



Canadian Stroke Network

Réseau Canadien contre
les accidents cérébrovasculaires

ICES

Institute for Clinical
Evaluative Sciences

Registry of the Canadian Stroke Network

Progress Report 2001–2005



September 2005

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About the Organizations Involved in this Report

The Canadian Stroke Network

The Canadian Stroke Network is one of Canada's Networks of Centres of Excellence, and is a collaborative effort that brings together researchers, students, government, industry and the non-profit sector. The Network, which began in 1999 with \$4.7 million in seed funding from the federal government, is a not-for-profit corporation governed by a Board of Directors and headquartered at the University of Ottawa. The Network puts Canada at the forefront of stroke research through its multi-disciplinary research program, high-quality training for Canadian scientists and clinicians, and national and global partnerships. At present, the Network has more than 100 researchers at 24 universities across the country (www.canadianstrokenetwork.ca).

The Canadian Stroke Network is dedicated to decreasing the physical, social and economic consequences of stroke on the individual and on society. In pursuit of this goal, it aims to:

- Promote research excellence;
- Train researchers and practitioners;
- Maximize economic benefits;
- Build national consensus on stroke policy; and,
- Create added value through partnerships

ICES—Ontario's resource for informed health care decision-making

ICES (Institute for Clinical Evaluative Sciences) is an independent, non-profit organization that conducts health services evaluations on a broad range of topical issues to enhance the effectiveness of health care for Ontarians. Internationally recognized for its innovative use of population-based health information, ICES knowledge provides evidence to support health policy development and changes to the organization and delivery of health care services.

Unbiased ICES evidence offers fact-based measures of health system performance; a clearer understanding of the shifting health care needs of Ontarians; and a stimulus for discussion of practical solutions to optimize scarce resources.

Key to ICES' work is our ability to link anonymous population-based health information on an individual patient basis, using unique encrypted identifiers that ensure privacy and confidentiality. This allows scientists to obtain a more comprehensive view of specific health care issues than would otherwise be possible. Linked databases reflecting 12 million of 30 million Canadians allow researchers to follow patient populations through diagnosis and treatment, and to evaluate outcomes.

ICES brings together the best and the brightest talent under one roof. Many of our faculty are not only internationally recognized leaders in their fields, but are also practising clinicians who understand the grassroots of health care delivery, making ICES knowledge clinically-focused and useful in changing practice. Other team members have statistical training, epidemiological backgrounds, project management or communications expertise. The variety of skill sets and educational backgrounds ensures a multi-disciplinary approach to issues management and creates a real-world mosaic of perspectives that is vital to shaping Ontario's future health care.

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Executive Summary

Purpose

In 1999, the Canadian Stroke Network (CSN) was established as one of Canada's Networks of Centres of Excellence. The mission of the CSN is to reduce the impact of stroke on Canadians through collaborations that create valuable new knowledge in stroke; to ensure the best knowledge is applied; and to build Canadian capacity in stroke. One of the inaugural projects was to develop a national stroke registry to monitor stroke patient processes and outcomes of care. The Registry of the Canadian Stroke Network (RCSN) was established in 2001 to allow for the measurement and monitoring of stroke care delivery and outcomes in Canadian patients at participating institutions, and to serve as a rich clinical database for investigator-initiated research projects.

Study

This report summarizes the methodology of the first three phases of the RCSN. In addition, this report uses the RCSN database to examine the following:

- Baseline characteristics of patients with stroke and transient ischemic attack (TIA);
- Pre-hospital and emergency care of patients;
- Stroke type and presentation by age and sex, outcomes by age and sex, onset to treatment time intervals, stroke evaluation and therapy, and in-hospital and six-month outcomes; and,
- Characteristics of patients who receive thrombolysis with tissue plasminogen activator (tPA): demographics and characteristics of patients receiving tPA, rates of administration by hospital, route and dosage, time intervals to receipt of therapy, post-treatment outcomes, and, if tPA was not given, the reasons why.

Key Points

- The RCSN began as a national registry with 21 participating sites from 8 provinces. In its latest phase (Phase 3), it collects data throughout the province of Ontario and in one institution in Halifax, Nova Scotia.
- The RCSN collects data on consecutive patients with stroke or TIA who present to the emergency department or are admitted to participating institutions.
- The RCSN is the largest Canadian database of stroke patients and is one of the largest stroke registries worldwide, with a current annual accrual rate of over 6,000 patients.
- The RCSN is one of only four registries in Ontario that have been "prescribed," or named, in the regulation in the Personal Health Information Protection Act (PHIPA), 2004, under s.39 (1)(c). (Prescription allows special circumstances under which registries can collect, use and disclose personal health information for research purposes under stringent predetermined data security privacy protection practices).
- Analyses from the RCSN show that patients at participating institutions receive high quality stroke care with respect to some performance indicators: 93% of those with ischemic stroke or TIA receive antithrombotic therapy, 10% receive thrombolysis with tPA, and 28% of those with ischemic stroke presenting to hospital within two hours of stroke onset receive tPA. However, only one in four patients arrives to hospital within two hours of stroke onset and only 28% of patients receive care on an acute stroke unit.

Implications

The RCSN is a large, high-quality clinical database of patients with acute stroke and TIA. It is used to measure and monitor the quality of stroke care delivery in participating institutions, and provides a rich clinical database for health care research.

Introduction

Since it was established in June 2001, the Registry of the Canadian Stroke Network (RCSN) has accrued clinical data on over 18,000 stroke patients at participating centres. The data collected characterize the entire stroke event from the onset of symptoms to the patient's status post-stroke to hospital discharge, allowing investigators to obtain a clear understanding of the proportions of stroke types, the prevalence of risk factors and the determinants of health outcomes. The Registry is intended to be part of a comprehensive stroke surveillance system that may be used to monitor and evaluate approaches to stroke care delivery, inform policy makers and formulate recommendations for best practice in stroke management.

This report summarizes the management structure and research methodology of the RCSN, and provides some basic analyses of the characteristics, care and outcomes of stroke patients seen at participating institutions.

Background

Objectives of the RCSN

The RCSN was established in 2001, with the goals of:

1. Determining the characteristics (age, sex, stroke severity, associated conditions and risk factor profile) of patients with stroke and TIA (transient ischemic attack) presenting to participating institutions;
2. Documenting the care that such patients receive, with a specific focus on recognized stroke care quality indicators including the use of neuroimaging, thrombolysis, stroke unit care, and antithrombotic agents;
3. Determining the impact on patient outcomes of variations in age, sex, stroke type and the type of services and interventions received; and,
4. Evaluating the outcomes of patients after stroke (www.rcsn.org).

Data collection is designed to fulfill two key purposes:

1. To allow the measurement and monitoring of stroke care delivery and outcomes in Canadian institutions; and,
2. To serve as a rich clinical database for investigator-initiated research projects.

Partnerships and collaborations

The RCSN is funded by the Canadian Stroke Network (CSN). Major partners of the RCSN are the Institute for Clinical Evaluative Sciences (ICES), which provides the infrastructure and support for data management and storage, and the Ontario Ministry of Health and Long-Term Care, which provides funding for most of the data collection in Ontario. The RCSN builds on the pilot stroke registry coordinated by the Heart and Stroke Foundation of Ontario in 2000.

Management structure

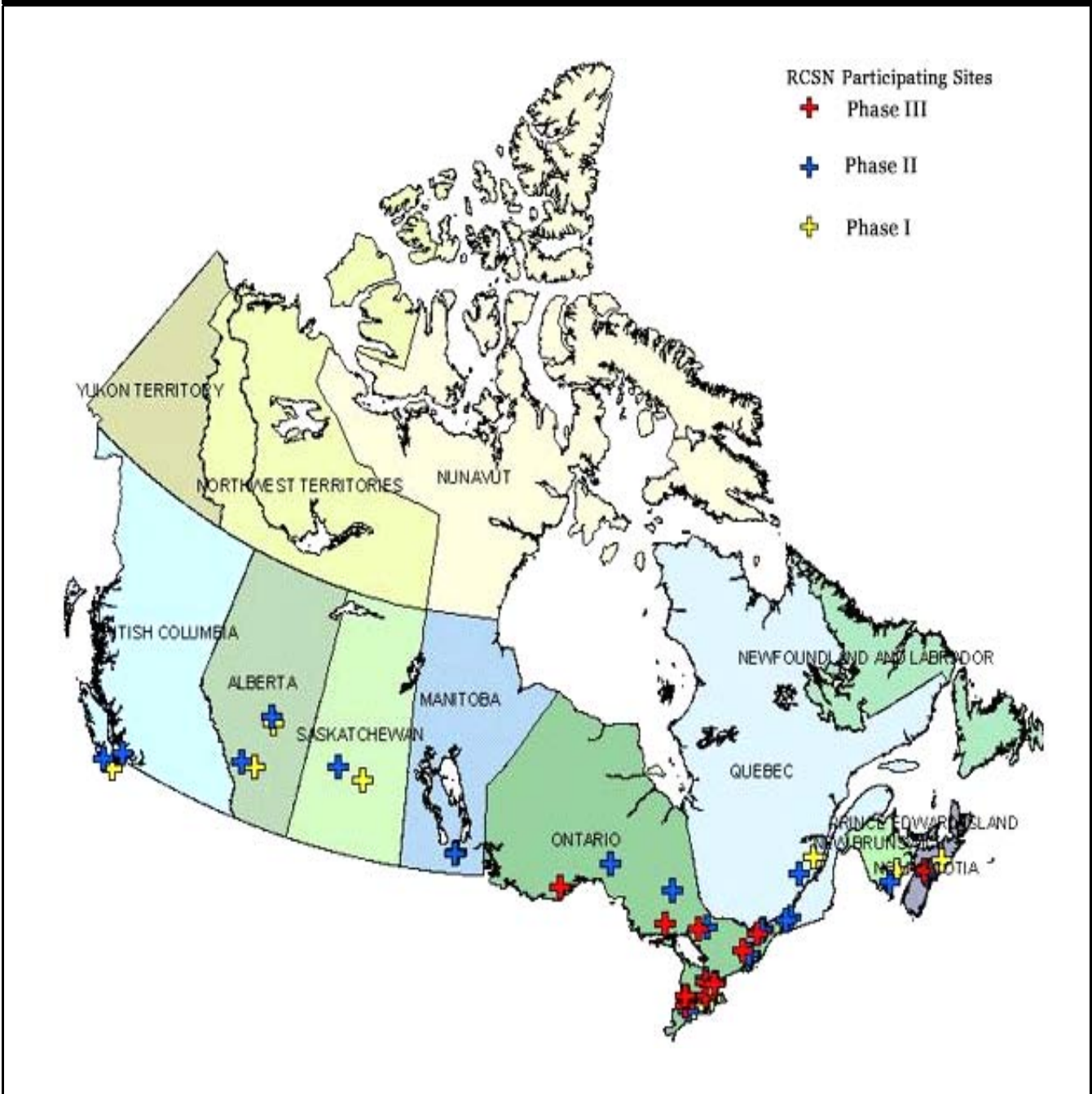
The RCSN Steering Committee is responsible for overseeing and reviewing major policy decisions related to the RCSN. The Steering Committee is chaired by one of the RCSN principal investigators, and membership comprises representatives from CSN, ICES, Heart and Stroke Foundation of Ontario, and Health Canada, as well as clinicians and researchers in neurology, health services research, and outcomes research. The RCSN Working Group, based at ICES, is responsible for the day-to-day management and coordination of RCSN activities. The RCSN Publications Committee reviews and prioritizes requests for data analyses. A multi-disciplinary Content Committee helps determine which data are collected by the RCSN, and the Data Privacy and Security Committee reviews issues related to data privacy and security. Committee membership is shown in Appendix A.

