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Original Article

Creation and Evolution of the Ontario Stroke Registry: Protocol and Two Decades of Data from a Population-Based Clinical Stroke Registry

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ABSTRACT: ***Background:*** Stroke clinical registries are critical for systems planning, quality improvement, advocacy and informing policy. We describe the methodology and evolution of the Registry of the Canadian Stroke Network/Ontario Stroke Registry in Canada. ***Methods:*** At the launch of the registry in 2001, trained coordinators prospectively identified patients with acute stroke or transient ischemic attack (TIA) at comprehensive stroke centers across Canada and obtained consent for registry participation and follow-up interviews. From 2003 onward, patients were identified from administrative databases, and consent was waived for data collection on a sample of eligible patients across all hospitals in Ontario and in one site in Nova Scotia. In the most recent data collection cycle, consecutive eligible patients were included across Ontario, but patients with TIA and those seen in the emergency department without admission were excluded. ***Results:*** Between 2001 and 2013, the registry included 110,088 patients. Only 1,237 patients had follow-up interviews, but administrative data linkages allowed for indefinite follow-up of deaths and other measures of health services utilization. After a hiatus, the registry resumed data collection in 2019, with 13,828 charts abstracted to date with a focus on intracranial vascular imaging, identification of intracranial occlusions and treatment with thrombectomy. ***Conclusion:*** The Registry of the Canadian Stroke Network/Ontario Stroke Registry is a large population-based clinical database that has evolved throughout the last two decades to meet contemporary stroke needs. Registry data have been used to monitor stroke quality of care and conduct outcomes research to inform policy.

RÉSUMÉ : Mise sur pied et évolution du Registre de l'AVC de l'Ontario : un protocole et deux décennies de données tirées d'un registre clinique populationnel de l'accident vasculaire cérébral. ***Contexte :*** Les registres cliniques de l'accident vasculaire cérébral (AVC) jouent un rôle crucial dans la planification de systèmes, l'amélioration de la qualité des soins, la défense des droits et l'élaboration de politiques. L'étude ici présentée décrit la méthode de travail et l'évolution du Registre de l'AVC de l'Ontario (anciennement Registre du Réseau canadien contre les accidents cérébraux vasculaires) au Canada. ***Méthode :*** Au moment du lancement du Registre en 2001, des coordonnateurs formés ont repéré de manière prospective des patients ayant subi un AVC aigu ou un accident ischémique transitoire (AIT) dans des centres complets de soins des AVC au Canada et ont obtenu leur consentement pour leur participation au registre et à des entrevues de suivi. À partir de 2003, les patients ont été repérés à l'aide de bases de données administratives, et l'obligation de consentement a été levée pour la collecte de données sur un échantillon de patients admissibles dans l'ensemble des hôpitaux de l'Ontario et dans un centre en Nouvelle-Écosse. Dans le cycle le plus récent de collecte de données, les patients admissibles consécutifs provenaient de partout en Ontario, mais ceux qui avaient subi un AIT ou qui avaient été examinés au service des urgences sans avoir été hospitalisés ont été exclus. ***Résultats :*** Entre 2001 et 2013, le registre comptait 110 088 patients. Seuls 1 237 patients ont passé des entrevues de suivi, mais le couplage de données administratives a permis un suivi indéfini des décès et d'autres mesures d'utilisation des services de santé. Après une pause, la collecte de données dans le registre a repris en 2019, et il y a eu extraction de données de 13 828 dossiers de patients jusqu'à maintenant, surtout de celles portant sur l'imagerie vasculaire intracrânienne, la détection des occlusions intracrâniennes et le traitement par thrombectomie. ***Conclusion :*** Le Registre de l'AVC de l'Ontario (anciennement Registre du Réseau canadien contre les accidents cérébraux vasculaires) est une grande base de données cliniques populationnelles qui a évolué au cours des deux dernières décennies pour répondre aux besoins actuels en matière d'AVC. Les données de ce Registre ont été utilisées pour surveiller la qualité des soins donnés aux personnes ayant subi un AVC et pour effectuer des recherches sur les résultats en vue d'élaborer des politiques.

