

Appendix 6

Measuring and Monitoring Working Group: Current Initiatives

Ontario Ministry of Health: *Performance Measure*

The Ministry's vision is to provide quality health care that everyone in the province can rely on. The Ministry's goal is a first class health system that provides better and more accessible health services for all Ontarians when and where they need them, at every stage of their lives.¹

The Ontario MOHLTC has a requirement to ensure accountability for services it funds. Therefore measures use to evaluate stroke should be consistent with the Ministry of Health's key performance indicators.

In support of its goals the Ministry has developed a plan to evaluate its performance in the areas of community services (preserving and protecting the health of citizens in their communities), professional services (providing access to primary and specialist care), institutional services (providing acute and long-term institutional care) and policy and planning (developing direction for health care and monitoring quality and performance).

A coordinated stroke strategy would be measured against at least one of these performance measures to ensure that it is aligned with the Ministry's corporate goals and is consistent with MOHLTC directions.

Institute for Clinical Evaluative Sciences: Stroke Care in Ontario: Hospital Survey Results

A 35-question survey was distributed to 190 hospitals in Ontario. This report represents an initial analysis of the survey responses and focuses on major findings. The overall response rate was 77%. The focus of this study was on acute inpatient care. These key findings provide a point in time assessment of stroke care in Ontario's acute hospitals:

- ◆ Twenty-four percent of responding hospitals reported having a care map for stroke patients while 36% were in the process of developing one;
- ◆ Acute stroke patients were admitted to a general medical ward at the majority of responding acute hospitals (71%). Only 4% of acute hospitals reported having a dedicated stroke unit;
- ◆ Family physicians were the attending physicians for stroke patients at 78% of the acute hospitals. At 12% of responding acute hospitals neurologists were

the attending physician although these specialists served as consultants at 39% of the acute sites;

- ◆ Most hospitals reported timely access to acute rehabilitation services with a median inpatient waiting time of 2 days for each physiotherapy, occupational therapy, and speech pathology. Waiting times for outpatient stroke rehabilitation and stroke rehabilitation provided through home care were longer than inpatient access to these services, with median waits of 7-11 days, depending on the rehabilitation specialist type and program. Waiting times for an urgent CT scan of the head varied from a median wait of 2 hours at hospitals with a CT scanner to 12 hours at hospitals without a scanner;
- ◆ Twenty-two acute hospitals (16%) in Ontario currently administer thrombolytic therapy to some acute stroke patients with another 16 sites (11%) planning to offer it within the next 12 months; and,
- ◆ Stroke patients in acute hospitals faced significant waiting times for transfers to other institutions with a median wait of 14 days for transfer to rehabilitation hospitals and 45 days to long-term institutions.

The University of Toronto-Ontario Hospital Association: *Hospital Report '99 Measuring Stroke Outcomes*

The principles for Hospital Report '99 with respect to stroke outcomes were to develop scientifically sound measures, useful and reliable outcomes, and a balanced set of measures for stroke care. The data will be provided to participating hospitals as a basis for quality improvement.

Researchers used a three-stage methodology to develop stroke outcomes, which included a literature review, expert consensus panel, and a record re-abstraction for validation of measures.

With respect to ischemic stroke, researchers have identified the strongest evidence for the following clinical outcomes: deep vein thrombosis (DVT), urinary tract infection (UTI), and seizures.

Strong evidence was found to substantiate the following additional outcome measures: pulmonary edema (PE), aspiration pneumonitis, fever, bacterial pneumonia, empyema, renal complications and failure, fractures in hospital, secondary intracerebral bleed, decubitus ulcer, malnutrition and dehydration. There was minimal evidence to support the following clinical outcomes: cardiac/respiratory arrest and gastrointestinal bleed.

A limitation of this process is that stroke outcomes are limited to inpatient acute care and do not address the continuum of stroke care. Researchers also report

concerns with the validity of the data collected.ⁱⁱ The indicators that will be reported on through this process will also be reported on through the Ontario Stroke Registry and the rehabilitation initiative of the Canadian Institute for Health Information (both reported on below).

Institute for Clinical Evaluative Sciences and Heart and Stroke Foundation of Ontario:
Ontario Stroke Registry

The Ontario Stroke Registry seeks to collect primary data on the provision of acute stroke care in hospitals. Data will be collected at the individual patient level.

The data collection form is currently being pilot tested at demonstration sites (London Health Sciences Centre, West GTA Stroke Network, Southeastern Ontario and Hamilton Health Sciences Corporation). The pilot test is being funded by the HSFO. It is anticipated that the pilot test will expand to include 7 or 8 hospital sites in Ontario and that the registry may expand into a national registry as part of the Canadian Stroke Network.

The database from the Ontario Stroke registry will be useful at the patient level to determine changes in patients' initial symptoms over time and in functional discharge scores. The database will also be useful for clinical trial research and may have implications for the application of universally accepted practice guidelines in the area of stroke care.

