aggregated outputs for data pooling.

Conflict of Interest Statement

All authors are members of the Steering Committee of the International Network for Standardised Population Insights and Real-world Evidence for Stroke (INSPIRE-STROKE). M.T.O., D.A.C., and B.N. are members of the Global Stroke Statistics consortium. M.T.O., V.F., and S.L.G. are members of the World Stroke Organisation-Lancet Neurology Commission on Stroke. V.F., L.L.D., M.T.O., and Y.B. are members of Global Burden of Diseases consortium. M.T.O. and S.L.G. are Review Board Members. D.A.C. and B.N. are Associate Editors. V.F. is the Editor in Chief of Neuroepidemiology. D.A.C. is the current Data Custodian for the Australian Stroke Clinical Registry (AuSCR) and Executive Officer of Stroke Society of Australasia. D.A.C. and M.F.K. are members of the AuSCR Operational and Quality Improvement Committee. D.A.C. reports receiving restricted grants from Boehringer Ingelheim, Moleac, Nicolab, Amazon Web Services outside the submitted work. A.Y.X.Y. holds a Tier 2 Canada Research Chair in Data-driven design of stroke systems. B.N. reports honoraria for D.M.C. work from Simbec-Orion. M.K.K. holds the Sir John and Lady Eaton Chair of Medicine, University of Toronto, Canada. Y.B. is currently vice-president of the French Neurovascular Society. Y.B. reported personal fees from BMS, Pfizer, Medtronic, Amgen, Servier, NovoNordisk, Novartis, Argenx, XO pharma, outside the submitted work. B.M.G reported receiving grants from National Institutes of Health (NIH), American Heart Association (AHA), and Duke ORBIT Interdisciplinary Hub (Duke University, Durham, NC). N.K.M. has no conflict of interest. He works for the US government; however, none of the opinions expressed herein should be construed as that of the US Government. All other authors report no conflicts of interest.

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Author Contributions

L.L.D., M.T.O., and M.F.K. conceptualised the manuscript. L.L.D. and M.T.O. drafted the manuscript. Subsequent drafts of the manuscript were reviewed and developed with input from all authors, all of whom approved the final version.

Data Availability Statement

The authors confirm that the data supporting the findings of this study are available within the article.

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