Keywords: administrative data; quality improvement; registry; stroke

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Highlights

- Stroke registries play an important role in measuring and monitoring quality of care.
- This paper describes the methods and development of the Registry of the Canadian Stroke Network/Ontario Stroke Registry and how it shaped national and provincial stroke systems.
- We also describe its evolution to meet contemporary stroke needs.

Introduction

Stroke is a major cause of mortality and morbidity worldwide, leading to important loss of productivity among survivors and high costs to healthcare systems.[1–3] Measuring and monitoring quality of care and outcomes in the population is critical to ensure excellence in care, adherence to best practice guidelines and identification of any inequities in care by geographic or sociodemographic factors.[4]

There are many stroke registries worldwide providing important data on care quality indicators and outcomes, such as Sweden's Riksstroke;[5] the Australian Stroke Clinical Registry;[6] the UK's Oxford Vascular Study;[7] the Sentinel Stroke National Audit Programme in England, Wales and Northern Ireland;[8] and the American Heart/Stroke Association's Get With the Guidelines-Stroke program[9] to name a few examples. Differences in healthcare system structure, funding models and privacy laws require that each clinical registry follows its own unique protocol. A formal description of registry methods is important. Understanding the variations in sampling strategy, selection of participating centers, patient consent and data collection process are critical in the interpretation of registry data and enable potential comparisons across different registries.[4,10] Furthermore, as stroke treatments and best practice guidelines evolve, registries must adapt to collect data relevant to contemporary treatments to inform the organization of stroke systems of care.

We describe the methods and evolution of the Ontario Stroke Registry, a population-based stroke registry in the province of Ontario, Canada. We also describe its latest iteration that focuses on the provision of endovascular thrombectomy (EVT) across the province.

Methods

Setting

Ontario is Canada's most populous province with currently 15 million residents. Residents of Ontario have access to a single-payer government healthcare system with universal access. The Ontario Ministry of Health tracks healthcare utilization using administrative data. These data thus reflect care for the full population, and they have been previously validated for secondary analysis for research and quality improvement purposes.[11,12] In Ontario, administrative data are housed at ICES (previously Institute for Clinical Evaluative Sciences), an independent, nonprofit health services research institute that is a *Prescribed Entity* under Ontario's Personal Health Information Protection Act.

Establishing a Canadian stroke registry

A Canadian national stroke registry was first established in 2001 under the name of the Registry of the Canadian Stroke Network. It was funded by a research grant from the Canadian Stroke Network, one of Canada's Networks of Centres of Excellence, with data collection in Ontario funded by the Ontario Ministry of Health and Long-Term Care. It involved primary data collection in consenting patients with acute stroke or transient ischemic attack (TIA) seen in the emergency department or admitted to 20 academic and comprehensive stroke centers across Canada (later expanded to 24 centers), with 6-month follow-up interviews to collect data on post-stroke functional status and quality of life (Phases 1 and 2, see Table 1). However, rural and nonacademic hospitals were excluded, and obtaining patient consent proved to be costly, impracticable and therefore prone to important selection biases.[13] In 2003, the registry changed to a model where a more representative sample of hospitals was included, chart abstraction was performed with a waiver of consent, and linkages to administrative data were performed to provide information on deaths, readmissions and other aspects of health services utilization. For reasons of feasibility, data collection was then limited to the provinces of Ontario and Nova Scotia (Phases 3 and 4, see Table 1). In 2011, the Canadian Stroke Network ended, ownership of the registry was transferred to ICES and the name was changed to the Ontario Stroke Registry.

Patient inclusion criteria, case ascertainment and sampling

From 2001 to 2002, data were collected on all consecutive patients with ischemic stroke, subarachnoid hemorrhage, intracerebral hemorrhage or TIA seen at comprehensive stroke centers, whether hospitalized or seen in an emergency department without admission and including those with in-hospital stroke. After 2003, data collection was expanded to include a periodic audit on a simple random sample of patients seen at all ($N \sim 150$) acute care hospitals in the province of Ontario (Table 1). This sampling strategy was adopted because it was not feasible to collect data on all of the estimated annual 25,000 patients with stroke or TIA. Initially, patients were identified through daily review of patient lists with prospective data collection, but subsequently, as the sampling strategy became more population-based, case lists were generated using validated International Statistical Classification of Diseases, 10th Revision, Canadian codes (ICD-10-CM) codes I63 and I64 for ischemic stroke, I61 for intracerebral hemorrhage, I60 for subarachnoid hemorrhage and G45 (excluding G45.4) for TIA.[14] Trained research coordinators confirmed the final diagnosis using retrospective chart review.