Each participating institution has a designated local principal investigator and a nurse coordinator who are responsible for patient recruitment and data collection. In Ontario, the Ministry of Health and Long-Term Care has designated a number of large tertiary care hospitals as Regional Stroke Centres, which provide stroke care and education to patients within their catchment area. At these centres, a Regional Stroke Manager is also involved in Registry management and decision-making. The investigators, regional managers and coordinators at participating sites are shown in Appendix B.

Methodology

The RCSN has had three phases, each with distinct methodology (Exhibit 2). Phases 1 and 2 recruited patients from acute care institutions across Canada, and required informed patient or surrogate consent for full data collection. Consenting patients participated in a six-month follow-up telephone interview to determine survival, functional status (as measured by the Stroke Impact Scale [SIS]) and quality of life (as measured by the Health Utilities Index Mark 2 and 3 [HUI 2/3]). Phase 3 eliminated the requirement for informed consent, and all consecutive patients seen at participating institutions were captured by the RCSN. Follow-up telephone interviews were no longer performed, and data collection was limited to 12 institutions in Ontario and one in Nova Scotia. Phase 3 also included population-based sampling of stroke patients seen at every acute care institution in Ontario, through the RCSN Phase 3 Ontario Stroke Audit. Phase 3 began in July 2003, and data collection is ongoing; the Ontario Stroke Audit was performed for patients seen in the emergency department (ED) or admitted to hospital with a diagnosis of stroke or TIA in fiscal year 2002/03, and is expected to be repeated on a biennial basis. Research ethics board approval is obtained for the entire RCSN project. In addition, each participating hospital obtains local institutional research ethics board approval.

Exhibit 1. Participating sites in the Registry of the Canadian Stroke Network



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Registry of the Canadian Stroke Network
See www.rcsn.org for additional details.

Exhibit 2. Summary of methodology of the Registry of the Canadian Stroke Network

	Phase 1	Phase 2	Phase 3	Ontario Stroke Audit 2002/03
Time period	Jun 2001–Feb 2002	Jun 2002–Dec 2002	Jul 2003–ongoing	Apr 2002–Mar 2003
Number of: Participating institutions	21	25	13	151
Provinces	8	8	2 (Ontario and Nova Scotia)	1 (Ontario)
Patients	4,439 1,701 consented	3,231 1,628 consented	> 10,000 (ongoing data collection)	3,542
Stroke events	4,612 1,797 consented	3,291 1,652 consented	> 10,000 (ongoing data collection)	3,542
6-month follow-up interviews	1,372	1,301	Not available	Not available
Site inclusion criteria	All tertiary care sites with stroke expertise and resources (stroke centres)	21 stroke centres 4 telestroke* sites	10 stroke centres 3 telestroke sites	All Ontario acute care hospitals with > 10 stroke admissions per year, excluding pediatric and psychiatric hospitals
Patient inclusion criteria	Acute stroke (< 14 days) or TIA* Admitted to hospital (a few emergency department patients were included) or in-hospital stroke	Acute stroke or TIA Seen in the emergency department or admitted to hospital Random sampling of eligible patients	Acute stroke or TIA Seen in the emergency department or admitted to hospital or in-hospital stroke	Acute stroke or TIA Seen in the emergency department or admitted to hospital Random sampling of eligible patients
Case ascertainment	Prospective patient logs by dedicated on-site coordinator	Prospective patient logs by dedicated on-site coordinator	Prospective patient logs by dedicated on-site coordinator	Identified from CIHI DAD* and NACRS* using ICD-10* codes I60, I61, I63, I64 and G45
Data collection	Patient interviews and chart abstraction	Patient interviews and chart abstraction	Retrospective chart abstraction (some prospective data collection through patient/provider interviews)	Retrospective chart abstraction
Consent required	Yes (obtained in 39%)	Yes (obtained in 51%)	No	No
Baseline data	Demographics, comorbid illness Stroke type, severity (based on the CNS*), time to presentation In-hospital therapy, investigations	Demographics, comorbid illness Stroke type, severity (CNS), time to presentation In-hospital therapy, investigations	Demographics, comorbid illness Stroke type, severity (CNS), time to presentation In-hospital therapy, investigations	Demographics, comorbid illness Stroke type, severity (CNS), time to presentation In-hospital therapy, investigations
Outcomes	In-hospital complications, mortality, length of stay, Rankin Score* at discharge, discharge destination Six-month telephone interview: death, recurrent stroke, use of medications, home care services, functional status (based on the SIS*), health status post-stroke (based on the EQ-SUM,* and quality of life (based on the EQ-5D* and HUI 2/3*).	In-hospital complications, mortality, length of stay, Rankin Score at discharge, discharge destination Six-month telephone interview: death, recurrent stroke, use of medications, home care services, functional status (based on the SIS-16),* health status post-stroke (based on the EQ-SUM), and quality of life (based on HUI 2/3).	In-hospital complications, mortality, length of stay, Rankin Score at discharge, discharge destination Linkages with administrative data provide information on deaths, admissions, physician visits and medication use after discharge	In-hospital complications, mortality, length of stay, Rankin Score at discharge, discharge destination Linkages with administrative data provide information on deaths, admissions, physician visits and medication use after discharge
* Telestroke site = institution with technology to reach neurology specialists using teleconferencing equipment; TIA = transient ischemic attack; CIHI DAD and NACRS = Canadian Institute for Health Information Discharge Abstract Database and National Ambulatory Care Reporting System; ICD-10 = International Classification of Diseases 10 th revision; CNS = Canadian Neurological Scale (which assesses stroke impairment in conscious patients); Rankin Score = a measure of functional status; SIS = Stroke Impact Scale (functional status); SIS-16 = an abbreviated 16-item version of the original SIS; EQ-SUM = a measure of post-stroke health status, EQ-5D = a measure of quality of life; HUI 2/3 = Health Utilities Index Mark 2 and 3 (a measure of quality of life)				

Data source: Protocol and Amendment 1, 2 and 3.

Data handling and quality control

Chart abstraction is completed by trained neurology research nurses. Data collected at each site are entered into a laptop computer with software designed specifically for RCSN data entry. To further increase the validity and reliability of the data, the RCSN database software performs internal data checks to determine that the data entered are complete, within predetermined ranges, and internally consistent.

At regular intervals, all chart abstractors perform chart abstraction on a series of test charts. These are compared to a gold standard chart and problem areas are identified and corrected. In addition, chart validation is performed on an annual basis with duplicate chart abstraction on a random sample of 10% of charts. To date, chart validation has showed excellent agreement ($\kappa > 0.8$) for key variables, including age, sex, stroke type and use of thrombolysis.

Data security and confidentiality

All laptops are password-protected and data are encrypted. Encrypted data are sent electronically on a secure telephone line to ICES in Toronto. Data received at ICES are stored on a secure server in a database that can be accessed only by a limited number of approved ICES staff. This server is completely isolated from the outside; it is not linked to the Internet and it has no drives or peripherals that allow the data to be copied. The physical security of ICES includes electronic controlled key access areas, video camera surveillance, glass breakage detectors, frosted glass in lower floor windows to ensure visual privacy and highly restricted access to the administrative data server.

ICES' confidentiality and security policies regarding data collection are stringently enforced to maintain confidentiality of all personal health information. All primary data are devoid of any personal information or identifiers. Unique study numbers are assigned to each study subject to prevent unauthorized identification of research participants. Any remaining data fields that may provide clues to personal identity are encrypted before the data files are released for research use.

Publications policies

Data from the RCSN are available for analysis for investigator-initiated research projects. Data requests, reviewed quarterly by the RCSN publications committee, must follow standardized guidelines (Appendix C).