Heart and Stroke Foundation of Ontario: *Coordinated Stroke Strategy Evaluation Framework*

This evaluation framework is designed around each of seven priorities as determined by the HSFO Coordinated Stroke Strategy's Evaluation Work Group and Steering Committee. It supports a two-year evaluation process focusing on health system change and case studies at the initial four sites (listed above) to evaluate a coordinated stroke strategy.

The focus is on evaluation of the process by which a coordinated stroke strategy is developed; the intermediate results achieved and the long-term outcomes anticipated across the continuum of stroke care and treatment. The framework sets out specific evaluation questions, indicators, data collection methods and the resources required for undertaking each.

Cardiac Care Network of Ontario: *Cardiac Procedures Database*

The Cardiac Care Network of Ontario (CCNO) is funded by the MOHLTC to coordinate the provision of adult cardiac surgical services across the province. It maintains a computerized registry of all cardiac-surgery patients with data on demographics, risk factors, history and symptoms, test results and waiting list

information. Data is aggregated at a central level but is used on provincial, regional and local levels.

A new patient registry for catheterization laboratory services (cardiac catheterization and angioplasty/intracoronary stents) is scheduled to be in full operation by April 1, 2000.

CCNO's data system focuses on one aspect of cardiovascular disease, cardiac surgery and services. It is established in regional cardiac care centers, many of which are likely to also treat large volumes of stroke cases, and hospitals performing catheterizations.

Canadian Institute for Health Information: *National Rehabilitation Prototype Reporting System*

The Canadian Institute for Health Information (CIHI) will launch a national reporting system in April 2000 for adult inpatient rehabilitation services. This system will facilitate comparative reporting among participating hospitals and provinces.

At the time of reporting, 22 hospitals in Ontario have agreed to participate. This cohort includes rehabilitation hospitals and acute general hospitals with rehabilitation inpatient units. All hospitals with a core service plan from CIHI can submit rehabilitation data to CIHI free of charge.

The indicators identify the health characteristics, socio-demographic characteristics of the service recipients. In addition, there are indicators of access, resource utilization, and client outcomes at discharge and at follow-up. It is anticipated that the indicators may interface with similar reporting systems in ambulatory, rehabilitation, and community settings.

From 1996 to 1999 CIHI completed a national pilot study to develop a minimum data set to measure and monitor the provision of rehabilitation care in hospitals. The intent of the pilot was to develop case mix groupings for rehabilitation and to evaluate the application of the FIM-FRG (Functional Independence Measure-Function Related Groups) in the Canadian context.

The CIHI National Rehabilitation Advisory Group and the National Rehabilitation Expert Group recommended that the FIM-FRG be part of the data set with enhancements to the cognition and communication indicators. The British Columbia Ministry of Health has recommended that the CIHI data set be the information standard for adult inpatient rehabilitation services.

The pilot was the precursor to the development of a national minimum data set and rehabilitation indicators. Of the 1,860 patient records from 31 hospitals that

were reviewed during this process, 500 records (or 28 percent) were for patients with a primary diagnosis of stroke.

Joint Policy and Planning Committee: *Rehabilitation Advisory Group*

The JPPC has established this committee to establish a single measurement tool in Ontario for funding hospital rehabilitation care. Its mandate over the next six to eight months is to evaluate and recommend the implementation of a classification and assessment tool for use as a basis for hospital inpatient and outpatient rehabilitation resource allocation, quality indicators, outcome measurement and care planning in Ontario.ⁱⁱⁱ Among the tools to be assessed are:

- ◆ The tool used in the CIHI Rehabilitation Pilot Project that is based upon the FIM-FRG; and,
- ◆ InterRAI Resident Assessment Instrument (Minimum Data Set) – Post Acute Tool (RAI-PAC).

Implementation of a single measurement tool will facilitate collection of data and information required to support an evaluation of a coordinated stroke strategy.

Canadian Institute for Health Information: *National Ambulatory Case Reporting System*

CIHI's National Ambulatory Case Reporting System (NACRS) is ready to be launched and will begin in April. It will be useful for stroke as it will capture everyone who visits emergency rooms and not just those who are admitted to hospital (as per the present system). This means that many previously uncounted transient ischemic attack (TIA) patients will now be included. The data being collected is not extensive, but it will include the basic age/sex, etc., as well as diagnosis and disposition of the patient with follow-up/referral information

Canadian Stroke Network: *Stroke Registry*

The Canadian Stroke Network (CSN) has recently been funded by Industry Canada as a seven-year network for centers of excellence project. It will foster research in stroke prevention, treatment, rehabilitation and community reintegration, as well as basic science. One initiative is the stroke registry for centers across the country with data collection and analysis to be completed by ICES.