Variables

The registry collected information on over 400 data elements including baseline demographics, comorbid conditions, pre-stroke functional status, stroke presentation (including the timing of stroke symptom recognition, hospital arrival, neuroimaging and interventions), stroke type and severity, results of neuroimaging, in-hospital processes of care, complications and mortality, length of stay and discharge destination and functional status at discharge; full case report forms available online.[15] From 2001 to 2008, data were also collected on variables such as ethnicity, language fluency and social support. Data elements were selected after wide consultation with clinicians, persons with lived experience, health authorities and other stakeholders and included information needed to evaluate the quality of stroke care delivery based on best practice guidelines. Duplicate chart abstraction on a random sample of 10% of patients showed excellent inter-rater agreement (kappa > 0.8) for key variables such as age, sex, stroke type and use of thrombolysis.

Follow-up data

From 2001 to 2002, 6-month follow-up interviews were performed to obtain information on survival, functional status based on the

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Table 1. Phases in the evolution of the Ontario Stroke Registry (OSR), originally known as the Registry of the Canadian Stroke Network

	Phases 1–2 (2001–2002)	Phase 3 (2003–2007)	Phase 4 (2008–2013)*	Phase 5 (2019/20, 2022/23)
Provinces	8	2 (Ontario, Nova Scotia)	1 (Ontario)	1 (Ontario)
Number of hospitals	24	153	145	54
Number of patients	7,903	42,986	59,199	13,828
Site inclusion criteria	CSC	All Ontario acute care sites with >10 stroke admissions/year One CSC in Nova Scotia	All Ontario acute care sites with >10 stroke admissions/year (>30/year in 2012/13)	All Ontario acute care sites with >70 stroke admissions/year
Pediatric hospitals included	No	No	Yes – 2010–2011	No
Sampling strategy	Consecutive consenting patients at CSC; minimal dataset collected on those who did not consent	Consecutive at CSC, simple random sample elsewhere	Consecutive at CSC, simple random sample elsewhere	Consecutive in hospitals with ≥70 admissions
Case ascertainment	Active surveillance	Active surveillance	Passive with administrative data	Passive with administrative data
Setting	ED, admitted	ED, admitted	ED, admitted	Admitted only
Stroke types	TIA, ischemic stroke, intracerebral hemorrhage, subarachnoid hemorrhage, in-hospital stroke	TIA, ischemic stroke, intracerebral hemorrhage, subarachnoid hemorrhage, in-hospital stroke	TIA, ischemic stroke, intracerebral hemorrhage, subarachnoid hemorrhage (except 2012/13), in-hospital stroke	Ischemic stroke, intracerebral hemorrhage
Patient consent	Yes	No	No	No
Follow-up	Interviews (n = 1,237) Administrative data	Administrative data	Administrative data	Administrative data

*Data collection was also performed on 46,275 patients seen at 40 stroke secondary prevention clinics in 2006–2012; details not shown here. CSC = comprehensive stroke centers; ED = emergency department; TIA = transient ischemic attack.

Stroke Impact Scale-16 and quality of life based on the Health Utilities Index Mark 2/3.[16,17] From 2003 onward, follow-up interviews were no longer performed, both for feasibility and due to bias arising from cohort attrition and missing data. Instead, data were deterministically linked using encoded unique patient identifiers to population-based administrative, survey and laboratory databases for information on sociodemographic factors, medication use, healthcare encounters, deaths and other outcomes. This allowed for long-term indefinite follow-up.