Selected Results from the RCSN

Data from the RCSN can be used to describe the characteristics of stroke patients seen at participating institutions, to determine the type of care received, and to evaluate outcomes after stroke. Selected results from the RCSN are presented in the following tables. First, overall results from each of the three phases are presented. Then, data from the first year (July 2003 to June 2004) of Phase 3 of the RCSN are used to examine stroke characteristics, care and outcomes by age, sex and stroke type. All results presented are based on the number of stroke events reported in the RCSN.

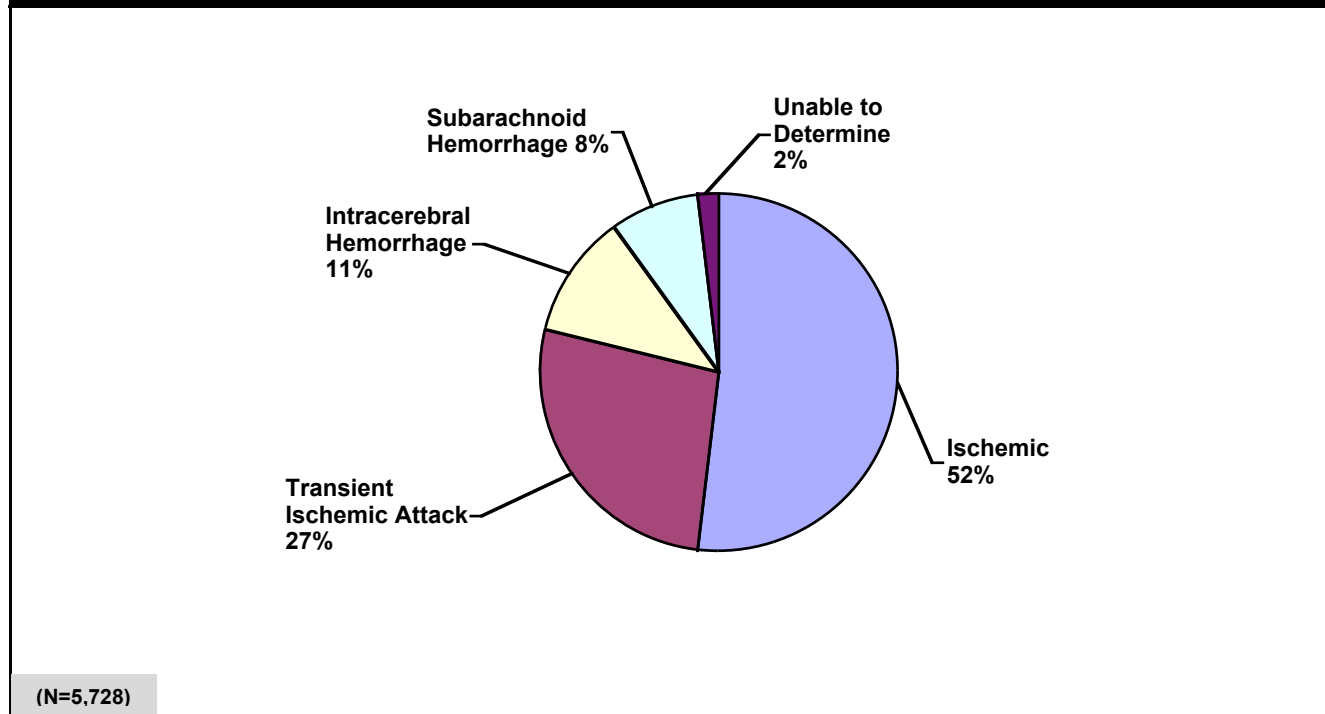
Due to methodological differences in sampling and patient selection among the three phases of the RCSN, results from each three phase are not directly comparable. Thus, we do not present statistical comparisons of results from the three phases, and no inferences should be drawn about temporal trends over the course of the study to date.

Baseline characteristics

Exhibit 3. Baseline Registry of the Canadian Stroke Network patient characteristics, Phase 1–3, 2001–2004			
Patient Characteristics	Phase 1 (Jun 2001–Feb 2002)	Phase 2 (Jun 2002–Dec 2002)	Phase 3 (Jul 2003–Jun 2004)
Total number of patients	4,483	3,047	5,728
Median Age (years)	71	73	72
Percent Male patients	52	52	51
Number of patients who consented to full data collection (Phase 1, 2)	1,742	1,570	5,728
Percent:			
With atrial fibrillation	13	15	13
With diabetes	22	22	23
With hypertension	56	61	64
With hyperlipidemia	29	31	33
With previous stroke/ transient ischemic attack	20	20	22
Smoking (current)	21	19	19
Previous myocardial infarction	13	16	15

Data source: Registry of the Canadian Stroke Network

Exhibit 4. Distribution of stroke types in Registry of the Canadian Stroke Network patients, Phase 3, July 2003–June 2004



Data source: Registry of the Canadian Stroke Network

Exhibit 5. Stroke presentation, by age and sex, in Registry of the Canadian Stroke Network patients, Phase 3, July 2003–June 2004

Stroke presentation	Sex		Women by Age Group					Men by Age Group				
	Women	Men	20–49	50–64	65–74	75+	All	20–49	50–64	65–74	75+	All
Sample size	2,790	2,938	300	516	573	1,396	2,785	300	780	749	1,102	2,931
Stroke type (number/percent of):												
Intracerebral hemorrhage	301 (10.8)	326 (11.1)	34 (11.3)	53 (10.3)	67 (11.7)	146 (10.5)	300 (10.8)	44 (14.7)	74 (9.5)	97 (13.0)	110 (10.0)	325 (11.1)
Ischemic stroke	1,393 (49.9)	1,588 (54.1)	95 (31.7)	181 (35.1)	307 (53.6)	807 (57.8)	1,390 (49.9)	118 (39.3)	412 (52.8)	421 (56.2)	632 (57.4)	1,583 (54.0)
Subarachnoid hemorrhage	282 (10.1)	143 (4.9)	86 (28.7)	115 (22.3)	44 (7.7)	37 (2.7)	282 (10.1)	48 (16.0)	57 (7.3)	19 (2.5)	19 (1.7)	143 (4.9)
Transient ischemic attack	740 (26.5)	805 (27.4)	65 (21.7)	148 (28.7)	145 (25.3)	381 (27.3)	739 (26.5)	75 (25.0)	221 (28.3)	195 (26.0)	314 (28.5)	805 (27.5)
Unable to determine	74 (2.7)	76 (2.6)	20 (6.7)	19 (3.7)	10 (1.7)	25 (1.8)	74 (2.7)	15 (5.0)	16 (2.1)	17 (2.3)	27 (2.5)	75 (2.6)
Unconscious	122 (5.0)	111 (4.0)	12 (6.1)	17 (4.4)	19 (3.6)	73 (5.4)	121 (4.9)	24 (9.8)	16 (2.3)	30 (4.2)	41 (3.8)	111 (4.0)
Canadian Neurological Scale score > 8*	1,545 (69.3)	1,809 (71.8)	141 (78.8)	276 (76.7)	344 (72.1)	780 (64.6)	1,541 (69.3)	162 (75.7)	512 (77.0)	458 (69.1)	674 (69.4)	1,806 (71.9)
Stroke discovered upon awakening	492 (17.6)	560 (19.1)	44 (14.7)	87 (16.9)	112 (19.5)	249 (17.8)	492 (17.7)	38 (12.7)	133 (17.1)	170 (22.7)	218 (19.8)	559 (19.1)
(N=5,728)	*a score > 8 indicates a less severe stroke											

Data source: Registry of the Canadian Stroke Network

Key messages

1. Among stroke patients in the RCSN, the prevalence of traditional cardiovascular risk factors was high: approximately 22% had diabetes, 60% had hypertension, 30% had hyperlipidemia, and 13% had atrial fibrillation.
2. The breakdown by stroke type in the RCSN was similar to that seen in other stroke registries and databases: ischemic stroke in 52%, TIA in 27%, intracerebral hemorrhage in 11% and subarachnoid hemorrhage in 8%. The stroke type could not be determined in 2% of cases.
3. Overall, 70% of patients had a Canadian Neurological Scale score > 8 on presentation (lower stroke severity), and 18% discovered their stroke on awakening; these are consistent with rates reported in the literature.

Pre-hospital and emergency care**Exhibit 6. Pre-hospital and emergency care of Registry of the Canadian Stroke Network patients, Phase 1–3, 2001–2004**

Risk Factors/Comorbidity	Phase 1	Phase 2	Phase 3
Sample size	1,705	1,565	5,631
Number/percent of:			
Patients arriving by ambulance	978 (60.8)	892 (57.4)	3,167 (57.6)
Patients arriving within 2 hours of stroke onset	393 (25.4)	452 (29.1)	1,576 (28.3%)
Median (inter-quartile range) Time from stroke onset to emergency department arrival (hours)	7.17 (2.00–24.17)	5.14 (1.68–17.38)	5.35 (1.73–17.58)
Number/percent of:			
Patients transferred from another emergency department	348 (21.5)	221 (14.5)	789 (14.4)
Emergency department arrivals pre-notified by emergency medical services	181 (27.8)	182 (31.5)	582 (26.8)
Patients treated with tissue plasminogen activator (ischemic strokes)	181 (8.1)	185 (10.2)	300 (10.1)
Patients treated with tissue plasminogen activator (ischemic stroke patients arriving within 2 hours of stroke onset)	Not available	Not available	232 (28)
Patients admitted to hospital	1,331 (86.9)	1,288 (82.7)	3,781 (69.6)
Notes: Phase 1 and 2 results are for patients who gave informed consent to participate in the RCSN; Phase 3 results are for patients enrolled between July 2003 and June 2004. Due to missing data, the number and percent shown may not correspond.			