Health Canada: *National Cardiovascular Surveillance System*

A basic national heart and stroke surveillance system exists in Canada. Surveillance measurements have largely consisted of morbidity and mortality

statistics published every two years through the collaborative efforts of the Heart and Stroke Foundation of Canada, Statistics Canada and Health Canada's Laboratory Centre for Disease Control. Data from population surveys are added on an ad hoc basis. There are no defined stroke indicators in this system.^{iv}

Those involved with the existing system agree that it is limited for several reasons^v:

- There is no overall development plan including specific indicators;
- Resources have not been dedicated toward its expansion;
- Data is not available in all provinces for all indicators;
- Not all data sources have been accessed for the surveillance system; and,
- There is a need for a broader dissemination strategy

Health Canada: *Canadian Heart and Stroke Surveillance System*

This initiative is in the early phase of its development and is being developed in response to the need for improved national information about stroke care. This system will facilitate funding agencies and service providers to address national stroke issues from a health systems perspective.

The goal of the Canadian Heart and Stroke Surveillance System (CHSSS) is to provide information on population health and determinants of health (including the health care system) to decision makers that will facilitate the best investment of resources in order to minimize morbidity and mortality related to cardiovascular disease in Canada.

A core set of indicators will be collected on a regular basis. The system will not develop one massive database but will collate data from existing databases and promote the development of new databases as needed to address gaps in data. An evaluation plan will be developed to assess the quality of the data in the system, the satisfaction of its users with the information and its dissemination, and the system's impact on policy maker's decisions.

The CHSSS will include information on each of the following components:

- ◆ Health outcomes of the population related to cardiovascular disease.
- ◆ Risk factors influencing cardiovascular disease in the population.

- ◆ Interventions for cardiovascular disease (prevention, treatment and rehabilitation)

The anticipated outcome of this surveillance system^{vi} will be accessible, timely, high quality information on:

- ◆ The status of cardiovascular health of the Canadian population as a whole and various sub-groups over time (risk factors, risk conditions, health problems);
- ◆ The impact of cardiovascular disease on the population;
- ◆ The cost of cardiovascular disease;
- ◆ The existence and use of efficacious preventive, therapeutic, rehabilitative, and supportive care policies, interventions and programs; and,
- ◆ Future predictions of cardiovascular disease and the need for services.

Summary: Potential and Current Resources

Table A illustrates the many initiatives underway at the provincial and national level to develop indicators and systems useful to measure and monitor stroke care in Ontario. For example, the Ontario Stroke Registry is being implemented at the patient care level and hopefully will be continued as part of the CSN. At the hospital level, CIHI is moving rapidly to implement a national rehabilitation reporting system with significant support from health services management and clinicians in the field. The Task Group agreed that no monitoring system is comprehensive across the continuum of care.

In fact, although there appear to be various avenues for collecting data on stroke care, the current measuring and monitoring systems are selective in terms of the type of information collected. Although it is proposed that future systems be comprehensive and collect data across the continuum of care, many of these initiatives are in the planning stage of development. It is the view of the Task Group that some of these initiatives may develop faster than others. Table B summarizes the current gaps and duplications in current and proposed information systems.

Table A: Potential Resources for a Stroke Information System

| Measuring and Monitoring Initiative | Prevention | Acute Care Inpatient | Acute Care Emergency | Rehabilitation | Community Integration |
|---|------------|----------------------|----------------------|----------------|-----------------------|
| Ontario Stroke Registry | | X | X | | |
| Hospital Report '99 | | X | X | | |
| HSFO Evaluation Framework | X | X | X | X | X |
| CIHI National Rehab Prototype Reporting System | | | | X | |
| Canadian Stroke Network | X | X | X | X | X |
| Ontario Component of the National Population Health Survey | X | | | | |
| Proposed Canadian Heart and Stroke Surveillance System (CHSS) | X | X | | X | X |

Table B: Characteristics of Current Measuring and Monitoring Systems

| Characteristics of the Measuring and Monitoring System | Ontario Stroke Registry | Hospital Report '99 | HSFO Evaluation Framework | CIHI National Rehab Prototype Reporting System | Canadian Stroke Network | Ontario Component of the National Population Health Survey | CHSSS |
|--|-------------------------|---------------------|---------------------------|--|-------------------------|--|-------|
| Actual (A) or Proposed (P) | A | A | A | A | P | A | P |
| One-Time (OT) or Ongoing (O) | OT | OT | OT | O | O | O | O |
| Comprehensive © or Selective (S) | S | S | C | S | C | S | S |

ⁱ Ministry of Health and Long-Term Care. 1999-2000 Business Plan. Page 2.

ⁱⁱ Not all patients with a stroke are admitted to hospital. Variations in coding practices can lead to discrepancies.

ⁱⁱⁱ JPPC, Rehabilitation Advisory Group, Terms of Reference

^{iv} Strauss B, Taylor G, Gubitz G. Stroke Systems: national stroke surveillance in Canada. Publication Pending. Page 4. Page 9.

^v Health Canada. Heart and Stroke Surveillance System.

^{vi} Surveillance is defined by Strauss et al as: "the ongoing, systematic collection, analysis, and interpretation of health data in the process of describing and monitoring a health event closely integrated with timely dissemination of information to those who need to know. This information is used for planning, implementing, and evaluating public health action and to assess the effectiveness of programs."