Data privacy and ethics

When the registry was established in 2001, the overall project was approved by the Research Ethics Board at Sunnybrook Health Sciences Centre in Toronto, and informed consent was required from patients or proxies for participation. However, despite concerted efforts by study personnel, under 50% of eligible patients consented to participate, and those who were enrolled were substantially different from those who were not, limiting the registry's ability to monitor the quality of stroke care delivery at participating sites.[13] In 2003, the registry was relaunched with a waiver of consent for chart abstraction, and the Canadian Stroke Network was designated as a "prescribed person" under section 39(1)(c) of Ontario's Personal Health Information Protection Act, which permits health information custodians to disclose personal health information without consent for the purposes of facilitating or improving the provision of stroke care in the province. In 2013, with the conclusion of the Canadian Stroke Network, ownership of the registry was transferred to ICES, itself a prescribed entity. With each data collection cycle, data sharing agreements between the registry team and the individual hospitals were established.

Extension of the ontario stroke registry for SMART-EVT

Due to lack of funding, there was a hiatus in registry data collection between 2013 and 2019. However, in 2015, EVT became a standard of care treatment for patients with ischemic stroke and large vessel occlusion.[18,19] Several initiatives were established to track processes of care and outcomes among patients treated with EVT, such as the Alberta provincial QuICR registry – Quality Improvement and Clinical Research[20] and its subsequent national extension Optimizing Patient Treatment In Major Ischemic Stroke with EVT (OPTIMISE).[21] However, there was almost no information on the patients who were *not* screened for large vessel occlusion or did *not* undergo EVT even when an occlusion was found. Ontario's stroke systems of care were not optimized for the provision of EVT. Only 51% of the population living in rural Ontario regions have access to a computed tomography angiography scan within 30 minutes of driving time and 32% are within 60 minutes of an EVT-capable hospital.[22] It was imperative to resume the registry activities to evaluate whether patients with stroke were appropriately screened for large vessel occlusion and whether there was equitable access to this treatment. In 2020, the Canadian Institutes of Health Research funded the research project "SMART-EVT: Stroke Metrics for quAlity, Reporting, and Translation in the implementation of EndoVascular Thrombectomy," which involved new data collection through the Ontario Stroke Registry (phase 5) with a focus on the evaluation of EVT delivery

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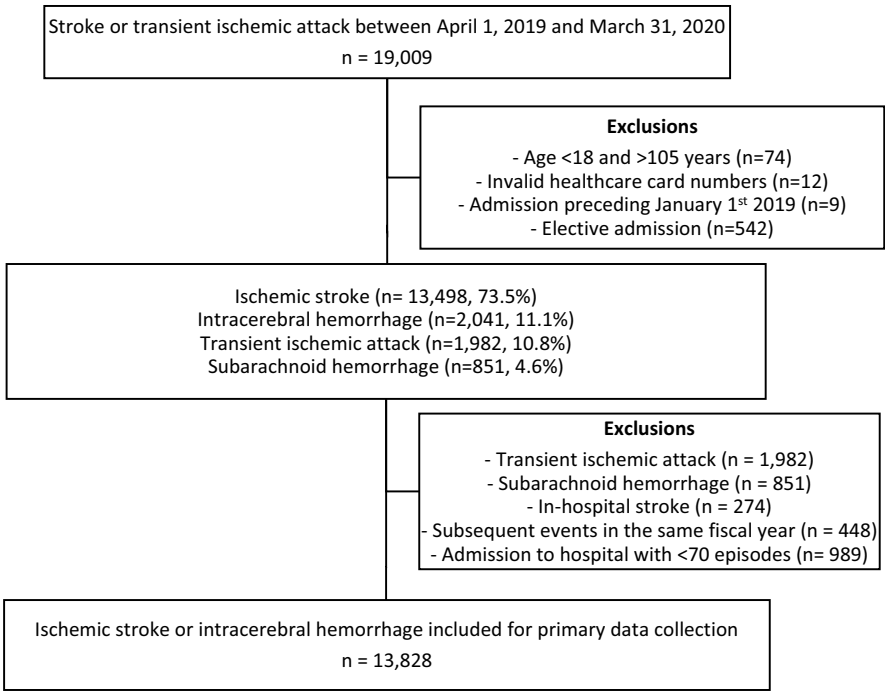

Figure 1. Cohort creation flowchart for the SMART-EVT project (Ontario Stroke Registry phase 5).

during the fiscal years 2019/20 and 2022/23. We anticipate that the project will provide novel and much-needed information on the frequency of screening for large vessel occlusion and treatment with EVT, the reasons for potential variations in screening and treatment and the outcomes of treatment in routine clinical practice and in important patient subgroups.