Data source: Registry of the Canadian Stroke Network

Key messages

1. Approximately one-quarter of patients arrived to hospital within two hours of stroke onset. Prompt hospital arrival for ischemic stroke patients increases their potential eligibility for treatment with thrombolytic therapies, and may result in improved outcomes for all stroke patients.
2. In Phase 2 and 3 one in ten patients with ischemic stroke were treated with tPA. In Phase 3 more than one in four patients arriving within two hours of their stroke onset received tPA.
3. The majority of stroke patients were admitted to hospital. The lower proportion of stroke admissions in Phase 3 is primarily due to differences in patient inclusion criteria for this phase of the RCSN, during which a concerted effort was made to include patients in the RCSN database who were discharged from the ED. Patients with a discharge diagnosis of TIA were the largest group discharged directly from the emergency department.

Thrombolysis

Exhibit 7. Demographics of Registry of the Canadian Stroke Network patients receiving tissue plasminogen activator, Phase 1–3, 2001–2004

Patient Demographics	Phase 1	Phase 2	Phase 3	All
Sample size	N = 181	N = 182	N = 302	N = 665
Time period	Jun 01–Feb 02	Jun 02–Dec 02	Jul 03–Jun 04	
Number/percent of:				
Male patients	113 (62.4)	98 (53.8)	167 (55.3)	378 (56.8)
Median/inter-quartile range				
Age (years)	70 (62–79)	74 (65–82)	74 (64–80)	73 (64–80)
Note: Phase 1 and 2 results are for patients who gave informed consent to participate in the RCSN; Phase 3 results are for patients enrolled between July 2003 and June 2004.				

Data source: Registry of the Canadian Stroke Network

Key messages

1. The median age of patients treated with tPA was 73, with the oldest patient being 94 years old. In general, age is not a limiting factor in determining eligible candidates for tPA administration.
2. Slightly more men were treated with tPA than women, which is consistent with the slightly higher number of men presenting to hospital with ischemic stroke.

Exhibit 8. Frequency of risk factors and comorbidities in Registry of the Canadian Stroke Network patients receiving tissue plasminogen activator, Phase 1–3, 2001–2004

Risk Factors/Comorbidity	Phase 1	Phase 2	Phase 3	All
Sample size (patients receiving tissue plasminogen activator)	N = 126	N = 115	N = 302	N = 543
Number/percent of:				
Patients with hypertension	85 (70.2)	71 (61.7)	198 (65.6)	354 (65.8)
Patients with diabetes	34 (27.6)	19 (16.5)	49 (16.2)	102 (18.9)
Patients that were smokers	59 (47.6)	40 (34.8)	115 (38.1)	214 (39.6)
Patients with hyperlipidemia	51 (41.1)	35 (30.4)	108 (35.8)	194 (35.9)
Patients with atrial fibrillation	22 (17.7)	24 (21.1)	46 (15.2)	92 (17.0)
Patients with congestive heart failure	15 (12.1)	7 (6.1)	24 (7.9)	46 (8.5)
Patients with coronary artery disease (includes angina, myocardial infarction, percutaneous transluminal coronary angioplasty, coronary artery bypass grafting)	52 (41.9)	31 (27.0)	88 (29.1)	171 (31.6)
Patients with valvular heart disease or valve replacement	**	**	12 (4.0)	17 (3.1)
Patients with peripheral vascular disease	**	**	9 (3.0)	16 (3.0)
Patients with renal dialysis	**	**	**	6 (1.1)
Patients with cancer	12 (9.8)	6 (5.2)	13 (4.3)	31 (5.8)
Patients with peptic ulcer/past gastrointestinal hemorrhage	**	9 (7.8)	23 (7.6)	34 (6.3)
Patients with cirrhosis	0 (0.0)	0 (0.0)	**	**
Patients with pregnancy	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Note: Phase 1 and 2 results are for patients who gave informed consent to participate in the RCSN; Phase 3 results are for patients enrolled between July 2003 and June 2004.				
** Results are suppressed for cell sizes ≤ 5				

Data source: Registry of the Canadian Stroke Network

Exhibit 9. Stroke severity in Registry of the Canadian Stroke Network patients receiving tissue plasminogen activator, Phase 1–3, 2001–2004

Stroke Severity		Phase 1	Phase 2	Phase 3	All
Sample size		N = 126	N = 115	N = 302	N = 543
Oxfordshire Community Stroke Project Classification	Number/percent of:				
	Lacunar syndrome	6 (6.7)	14 (12.3)	36 (12.3)	56 (11.3)
	Partial anterior circulation syndrome	28 (31.5)	33 (28.9)	128 (43.7)	189 (38.1)
	Posterior circulation syndrome	9 (10.1)	12 (10.5)	22 (7.5)	43 (8.7)
	Total anterior circulation syndrome	45 (50.6)	53 (46.5)	104 (35.5)	202 (40.7)
Canadian Neurological Scale Score	Median/inter-quartile range	6 (4–7)	6 (4–8)	6 (5–7)	6 (4–8)
Canadian Neurological Scale Score \geq 8	Number/percent	21 (23.6)	31 (27.4)	61 (21.3)	113 (23.1)
National Institutes of Health Stroke Scale Score	Median/inter-quartile range	15 (10–18)	14 (8–17)	13 (9–17)	14 (9–17)
National Institutes of Health Stroke Scale Score \geq 12	Number/percent	53 (67.9)	57 (59.4)	129 (62.3)	239 (62.7)
Level of Consciousness = Alert	Number/percent	95 (75.4)	96 (85.0)	262 (86.8)	453 (83.7)
Note: Phase 1 and 2 results are for patients who gave informed consent to participate in the RCSN; Phase 3 results are for patients enrolled between July 2003 and June 2004.					

Data source: Registry of the Canadian Stroke Network

Key messages

1. The majority of patients treated with tPA had severe initial deficits, with 53% having initial National Institutes of Health Stroke Scale scores of more than 12, and CNS scores in the mid-range of the scale.
2. The majority of patients who received tPA were alert at presentation to hospital (84%). Some patients with a depressed level of consciousness also received tPA.

Exhibit 10. Frequency of intravenous and intra-arterial tissue plasminogen activator administration and dosage levels in Registry of the Canadian Stroke Network patients, Phase 1–3, 2001–2004

Tissue Plasminogen Activator Route and Dosage		Phase 1	Phase 2	Phase 3	All
Sample size		N = 126	N = 115	N = 302	N = 543
Route	Number/percent of:				
	Intravenous/intra-arterial	6 (5.1)	6 (5.2)	12 (4.0)	24 (4.5)
	Intra-arterial	13 (11.0)	8 (7.0)	10 (3.3)	31 (5.8)
	Intravenous	99 (83.9)	101 (87.8)	280 (92.7)	480 (89.7)
Intravenous Dose	Median/inter-quartile range (mg)	64 (56–75)	61 (50–72)	66 (54–76)	64 (54–75)
Intra-arterial Dose	Median/inter-quartile range (mg)	26 (12–56)	12 (7–30)	10 (8–17)	12 (8–24)
Note: Phase 1 and 2 results are for patients who gave informed consent to participate in the RCSN; Phase 3 results are for patients enrolled between July 2003 and June 2004.					

Data source: Registry of the Canadian Stroke Network

Key messages

1. Most of the patients receiving tPA had it administered through an intravenous (IV) route (90%).
2. Of the 10% of patients receiving intra-arterial (IA) tPA, just under half were treated with combined IV and IA tPA, likely following the IMS (Interventional Management of Stroke) protocol.

Exhibit 11. Time intervals from discovery of stroke symptoms to administration of tissue plasminogen activator in Registry of the Canadian Stroke Network patients, Phase 1–3, 2001–2004

Time Intervals		Phase 1	Phase 2	Phase 3	All
Sample size		N = 126	N = 115	N = 302	N = 543
Number/percent of: Patients discovering symptoms on awakening		6 (5.4)	**	6 (2.0)	17 (3.2)
Number/percent of: Patients with stroke onset to arrival (LSN* to emergency department) in:	> 6 hours	**	**	8 (2.7)	15 (2.8)
	3–6 hours	9 (7.7)	7 (6.2)	11 (3.7)	27 (5.1)
	2–3 hours	20 (17.1)	21 (18.6)	50 (16.7)	91 (17.2)
	< 2 hours	86 (73.5)	80 (70.8)	231 (77.0)	397 (74.9)
LSN to emergency department	Median/inter-quartile range (minutes)	71 (49–125)	77 (50–132)	68 (50–105)	70 (49–120)
Number/percent of: Patients with LSN to emergency department < 2 hours		86 (73.5)	80 (70.8)	231 (77.0)	397 (74.9)
Emergency department to CT*	Median/inter-quartile range (minutes)	40 (24–72)	36 (23–57)	29 (14–49)	31 (17–54)
Number/percent of: Patients with emergency department to CT < 30 minutes		28 (34.6)	36 (38.7)	141 (51.5)	205 (45.8)
CT to tissue plasminogen activator	Median/inter-quartile range (minutes)	43 (25–92)	49 (33–68)	51 (33–72)	50 (31–73)
Number/percent of: Patients with CT to tissue plasminogen activator < 20 minutes		9 (15.0)	11 (13.9)	22 (8.5)	42 (10.5)
Emergency department to tissue plasminogen activator	Median/inter-quartile range (minutes)	75 (55–122)	87 (61–108)	80 (60–108)	80 (60–110)
Number/percent of: Patients with emergency department to tissue plasminogen activator < 60 minutes		29 (30.5)	19 (20.9)	67 (24.3)	115 (24.9)
LSN to tissue plasminogen activator	Median/inter-quartile range (minutes)	166 (129–190)	165 (142–185)	160 (135–185)	161 (135–185)
Number/percent of: Patients with LSN to tissue plasminogen activator < 3 hours		59 (67.0)	58 (64.4)	201 (72.8)	318 (70.0)
<p>Note: Phase 1 and 2 results are for patients who gave informed consent to participate in the RCSN; Phase 3 results are for patients enrolled between July 2003 and June 2004. Shaded areas represent the numbers of patients achieving the identified target times.</p> <p>*LSN = Last Seen Normal (prior to onset of stroke symptoms); CT = Computerized Tomography Scan (CAT Scan)</p> <p>** Results are suppressed for cell sizes ≤ 5</p>					

Data source: Registry of the Canadian Stroke Network

Key messages

1. Three-quarters of patients receiving tPA arrived to hospital within two hours of stroke onset.
2. The median ED-to-CT time of 31 minutes is comparable to other reported time intervals, however the CT-to-needle time of 50 minutes is longer than reported in other studies.
3. Seventy percent of patients receiving tPA were treated within three hours of stroke onset (most IV tPA protocols specify that therapy must be administered within this time window).
4. A small number (3%) of patients who awoke with their symptoms were treated despite not knowing the exact time of stroke onset.