Cohort creation for SMART-EVT

For phase 5 of the registry, we again used passive surveillance with administrative data linkage to generate the case list for data collection. To avoid double-counting inter-hospital transfers as multiple events, we created unique episodes of care using ICES' standard definition: (1) any admissions within 6 hours of the previous discharge, (2) any admissions within 12 hours of the previous discharge where discharge codes indicate transfer between two acute care hospitals and (3) any admissions within 48 hours of the previous discharge where the "institution from" and "institution to" numbers match. We excluded patients aged < 18 and > 105 years, those with invalid healthcare card numbers, admission date before January 1, 2019, elective admission without preceding emergency department visit and stroke events occurring while already hospitalized for another condition, and for patients who had more than one stroke episode during the fiscal year, we only included the first event. We retained admissions for ischemic stroke or intracerebral hemorrhage to hospitals with ≥ 70 annual admissions. Patients diagnosed with TIA or those discharged from the emergency department were not included as they would be unlikely to be EVT candidates. As shown in Figure 1, there were a total of 19,009 hospitalizations for stroke or TIA in Ontario during fiscal year 2019/20. After applying the exclusion criteria, we created a case list of 13,828 unique patients admitted with ischemic stroke or intracerebral hemorrhage across 54 hospitals. This sampling strategy included 93.3% of all eligible episodes.

Privacy impact assessment, data sharing agreements and security

Data collection was approved by the ICES Chief Privacy Officer through a Privacy Impact Assessment obviating the need for approval by individual hospital research ethics boards. Data sharing agreements between ICES and each of the 54 hospitals were obtained. ICES shared the hospital-specific case list containing patient identifiers and the date of admission of interest with the health data record manager of each hospital. In hospitals with paper chart systems, the health data record team retrieved the appropriate paper chart for trained abstractors to review. In hospitals with electronic health records, abstractors were given access to the electronic system. To maximize data collection on EVT-related variables, when patients were cared for at multiple hospitals in one episode of care, abstractors were sent to the hospital with the highest level of stroke care, that is, comprehensive stroke centers with EVT and thrombolysis capability, followed by primary stroke centers with thrombolysis capability and finally non-designated centers. Data were entered on an electronic clinical report form using an encrypted research laptop by the abstractor through REDCap (Research Electronic Data Capture), a secure web application with two-factor authentication and end-to-end encryption. Abstractors only had access to the patient identifiers of the specific hospital case list they were working on. Once data were downloaded at ICES for analysis, data were de-identified and variables with fewer than five counts were suppressed to reduce re-identification risk. Encoded patient-level unique identifiers were retained at ICES to allow for deterministic linkage to population-based administrative data.

Data collection and quality monitoring

Chart abstractors reviewed charts to collect information on important patient characteristics and stroke process measures, investigation results, treatments and outcomes at the time of

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discharge that would otherwise not be obtainable from administrative data (e.g., patient baseline functional status, time of last known well, stroke severity, whether neurovascular imaging was performed, whether an intracranial occlusion was present and among those with large vessel occlusion, whether EVT was performed). The full case report form is in Supplemental Table 1 and also publicly available on the ICES website.[15]

We took several steps to ensure high data quality. First, a REDCap database was programmed to manage internal quality checks and to force entry for key variables to minimize missing data. Second, most abstractors already had knowledge of stroke or health data records as they held day-time jobs as stroke clinical or research coordinators or worked in hospital medical health records departments. Third, all abstractors, regardless of their baseline knowledge of stroke, underwent a 3-hour training session with the principal investigator (PI) followed by full data abstraction of 10 test charts, which were compared to the gold standard answers entered by the PI. Each abstractor received subsequent one-on-one feedback based on their answers. Abstractors were compensated for their time spent on training and testing. Abstractors could communicate with the PI by email, phone or text messages for clarification of specific challenging cases during their work, and monthly frequently asked questions were sent to all abstractors so all could learn from each other's questions. Finally, we downloaded data at regular intervals to perform logic checks and to ensure missing data and the use of "unable to be determined" answers were kept to a minimum. Data downloads for quality checks occurred monthly initially and quarterly later.