Exhibit 12. Emergency and in-hospital management of Registry of the Canadian Stroke Network patients receiving tissue plasminogen activator, Phase 1–3, 2001–2004

Type of Management		Phase 1	Phase 2	Phase 3	All
Sample size		N = 126	N = 115	N = 302	N = 543
Number/percent of:					
Patients arriving by ambulance		106 (85.5)	106 (93.8)	254 (87.9)	466 (88.6)
Patients emergency medical services declared acute stroke		n/a	n/a	89 (56.7)	89 (56.7)
Emergency department arrivals pre-notified by emergency medical services		33 (40.2)	32 (47.8)	74 (47.4)	139 (45.6)
Patients with stroke protocol activated in emergency department		67 (53.2)	95 (82.6)	258 (89.6)	420 (79.4)
Patients with hypertension pre-tissue plasminogen activator (systolic blood pressure > 185 or diastolic blood pressure >110)		11 (9.4)	15 (14.0)	40 (13.2)	66 (12.5)
Patients admitted to:	Intensive Care Unit	48 (42.5)	33 (28.7)	94 (31.2)	175 (33.1)
	Medical ward	32 (28.3)	**	**	37 (7.0)
	Neurology	11 (9.7)	30 (26.1)	56 (18.6)	97 (18.3)
	Other	**	17 (14.8)	16 (5.3)	37 (7.0)
	Stepdown unit	7 (6.2)	18 (15.7)	54 (17.9)	79 (14.9)
	Stroke unit	11 (9.7)	15 (13.0)	78 (25.9)	104 (19.7)
Patients who received tissue plasminogen activator for an in-hospital stroke		Not available	Not available	14 (4.6)	14 (4.6)
Intensive Care Unit length of stay overall	Median/inter-quartile range (days)	Not available	Not available	1 (1–2)	1 (1–2)
Hospital length of stay	Median/inter-quartile range (days)	13 (5–21)	9 (5–21)	10 (5–20)	11 (5–21)
Note: Phase 1 and 2 results are for patients who gave informed consent to participate in the RCSN; Phase 3 results are for patients enrolled between July 2003 and June 2004. ** Results are suppressed for cell sizes ≤ 5					

Data source: Registry of the Canadian Stroke Network

Key messages

1. The majority of patients who received tPA arrived by ambulance, and had an acute stroke protocol activated in the ED.
2. Most patients were admitted to an intensive care unit, stepdown unit or stroke unit.

Exhibit 13. Post-treatment outcomes of Registry of the Canadian Stroke Network patients receiving tissue plasminogen activator, Phase 1–3, 2001–2004

Outcome		Phase 1	Phase 2	Phase 3	All
Sample size		N = 126	N = 115	N = 302	N = 543
Number/percent of:					
In-hospital deaths		20 (16.0)	8 (7.0)	50 (16.6)	78 (14.4)
Patients with neurological worsening		22 (19.3)	24 (22.4)	62 (20.6)	108 (20.7)
Patients with new stroke		10 (8.8)	6 (5.7)	15 (5.0)	31 (6.0)
Patients with secondary hemorrhage		Not available	8 (7.0)	32 (10.6)	40 (7.4)
Patients with secondary symptomatic hemorrhage		Not available	**	20 (6.7)	25 (4.6)
Patients with secondary parenchymal hemorrhage		Not available	Not available	12 (4.0)	12 (2.3)
Patients with seizure		6 (5.4)	**	**	13 (2.5)
Patients with non-stroke complications		31 (27.4)	37 (34.6)	89 (29.6)	157 (30.1)
Patients with Rankin Score* at discharge:	0	Not available	14 (12.4)	24 (8.4)	38 (9.5)
	1	Not available	16 (14.2)	33 (11.5)	49 (12.3)
	2	Not available	12 (10.6)	37 (12.9)	49 (12.3)
	3	Not available	14 (12.4)	41 (14.3)	55 (13.8)
	4	Not available	34 (30.1)	71 (24.7)	105 (26.3)
	5	Not available	15 (13.3)	31 (10.8)	46 (11.5)
	6 (dead)	Not available	8 (7.1)	50 (17.4)	58 (14.5)
Patients with Rankin Score \leq 2 at discharge		Not available	42 (40.0)	94 (32.8)	143 (34.5)
Patients discharged to:	Acute care	10 (10.6)	16 (14.8)	28 (11.1)	54 (11.9)
	Home	40 (42.6)	47 (43.5)	114 (45.2)	201 (44.3)
	Long-term care	6 (6.4)	7 (6.5)	22 (8.7)	35 (7.7)
	Other	**	**	**	9 (2.0)
	In-patient rehabilitation	35 (37.2)	31 (28.7)	87 (34.5)	153 (33.7)
Note: Phase 1 and 2 results are for patients who gave informed consent to participate in the RCSN; Phase 3 results are for patients enrolled between July 2003 and June 2004.					
*Rankin Score = a measure of functional status					
** Results are suppressed for cell sizes \leq 5					

Data source: Registry of the Canadian Stroke Network

Key messages

1. The in-hospital mortality rate of 14% for patients who received tPA was similar to that of patients with ischemic stroke who did not receive tPA.
2. One in five patients receiving tPA had neurological worsening.
3. The symptomatic secondary hemorrhage rate of 4.6% was similar to that seen in other published studies of tPA use.
4. At discharge, 34% achieved a modified Rankin Score \leq 2 (considered functionally independent). This outcome cannot be compared to the 90-day outcomes used in most clinical trials of acute stroke management.

Exhibit 14. Reasons for not administering tissue plasminogen activator, Registry of the Canadian Stroke Network patients with ischemic stroke, Phase 1–3, 2001–2004

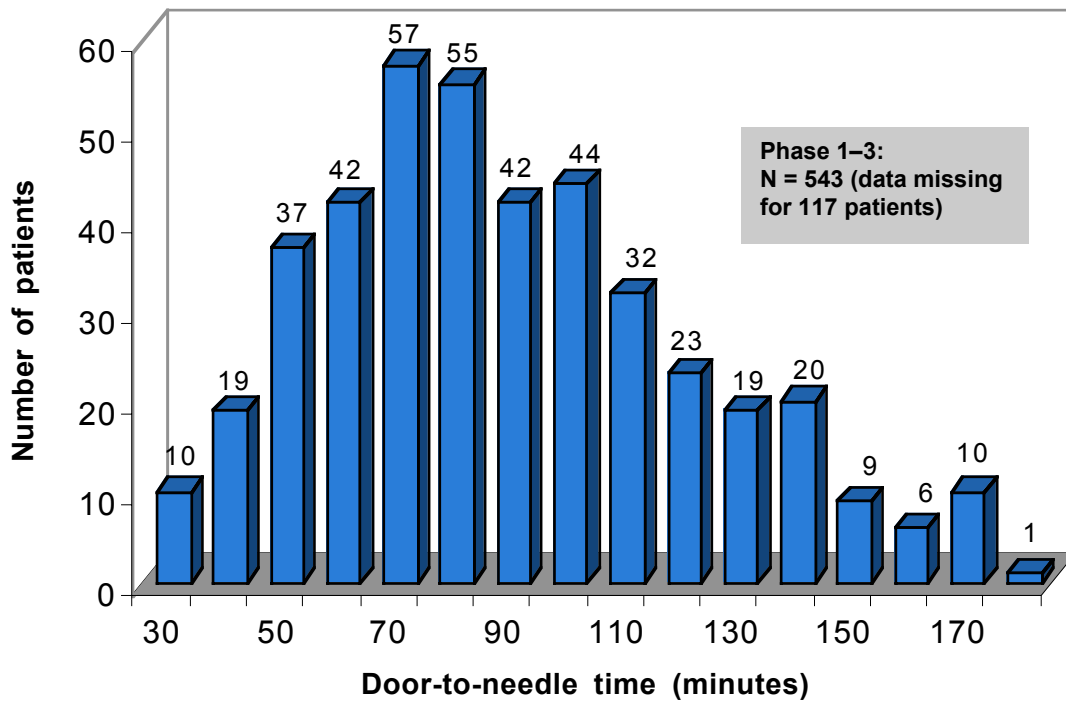
Reasons	Phase 1	Phase 2	Phase 3	All
Sample size	N = 1,074	N = 950	N = 4,082	N = 6,106
Number/percent of:				
Patients that arrived too late (time from stroke onset to emergency department arrival > 2.5 hours)	747 (73.3)	681 (71.8)	2,759 (68.3)	4,187 (69.7)
Patients too mild (Deficit too mild or rapidly improving)	157 (15.2)	144 (15.2)	811 (19.9)	1,112 (18.3)
Patients rapidly improving	85 (8.3)	80 (8.4)	559 (13.7)	724 (12.0)
Patients with too severe a deficit	17 (1.7)	12 (1.3)	66 (1.6)	95 (1.6)
Patients with contraindication	30 (2.9)	33 (3.5)	236 (5.8)	299 (4.9)
Patients with comorbidities	17 (1.7)	16 (1.7)	88 (2.2)	121 (2.0)
Patients with no consent	**	**	43 (1.1)	48 (0.8)
Patients with system delay (protocol not initiated, no Computerized Tomography Scan [CAT scan], > 3 hours)	58 (5.5)	57 (6.0)	186 (4.6)	301 (4.9)
With other unspecified reason	0 (0.0)	0 (0.0)	59 (1.4)	59 (1.0)
Unable to determine	Not available	Not available	87 (2.1)	87 (2.1)
Note: Phase 1 and 2 results are for patients who gave informed consent to participate in the RCSN; Phase 3 results are for patients enrolled between July 2003 and June 2004.				
** Results are suppressed for cell sizes ≤ 5				

Data source: Registry of the Canadian Stroke Network

Key messages

1. As expected, arriving too late (outside the three-hour window) was the most common reason for not giving tPA (70%). This implies that improving public awareness and emergency medical services protocols to enhance the rapid delivery of stroke patients to stroke centres, are the most important strategies to increase tPA use.
2. “Deficit too mild” or “rapid improvements” were the next most common reasons that tPA was not given.
3. Only a small number of patients were excluded because of contraindications, comorbidities or lack of consent.
4. Within the treating hospital, system delays that would be amenable to improvement accounted for 5% of the reasons for not giving tPA. These cases should be treated as sentinel events and investigated to facilitate quality improvement in the management of tPA cases.

Exhibit 15. Time from hospital arrival to tissue plasminogen activator administration for Registry of the Canadian Stroke Network patients, Phase 1–3, 2001–2004

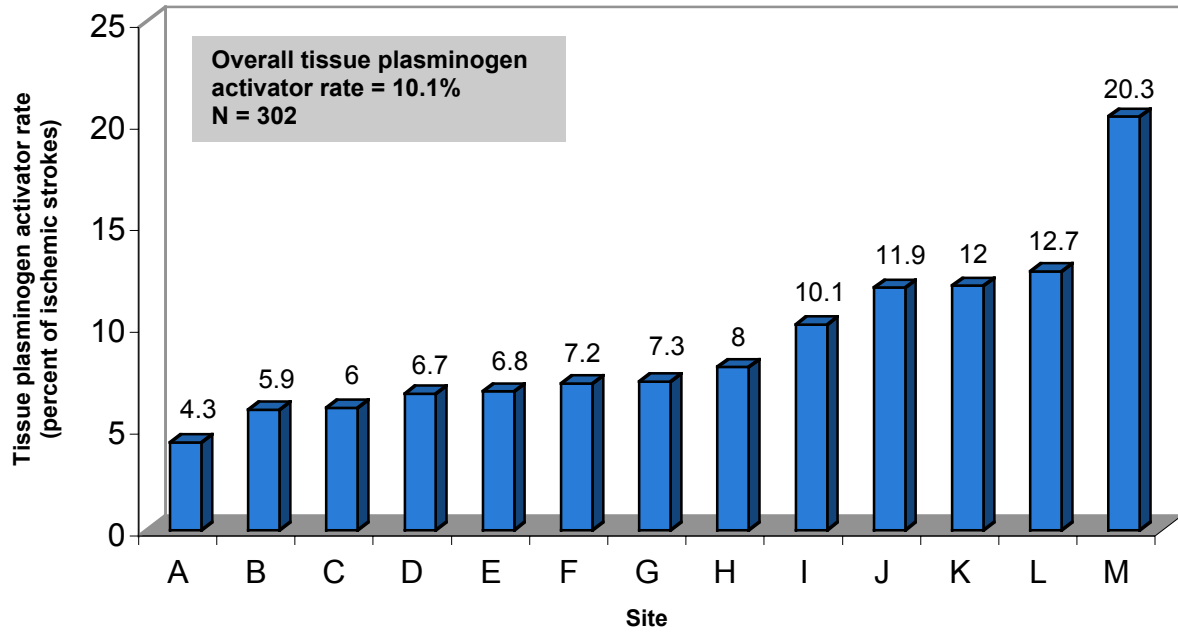


Data source: Registry of the Canadian Stroke Network

Key messages

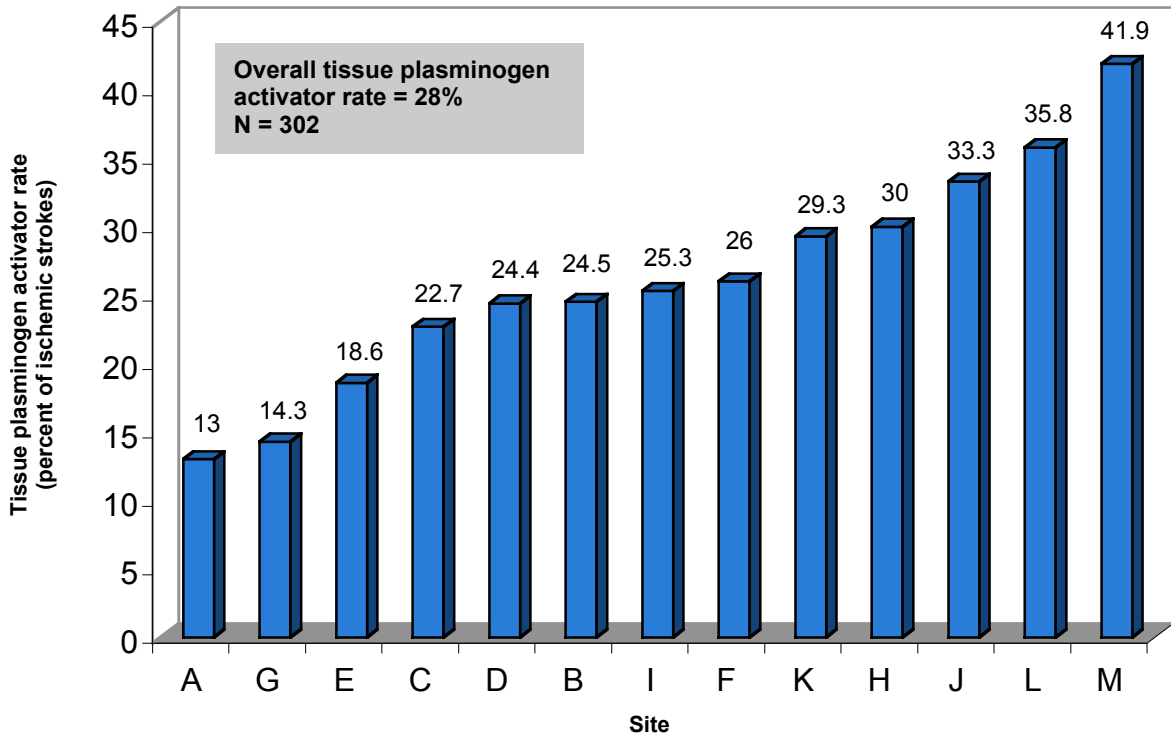
1. The door-to-needle times are relatively long, with most patients being treated more than 60 minutes after arrival. These data indicate opportunities for quality improvement initiatives to reduce door-to-needle times for potential tPA patients.
2. Treatment within 60 minutes is clearly possible and is being achieved in a small number of patients.

Exhibit 16. Rate of tissue plasminogen activator administration for all Registry of the Canadian Stroke Network patients with ischemic stroke, by site, Phase 3, July 2003–June 2004



Data source: Registry of the Canadian Stroke Network

Exhibit 17. Rate of tissue plasminogen activator administration to Registry of the Canadian Stroke Network patients with ischemic stroke arriving to hospital within two hours, by site, Phase 3, July 2003–June 2004



Data source: Registry of the Canadian Stroke Network

Key messages

1. There is considerable variability in tPA administration among hospitals.
2. Further research should be done to determine reasons for this variability, with targeted interventions in hospitals with low rates of tPA usage.
3. About one in ten patients with acute ischemic stroke is treated with tPA.
4. For patients arriving within two hours of ischemic stroke onset, one in four is treated with tPA.

In-hospital care

Exhibit 18. Stroke evaluation and therapy in admitted Registry of the Canadian Stroke Network patients, Phase 1–3, 2001–2004			
Hospital Stroke Care	Phase 1	Phase 2	Phase 3
Sample size	N = 1,331	N = 1,288	N = 3,781
Number/percent of:			
Patients receiving neurology consultation	946 (76.9)	678 (52.7)	1,792 (47.4)
Patients admitted to a stroke unit	245 (18.9)	267 (20.9)	1,062 (28.1)
Patients receiving physiotherapy	852 (71.1)	930 (72.4)	2,708 (71.6)
Patients receiving occupational therapy	791 (66.6)	880 (68.5)	2,479 (65.6)
Patients receiving speech language pathology	519 (47.1)	566 (44.1)	1,609 (42.6)
Patients receiving social work	485 (40.2)	544 (42.3)	1,807 (47.8)
Patients receiving nutrition assessment	439 (40.6)	449 (37.4)	1,401 (37.1)
Patients receiving swallowing assessment	Not available	501 (39.0)	1,573 (41.6)
Patients receiving neuroimaging (Computerized Tomography Scan [CAT Scan]/Magnetic Resonance Imaging)	Not available	1,257 (97.7)	3,727 (98.6)
Patients receiving carotid imaging	669 (56.3)	679 (52.8)	1,810 (53.6)
Patients receiving lipid measurement	561 (50.2)	695 (54.0)	1,965 (58.2)
Number of:			
Patients with ischemic stroke or transient ischemic attack	N = 1,001	N = 1,022	N = 2,819
Number/percent of:			
Patients receiving acetylsalicylic acid (ASA) within 48 hours	Not available	Not available	2,432 (86.6)
Patients receiving any antithrombotic agent	799 (95.0)	781 (90.3)	2,344 (92.9)
Patients receiving warfarin for atrial fibrillation	106 (70.2)	135 (75.0)	382 (75.2)
Patients receiving angiotensin converting enzyme inhibitor	418 (49.7)	388 (44.9)	1,379 (54.6)
Patients receiving statin	329 (39.1)	431 (49.8)	1,442 (57.1)
Notes: Phase 1 and 2 results are for patients who gave informed consent to participate in the RCSN; Phase 3 results are for patients enrolled between July 2003 and June 2004. Due to missing data, the number and percent shown may not correspond.			