Results and impact

Data from the registry have led to several hundred peer-reviewed manuscripts and reports to date.[15] These data have played a key role in informing clinicians, researchers, administrators and knowledge users to impact policy, such as the development of regional stroke systems of care, the implementation of thrombolysis and the expansion of stroke units. In Ontario, we showed that establishing stroke systems of care was associated with increased use of neuroimaging, thrombolysis, admission to stroke units and decline in mortality.[23,24] Registry data were also used to conduct novel methodology work validating administrative data to reduce the burden of primary data collection and improve the sustainability of the registry, including deriving and validating case definitions for stroke case ascertainment, evaluating the quality of stroke data collected by the Canadian Institute for Health Information, validating the home-time outcome metric and developing the Passive Surveillance Stroke Severity (PaSSV) indicator for baseline stroke severity.[15,25–30] The process of waiver of patient consent in the later phases of the registry and its positive impact on the representativeness of the registry population contributed to shaping the design of other stroke registries.[10,31,32] Dedicated studies to validate EVT-related metrics on processes of care and outcomes and intracranial vascular imaging are still lacking and will be feasible with the newest data collection cycle.

Discussion

In this methods paper, we describe the inception of the Registry of the Canadian Stroke Network/Ontario Stroke Registry and its evolution over more than two decades. This information is meant to describe the strengths and limitations of the Ontario Stroke Registry data, foster collaboration nationally with investigators and trainees who wish to use its data and support other Canadian registry efforts that leverage routinely collected administrative data.

A strength of the Ontario Stroke Registry is its emphasis on performing data collection on a population that reflects the entire eligible population in the province, including patients with stroke treated in rural regions or hospitalized in non-academic centers without local research infrastructure. This approach improves the generalizability of findings arising from registry data, allows for an accurate assessment of the quality of care delivery and enables the identification of health inequities. Another strength of the registry is the ability to link to population-based administrative data with a waiver of consent, improving project efficiency and providing indefinite follow-up and complete ascertainment of events such as deaths, recurrent stroke hospitalizations and other health outcomes. This approach does not allow investigators to be in direct contact with patients, which limits the assessment of patient-reported outcome measures, and this could be a priority for future iterations of the registry. Finally, the registry incorporates multiple approaches to optimize data completeness and quality.

Clinical stroke registries are important because there is currently no other mechanism for measuring and monitoring the full spectrum of the quality of acute stroke care delivery and for ensuring that stroke systems of care are functioning as designed. Although administrative data can be used for evaluating many aspects of stroke care, they lack key data on variables required for monitoring the real-world use and effectiveness of interventions and for understanding where there are gaps in care or undesirable outcomes. For example, without information on neuroimaging results or the time of stroke onset, it is impossible to know who is eligible for reperfusion therapy. Without information on stroke severity, it is impossible to perform appropriate risk adjustment when evaluating stroke outcomes.[12]

Our experience also reflects the critical need for dedicated funding to support continuous data collection. Worldwide, many high-income countries have established clinical stroke registries for stroke monitoring, evaluation and research, and most of these initiatives are funded fully or partially by governmental sources.[5,10,33] When the Ontario Ministry of Health funding ended for the Ontario Stroke Registry in 2013, there was a gap in data collection before alternative sources of funding could be acquired.

Conclusion

We describe an approach to collecting population-based clinical data for stroke research, systems change and quality improvement in the setting of a universal healthcare system using primary data collection while leveraging routinely collected administrative data.

Supplementary material. The supplementary material for this article can be found at https://doi.org/10.1017/cjn.2025.13.

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Author contributions. AYXY was responsible for the concept, design, manuscript drafting and funding management. FLS was responsible for the concept, design and critical revision. JF was responsible for the concept, design and critical revision. MDH was responsible for the concept, design and critical

revision. PL was responsible for the concept, design and critical revision. MKK was responsible for the concept, design, critical revision and funding management.

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