Data source: Registry of the Canadian Stroke Network

Key messages

1. Almost all patients underwent neuroimaging and the vast majority of patients with ischemic stroke received antithrombotic agents, usually within 48 hours.
2. A substantial proportion (> 70%) of stroke patients received physiotherapy and over 70% of patients with atrial fibrillation received warfarin at discharge.
3. Rates for other recognized stroke quality of care indicators were lower: less than 28% received care on an acute stroke unit, and less than 42% were reported to have undergone a swallowing assessment.

Stroke outcomes

Exhibit 19. Stroke outcomes of Registry of the Canadian Stroke Network patients, Phase 1–3, 2001–2004				
	Stroke Outcome	Phase 1	Phase 2	Phase 3 (Jul 2003 – Jun 2004)
All Patients	Sample size	N = 2,599	N = 2,373	N = 3,781
	Number/percent of: In-hospital deaths	279 (12.8)	321 (13.5)	571 (15.1)
	Median/inter-quartile range (days) Length of stay	9 (4–21)	10 (4–21)	9 (4–19)
Consented Patients	Sample size	N = 1,329	N = 1,261	N = 3,781
	Number/percent of: Patients with Discharge Rankin Score* ≤ 2	175 (67.3)	630 (54.4)	1,538 (42.6)
	Number/percent of: Patients alive at discharge	N = 1,236	N = 1,163	N = 3,210
	Number/percent of: Patients discharged to long-term care/nursing home	78 (6.3)	79 (6.8)	341 (10.6)
	Patients discharged to rehabilitation	270 (21.8)	299 (25.7)	788 (24.5)
	Patients receiving follow-up with stroke prevention clinic	Not available	291 (25.0)	865 (26.9)
	Median Stroke Impact Scale score at 6 months	87.5	89.1	Not available
	Median Health Utilities Index Mark 2 and 3 score at 6 months	0.92	0.89	Not available
Notes: Phase 1 and 2 results are for patients who gave informed consent to participate in the RCSN; Phase 3 results are for patients enrolled between July 2003 and June 2004. Due to missing data, the numbers and percent shown may not correspond.				
*Rankin Score = a measure of functional status				

Data source: Registry of the Canadian Stroke Network

Key messages

1. The in-hospital mortality rate of 15% and median length of stay of nine days are consistent with results from other stroke studies.
2. Approximately one in four patients received follow-up in a stroke prevention clinic. This proportion is expected to increase over time with the designation of new stroke prevention clinics in the province of Ontario.
3. At six months after stroke, stroke survivors had a relatively high self-reported quality of life, with a median Health Utilities Index Mark 2/3 score of 0.89 (score of 1 indicates perfect health, and 0 indicates death).

Exhibit 20. Outcomes for Registry of the Canadian Stroke Network patients with ischemic stroke, by age and sex, Phase 3, July 2003–June 2004

Outcomes	Women by Age Group					Men by Age Group				
	20–49	50–64	65–74	75+	All Women	20–49	50–64	65–74	75+	All Men
Sample size	N = 91	N = 172	N = 265	N = 800	N = 1,328	N = 101	N = 351	N = 399	N = 604	N = 1,455
Number/percent of: In-hospital deaths	**	7 (4.1)	21 (7.9)	111 (13.9)	144 (10.8)	8 (7.9)	20 (5.7)	34 (8.5)	88 (14.6)	150 (10.3)
Median/inter-quartile range (days) Length of stay	7 (3–13)	7 (4–15)	8 (4–18)	11 (5–23)	9 (4–20)	6 (3–12)	7 (4–13)	8 (4–17)	9 (5–20)	8 (4–17)
Number/percent of: Patients with Rankin Score* ≤ 2	55 (62.5)	96 (58.2)	112 (44.4)	279 (36.7)	542 (42.8)	62 (66.0)	189 (55.8)	175 (47.0)	249 (43.2)	675 (48.9)
Number of: Patients alive at discharge	N = 91	N = 172	N = 265	N = 800	N = 1,328	N = 101	N = 351	N = 399	N = 604	N = 1,455
Number/percent of: Patients discharged to long-term care/nursing home	**	**	17 (7.0)	158 (22.9)	178 (15.0)	**	6 (1.8)	33 (9.0)	67 (13.0)	106 (8.1)
Patients discharged to rehabilitation	20 (23.3)	43 (26.1)	72 (29.5)	167 (24.2)	302 (25.5)	15 (16.1)	101 (30.5)	95 (26.0)	131 (25.4)	342 (26.2)
Patients that received follow-up with stroke prevention clinic	44 (51.2)	54 (32.7)	78 (32.0)	168 (24.4)	344 (29.1)	28 (30.1)	142 (42.9)	124 (34.0)	151 (29.3)	445 (34.1)
*Rankin Score = a measure of functional status										
**Results are suppressed for cell sizes ≤ 5										

Data source: Registry of the Canadian Stroke Network

Exhibit 21. Outcomes for Registry of the Canadian Stroke Network patients with hemorrhagic stroke, by age and sex, Phase 3, July 2003–June 2004

Outcomes	Women by Age Group					Men by Age Group				
	20–49	50–64	65–74	75+	All Women	20–49	50–64	65–74	75+	All Men
Sample size	N = 108	N = 153	N = 96	N = 164	N = 521	N = 79	N = 119	N = 106	N = 111	N = 415
Number/percent of: In-hospital deaths	18 (16.7)	26 (17.0)	27 (28.1)	82 (50.0)	153 (29.4)	11 (13.9)	19 (16.0)	38 (35.8)	49 (44.1)	117 (28.2)
Median/inter-quartile range (days) Length of stay	11 (5–24)	13 (7–25)	10 (4–21)	7 (3–21)	11 (4–23)	11 (5–22)	12 (5–25)	9 (3–28)	9 (3–22)	10 (4–25)
Number/percent of: Patients with Discharge Rankin Score* ≤ 2	57 (53.3)	60 (40.0)	20 (21.3)	14 (9.0)	151 (29.8)	44 (56.4)	53 (45.7)	17 (17.3)	15 (13.8)	129 (32.2)
Number of: Patients alive at discharge	N = 108	N = 153	N = 96	N = 164	N = 521	N = 79	N = 119	N = 106	N = 111	N = 415
Number/percent of: Patients discharged to long-term care/nursing home	**	**	**	27 (32.9)	33 (8.9)	**	**	**	17 (27.4%)	22 (7.4)
Patients discharged to rehabilitation	13 (14.4)	29 (22.8)	16 (22.9)	17 (20.7)	75 (20.3)	15 (22.1)	22 (22.0)	17 (25.0)	10 (16.1)	64 (21.5)
Patients receiving follow-up with stroke prevention clinic	**	7 (5.5)	7 (10.0)	8 (9.8)	26 (7.0)	**	10 (10.0)	15 (22.1)	12 (19.4)	42 (14.1)

* Rankin Score = a measure of functional status
**Results are suppressed for cell sizes ≤ 5

Data source: Registry of the Canadian Stroke Network

Key messages

1. The overall in-hospital mortality rate was 13% and median length of stay was nine days. Overall, 45% of patients had a Rankin Score ≤ 2 at discharge, indicating a good outcome. Approximately 25% of patients were referred to stroke prevention clinics for follow-up.
2. In-hospital mortality was similar in women and men, but increased in the older age groups, and was greater for hemorrhagic stroke compared to ischemic stroke. Length of stay was slightly longer for women than for men.
3. The proportion of patients with a good outcome (Rankin Score < 2 at discharge) was slightly lower in women than in men, decreased with increasing age, and was much lower with hemorrhagic stroke compared to ischemic stroke.

Conclusions and Future Directions

The Registry of the Canadian Stroke Network was developed to measure and monitor stroke care delivery in Canada, and to provide a rich clinical database for investigator-initiated research projects.

The results to date indicate that Canadians are receiving high quality stroke care in many domains, but that areas for improvement remain. The Canadian Stroke Quality of Care Study Group is developing quality of care performance indicators to be used for ongoing evaluation and surveillance of the quality of stroke care delivery. In the future, the Registry will be used to measure and monitor stroke care based on these specific quality indicators. Audit and feedback strategies will be used to inform participating sites about their stroke care performance, and to encourage improvements in stroke care delivery.

The Registry has already been used for a large and diverse number of investigator-initiated research projects (Appendix D). It is anticipated that through ongoing data collection and linkages to other databases, the RCSN will prove to be an invaluable database for researchers, policy makers, administrators and health care providers in the area of stroke, and should contribute to improving the health care of all Canadians.

Appendix A. RCSN Committees

Steering Committee

F. Silver (Co-Chair, Phase 1–3), S. Phillips, (Co-Chair, Phase 1), M. Kapral (Co-Chair, Phase 2 and 3), A. Hakim, M. Hill, A. Laupacis, M. Lewis, N. Mayo, G. Taylor, J. Tu, K. Willis

Coordinating Centre at the Institute for Clinical Evaluative Sciences, Ontario

M. Kapral, F. Silver, J. Fang, A. Laupacis, J. Richards, P. Lindsay, A. Robertson, J. Tu

Data Privacy and Security Committee

D. Willison, (Chair, Phase 1 and 2), A. Buchan, A. Laupacis, P. Peladeau, A. Penn, J. Richards, F. Silver, P. Slaughter (Chair, Phase 3), J. Williams

Publications Committee

J. Tu (Chair), J. Fang, D. Gladstone, M. Hill, M. Kapral, S. Phillips, J. Richards, F. Silver, P. Lindsay, K. Willis, W. Rosamond

Content Committee

S. Phillips (Chair, Phase 1), M. Kapral (Chair, Phase 2 and 3), C. Bolton, R. Cote, G. deVeber, D. Feeny, V. Flintoft, T. Hakim, M. Hill, W. Hopman, C. Jaigobin, J. Kennedy, K. Lafferty, A. Laupacis, K. Leeb, D. Matchar, N. Mayo, S. Nagpal, C. O'Callaghan, A. Penn, P. Porter, J. Richards, R. Riopelle, F. Silver, T. Steele, I. Stiell, J. Tu, P. Urzua, A. Wielgosz, D. Willison, E. Wilson, C. Wong

Appendix B. RCSN Site Participants and Managers

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Queen Elizabeth II Health Sciences Centre, Halifax, NS

S. Phillips, MD (Principal Investigator), G. Gubitza, MD (Principal Investigator), W. Simpkin, RN (Coordinator)

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Hôpital de l'Enfant-Jésus, Quebec City, QC

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R. Dell'Aquila, MD (Principal Investigator), A. McLellan, RN (Coordinator), M. Foster, RN (Coordinator)

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Stratford General Hospital, Stratford, ON

D. Tamblin, MD (Principal Investigator), S. Albrecht, RN (Coordinator) – data collection ceased March 2004

Appendix C. RCSN Publications Policies

All proposals for research projects using the Registry should be submitted to the Principal Investigator (PI) of the RCSN via fax or e-mail. The Publications Committee (consisting of representatives selected by the Executive Committee of the RCSN and CSN Management) will review research project proposals every three months. This corresponds to submission deadline dates of January 1, April 1, July 1 and October 1 of each calendar year.

A response will be issued within one month. Priority will be given to projects that are scientifically novel, high-impact, answerable, and led by an investigator with a demonstrated track record in publications. The responses will be categorized as follows: the project is approved as submitted; approval conditional upon the PI meeting specifications of the Publications Committee; recommended for revision and re-submission; or rejected with reasons for the rejection.

Each proposal for a project should consist of a two-page research outline that addresses the following issues:

- Title of the project.
- Questions to be answered by the study.
- PIs and Institutions, and contact information for the PI.
- Sponsoring Registry Investigator (if a non-Registry Investigator is the principal author).
- Background: In one or more paragraphs, the rationale for the study along with a summary of previous studies in this area. Appropriate references should be included.
- Methods: In general terms, the statistical methods that will be used for the study. A list of required data fields and time frame of the requested data should also be attached.
- A two-page "biosketch" for first-time investigators with relevant publications in the past three years.
- An appendix with draft tables and figures that will be requested from the programmer. These draft tables should specify the programming and analysis requirements in as much detail as possible in order to use programmer time efficiently. The PI may wish to speak directly with the programmer prior to submitting the project.

Each PI may have a maximum of two approved projects in progress at any given time. Once papers using the Registry data have been submitted for publication, then additional projects may be requested.

Once a project is approved, the investigators will be informed of the approximate timeline upon which the programmer will be available to conduct analyses. The programmer and PI will work together directly once the analysis is underway. Each project will receive a maximum of 80 hours of programmer time from the Registry programmer. In the event the project cannot be completed within the 80-hour time limit, the PI will need to fund any additional programming support.

No more than nine months shall elapse between approval of the project and submission of a manuscript for publication. All papers written using the Registry data must be submitted to the Publication Committee prior to submission and should acknowledge the RCSN and the CSN. A copy of all abstracts, publications, and presentations completed using Registry data must be submitted to CSN management central office prior to publication. The status of all manuscripts will be tracked at ICES.

PIs may be required to sign a confidentiality agreement to ensure reciprocal confidentiality between the CSN, the Publications Committee and the PI. The CSN may post a list of all approved projects on the CSN website.

Because of privacy and confidentiality legal issues, data security issues, and to maintain consistency in the integrity of the Registry data, all of the individual-level Registry data must remain at ICES. All PIs must sign an ICES/RCSN privacy and confidentiality agreement prior to the commencement of a project. This agreement commits the investigator to maintaining complete patient and hospital confidentiality with regards to all Registry data. Additionally, ICES conducts privacy impact assessment on each project using a standardized template, which includes information required by the Regulation to the PHIPA, 2004.

Appendix D. Selected RCSN Publications

1. Nadeau JO, Shi S, Fang J, Kapral MK, Richards JA, Silver FL, Hill MD on behalf of the Investigators for the Registry of the Canadian Stroke Network. TPA for stroke in the Registry of the Canadian Stroke Network. *The Canadian Journal of Neurological Sciences* 2005; (in press).
2. Di Legge S, Fang J, Saposnik G, Hachinski V. The impact of lesion side on the acute stroke treatment. *Neurology* 2005 Jul; 81–86.
3. Nadeau J, Fang J, Kapral MK, Silver F, Hill MD on behalf of the Investigators for the Registry of the Canadian Stroke Network. Outcome after stroke upon awakening. *The Canadian Journal of Neurological Sciences* 2005 May; 32:232–36.
4. Kapral MK, Fang J, Hill MD, Silver FL, Richards JA, Jaigobin C, Cheung AM for the Investigators of the Registry of the Canadian Stroke Network. Sex differences in stroke care and outcomes: results from the Registry of the Canadian Stroke Network (RCSN). *Stroke* 2005 Apr; 36:809–14.
5. Lindsay MP, Kapral MK, Gladstone DJ, Holloway R, Tu JV, Laupacis A, Grimshaw J. The Canadian stroke quality of care study: identification of performance indicator for acute stroke care. *Canadian Medical Association Journal* 2005 Feb; 172(3):Online 1–8.
6. Lindsay MP, Kapral MK, Gladstone DJ, Holloway R, Tu JV, Laupacis A, Grimshaw J. The Canadian stroke quality of care study: establishing indicators for optimal acute stroke care. *Canadian Medical Association Journal* 2005 Feb; 172(3):363–65.
7. Kapral MK, Laupacis A, Phillips S, Silver FL, Hill MD, Fang J, Richards JA, Tu JV for the Investigators of the Registry of the Canadian Stroke Network. Stroke care delivery in institutions participating in the Registry of the Canadian Stroke Network. *Stroke* 2004 July; 35:1756–62.
8. Tu JV, Willison DJ, Silver FL, Fang J, Richards JA, Laupacis A, Kapral MK for the Investigators of the Registry of the Canadian Stroke Network. The impracticability of obtaining informed consent in the Registry of the Canadian Stroke Network. *New England Journal of Medicine* 2004 Apr; 350:1414–21.
9. Lindsay PM, Kelloway L, McDonnell H. Research to practice: nursing stroke assessment guidelines link to clinical performance indicators. *AXON* 2005 Jun; 26(4):22–26.

Appendix E. Glossary of Terms

	Term/Acronym	Definition
1.	AIS	Acute Ischemic Stroke
2.	CAD	Coronary Artery Disease
3.	CABG	Coronary Artery Bypass Grafting
4.	CNS Score	Canadian Neurological Scale, designed to assess neurological function in conscious stroke patients. The score could range from 0–11.5 with higher scores indicating less impairment.
5.	CSN	Canadian Stroke Network
6.	CSS	Canadian Stroke Strategy
7.	CT	Computerized Tomography Scan (CAT Scan)
8.	ED	Emergency Department
9.	EMS	Emergency Medical Services (ambulance)
10.	EQ-5D	Euroqol (measures quality of life)
11.	EQ-SUM	Euroqol Stroke Utility Measure (measures health status after stroke)
12.	HUI 2/3	Health Utilities Index Mark 2 and 3 (measures quality of life)
13.	IA	Intra-arterial
14.	ICH	Intracerebral hemorrhage
15.	ICU	Intensive Care Unit
16.	IV	Intravenous
17.	LACS	Lacunar Syndrome
18.	LOC	Level of Consciousness
19.	LOS	Length of Stay
20.	LSN	Last Seen Normal, time prior to onset of stroke symptoms
21.	MoH	Ontario Ministry of Health and Long-Term Care
22.	NIHSS	National Institutes of Health Stroke Scale, based on a possible score out of 42, and where lower scores imply less impairment. Scores > 12 indicate more significant impairments.
23.	OCSF Classification	Oxfordshire Community Stroke Project (OCSF) classification, based on neurological signs and syndromes, contains four subtypes of ischemic stroke: lacunar syndrome (LACS), total anterior circulation syndrome (TACS), partial anterior circulation syndrome (PACS), posterior circulation syndrome (POCS).
24.	PACS	Partial Anterior Circulation Syndrome
25.	POCS	Posterior Circulation Syndrome
26.	Pre-notification	EMS personnel notified the receiving hospital in advance of patient's arrival.
27.	PTCA	Percutaneous Transluminal Coronary Angioplasty
28.	PVD	Peripheral Vascular Disease
29.	Rankin	Rankin, a scale designed to grade the level of stroke disability
30.	RCSN	Registry of the Canadian Stroke Network
31.	SAH	Subarachnoid hemorrhage
32.	SIS	Stroke Impact Scale (a 59-item scale which measures various aspects of stroke recovery, including strength, hand function, mobility, activities of daily living, emotion, memory, communication and social participation)
33.	SIS-16	Stroke Impact Scale-16 (an abbreviated 16-item scale based on the original Stroke Impact Scale; measures physical function after stroke)
34.	TACS	Total Anterior Circulation Syndrome—which includes both cortical and subcortical symptoms from anterior and middle cerebral artery territory
35.	TIA	Transient Ischemic Attack, or "mini-stroke"
36.	tPA	Tissue plasminogen activator
37.	UTD	Unable to Determine, based on available data in the patient's medical records, or based on clinical presentation and/or findings.